

# Consent Page: Top portion



## The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey

This page provides important information about this study, and explains the risks and benefits of participating.

This research is being done to find out what factors cause Chronic Kidney Disease (CKD) to become worse in children and young adults. The National Institutes of Health (NIH) is working with your center to do this research. You are being asked to do this survey because you have been a part of the CKiD study.

*Parents/legal guardians, who are giving permission for a child, please note: in sections that follow "you" refers to "your child".*

Taking part in this study is completely voluntary. You do not have to participate if you don't want to. You may also leave the study at any time. If you leave the study before it is finished, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. If we lose contact with you we may use public resources such as online searches or social media to locate and contact you. We may also ask your kidney doctor to try to contact you, even after you receive care at an adult healthcare facility. We will do this unless you tell us that you no longer want to be a part of the study. There is no direct benefit to you from being in this study; however the information gained from this research may help other children with CKD in the future.

If you decide to continue to take part in the study, the following will occur:

- You will fill out a survey online which takes approximately 10 minutes to complete. We will contact you by phone, email, or text when it is time for you to complete the survey. The survey asks for information about your medical history, diagnosis of diseases, participation in other research studies, current medications, employment status, educational background, quality of life, healthcare resources, lab results (such as serum creatinine) and vital signs (height, weight, blood pressure) if known.
- You will complete an online questionnaire about your feelings and behavior. This questionnaire will take about 10 minutes to complete as well. You will also complete an online questionnaire about your experience and how you are feeling as you make the transition to adult medical care, if applicable. This questionnaire will take about 5 minutes to complete.
- We will also ask you to provide us with your contact information, and how you would like us to contact you (phone call, text message, email). Study staff will communicate with you about when to complete your next survey or any other study information you may need to know. Information about the study may be sent to you from staff where you are being followed for study activity, and by the CKiD Clinical Coordinating Centers.
- Your health information will be collected from your kidney doctor and medical record from time to time. This will happen as long as the CKiD study continues because researchers may need to know how your health has changed over time. We will continue to check for information even if you are no longer taking part in the study. If you decide you no longer want your health information collected from your medical record you must inform the study doctor or study team that you would like to withdraw your permission to review your medical record for health information about you. Information collected will include the following: diagnosis of diseases, laboratory and test results, medications, hospitalizations, surgeries, medical treatments, neonatal history, maternal medical history, and vital signs (height, weight, blood pressure, height and weight) done at regular clinic visits. If applicable, we will also collect information about your health status and healthcare involving dialysis treatment or transplantation. Tests and images related to kidney function (such as kidney ultrasound or ambulatory blood pressure monitoring reports) may also be reviewed by a researcher selected by the CKiD study. This may be a physician outside of your institution. Any information sent for review will not include personal identifiers such as name, medical record number, social security number, and/or date of birth.
- If you transfer care or receive treatment at a different hospital, you may be asked to sign a medical record release form. Or, if you have given your health care provider permission to electronically share your medical information with all your other health care providers, we may be able to see your medical records from other hospitals that use the same electronic medical record system.
- At any time during your participation, if you are able to come in for in-person study visits, you can return to completing in-person study visits (such as the Regular Follow-Up study visits or Post-Kidney Replacement Therapy (KRT) study visits). If you are 16 years old or older, you may also have the option to complete a remote study visit. A remote study visit will allow the entire visit to be completed from your home.
- You will also have the opportunity to engage in a CKiD Facebook group. The group will be moderated by an administrator who also works on the CKiD study. The group will be a private page, and only CKiD study participants, families and designated CKiD study personnel moderators will be allowed to see the Facebook page's content. Content will include highlights of the study, milestones and scientific contributions summarized as "CKiD Discoveries." This will also give you the opportunity to interact with other CKiD participants across the US and Canada. Joining this Facebook group is completely voluntary, and you may leave the group at any time.

## Consent Page: Middle portion

You will also have the opportunity to engage in a CKiD Facebook group. The group will be moderated by an administrator who also works on the CKiD study. The group will be a private page, and only CKiD study participants, families and designated CKiD study personnel moderators will be allowed to see the Facebook page's content. Content will include highlights of the study, milestones and scientific contributions summarized as "CKiD Discoveries." This will also give you the opportunity to interact with other CKiD participants across the US and Canada. Joining this Facebook group is completely voluntary, and you may leave the group at any time.

Taking part in this study has certain risks. You may get tired, bored, and/or frustrated when completing the survey and/or questionnaires. Some questions may make you feel upset or uncomfortable.

As with all studies in which data is collected from the participant, there is a risk for the loss of confidentiality of sensitive information. Every precaution will be taken to secure participants' personal information to ensure confidentiality. There is also a risk for loss of confidentiality when participating in social media platforms like a Facebook group.

The CKiD Facebook group is private and only those who are approved to be in it can see the content and members. Members of the group will be able to see your publicly available Facebook information. However, other CKiD participants and study personnel, who moderate the page, will not be able to see any content that you have made private.

Being in this study will not cost you anything. You will be compensated for each survey/questionnaire you complete.

To perform this study, we need to collect health information about you.

All the information that is recorded for the study is only identified by a coded number. The CKiD researchers at your center will be able to link this code with your information. We will do our best to keep your information private and confidential, but we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law.

People working on this study will need to see your health information including but not limited to: your study ID number, dates of study visits, and dates of hospitalizations and medical procedures. They may need to share this information with other institutions to conduct the research and to assure the quality of the data. People who may see this information include:

- Members of the research staff at your center
- Institutional Review Boards (IRBs)/Research Ethics Boards (REBs) for your site
- Children's Hospital of Philadelphia (CHOP), whose IRB is reviewing this study
- People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections, or the Food and Drug Administration (FDA)
- The Data Coordinating Center at the Johns Hopkins Bloomberg School of Public Health
- The Clinical Coordinating Centers at Children's Hospital of Philadelphia (CHOP) and Children's Mercy Hospital
- Groups monitoring the safety of this study (e.g. the Observational Safety Monitoring Board)
- The National Institutes of Health who is sponsoring this research and its designees
- Members of the research staff at other centers and hospitals that are part of this research
- Psychological Assessment Resources (PAR, Inc.), a company which publishes psychological assessments and provides a platform for on-line administration and scoring.
- REDCap, a secure web-based platform for building and managing online surveys and databases
- Online networking services (i.e. Twilio, Doximity) that offer telehealth tools such as distribution of surveys and notifications to participants via SMS text messages or voice calls.
- The National Institutes of Health who is sponsoring this research;

## Consent Page: Bottom portion

If you have blood samples collected at Quest Diagnostics Laboratory during this study, they will not be used for future research.

Results of this study may be published or presented at meetings. Your identity will be kept private in any publication or presentation. By law, we are required to protect your health information although some people and organizations who receive your information may not be required to do so under Federal privacy laws.

There is no time limit for destroying the information collected for this study. However, you can cancel your permission to use and share your information at any time by sending a letter to the study doctor at your CKiD site. Your cancellation would not affect information already obtained about you in this study.

To help us protect your privacy, we have a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

The Certificate of Confidentiality does not prevent the researchers from disclosing, without your consent, information that they are required by law to disclose to government authorities. For example, researchers must comply with laws requiring the reporting of suspected child abuse and neglect and communicable diseases.

If you have questions, please contact your clinical site coordinator. If you do not have your clinical site coordinator's contact information, click on the link below for a complete list of all CKiD sites and the phone number of the study doctor at your CKiD site.

By clicking "I AGREE. Please continue to the survey", you consent to take part in this study and accept that you understand the information described on this page. You are also agreeing to share and/or use your health information for this research as explained above. If you do not agree to our collecting, using and sharing your health information, you cannot participate in this study.

[I AGREE. Please continue to the survey. »](#)

[I DO NOT WANT TO COMPLETE SURVEY](#)

[Click here if you have questions, and would like to contact your CKiD study doctor »](#)

The participant will see this page if they click on “[Click here if you have questions and would like to contact your CKiD study doctor](#)” from the consent page:



## The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey

Below is a list of CKiD sites. If you have questions, call your clinical site and ask for the CKiD study coordinator.

| Site Name  | Study Doctor / PI        | Office Number          |
|--|--------------------------|------------------------|
| Ann & Robert H. Lurie Children's Hospital of Chicago                               | Dr. Priya Verghese       | 312-227-4000           |
| Boston Children's Hospital   | Dr. Nancy Rodig          | 617-355-6129           |
| British Columbia Children's Hospital   | Dr. Tom Blydt-Hansen     | 604-875-2345 Ext 7835  |
| Levine Children's Hospital   | Dr. Susan Massengill     | 704-381-8800           |
| Case Western Reserve University/Cleveland Clinic Children's Hospital at Montefiore | Dr. Katherine Dell       | 216-444-6123           |
| Children's Hospital at Montefiore  | Dr. Frederick Kaskel     | 718-655-1120           |
| Children's Mercy Hospital  | Dr. Bradley Warady       | 816-302-3010           |
| Children's National Medical Center   | Dr. Asha Moudgil         | 202-476-5058           |
| Children's Healthcare of Atlanta / Emory   | Dr. Larry Greenbaum      | 404-727-6994           |
| Children's Hospital of Philadelphia  | Dr. Susan Furth          | 215-590-2449           |
| Cincinnati Children's Hospital   | Dr. Donna Claes          | 513-636-4531           |
| Helen DeVos Children's Hospital at Spectrum  | Dr. Jason Thomas         | 616-267-0359           |
| Driscoll Children's Hospital   | Dr. Amy Becker           | 361-694-5022           |
| East Carolina University   | Dr. Liliana Gomez Mendez | 267-744-4965           |
| Hospital for Sick Children (Sick Kids)   | Dr. Rulan Parekh         | 416-813-7654 Ext 28042 |
| Icahn School of Medicine at Mount Sinai  | Dr. Jeffrey M. Saland    | 212-241-6187           |
| INOVA Fairfax Hospital for Children  | Dr. Davoud Mohtat        | 703-876-2788           |
| Johns Hopkins Children's Center  | Dr. Meredith Atkinson    | 410-955-2467           |
| Loma Linda University  | Dr. Cheryl Sanchez-Kazi  | 909-651-1904           |
| Medical College of Wisconsin   | Dr. Rajasree Sreedharan  | 414-337-7140           |
| Nationwide Children's Hospital, Ohio State Univ.                                   | Dr. Hiren Patel          | 614-722-4360           |
| Nemours Hospital for Children - Delaware Valley                                    | Dr. Sonal Bhatnagar      | 302-651-4426           |
| University of Oklahoma Health Sciences Center                                      | Dr. Ikuyo Yamaguchi      | 405-271-6142           |
| Oregon Health and Science University   | Dr. Amira Al-Uzri        | 503-494-7327           |

[EXIT](#)

[BACK »](#)

The participant will see this page if they click on “**I DO NOT WANT TO COMPLETE SURVEY**” from the consent page:



## CKID Follow-Up Survey

**DECLINED**

We thank you for your time. Your response has been recorded.

**EXIT**

The participant will see this page if they click on **“I WANT TO COMPLETE SURVEY”** from the consent page:



## The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey

**Welcome to the CKiD Follow-up System and thank you for completing this survey. The survey should take about 5 to 10 minutes to complete. You will be compensated for your time. The information you provide is confidential and very important in helping us evaluate chronic kidney disease. To get started, please enter your date of birth.**

Participant ID:

Birthday:  /  /  (mm/dd/yyyy)

Date of Survey Entry:

**ENTER »**

The following screen shots contain all possible questions. Skip patterns are built into the survey (and indicated in red text for the purpose of these screen shots).

## Follow-Up Survey

A1. What is your current weight?

 lbs

0%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

A2. What is your current Height/Stature?

ft  in

 Save & Finish Later

« BACK

NEXT »



## Follow-Up Survey

A3. Self-report Serum Creatinine (SCr):

mg/dL     Don't know

2%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

A4. Are you currently anemic?

- Yes
- No (Skip to B1)
- Don't know (Skip to B1)

3%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

A4a. Self-report Hemoglobin (Hgb):

g/dL     Don't know

3%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

A4b. Self-report Hematocrit (HCT):

%     Don't know

3%

Save & Finish Later

« BACK

NEXT

## Follow-Up Survey

*The following questions ask about transplants that you may have had.*

### Section B: Transplantation

B1. Have you ever had a kidney transplant?

- Yes
- No (Skip to B2)
- Don't know (Skip to B2)

0%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### **Transplantation:** (continued ...)

B1a. How many kidney transplants have you had?

- One
- Two
- Three or More
- Don't know



[Save & Finish Later](#)

[« BACK](#)

[NEXT »](#)

## Follow-Up Survey

### **Transplantation:** (continued ...)

B1b. Was your most recent kidney transplant from a living relative, a living non-relative, or from a deceased donor?

- Living Donor - Related
- Living Donor - Not Related
- Deceased donor
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplantation: (continued ...)

#### B1c. Date of Most Recent Kidney Transplant:

Please enter the date of your transplant. If you do not know the month or day, please enter the year. Otherwise, select "I Don't know/I'm not sure".

/  /  (mm/dd/yyyy)

| June |     | July 2013 |     |     |     |     | August |
|------|-----|-----------|-----|-----|-----|-----|--------|
| Sun  | Mon | Tue       | Wed | Thu | Fri | Sat |        |
|      | 1   | 2         | 3   | 4   | 5   | 6   |        |
| 7    | 8   | 9         | 10  | 11  | 12  | 13  |        |
| 14   | 15  | 16        | 17  | 18  | 19  | 20  |        |
| 21   | 22  | 23        | 24  | 25  | 26  | 27  |        |
| 28   | 29  | 30        | 31  |     |     |     |        |
|      |     |           |     |     |     |     |        |

I Don't know/I'm not sure

B1d. When you see your doctor about your kidney transplant, how does he/she say it's doing? If you have more than one kidney transplant, please answer based on your most recent transplant.

- My kidney function is good/excellent (Skip to C1)
- My kidney is OK but I might need another transplant or dialysis in the near future (in 1 year or so)
- My kidney is not working well and I am on dialysis
- I Don't know/I'm not sure (Skip to C1)

31%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

**Transplantation:** (continued ...)

B2. **In the past year**, have you talked about kidney transplant with your nephrologist or health care provider?

- Yes
- No (Skip to C1)
- Don't know (Skip to C1)



Save & Finish Later

« BACK

NEXT »



## Follow-Up Survey

### Transplantation: (continued ...)

B3. Which donor option(s) has/have been discussed?

• Living Donor:  Yes  No  Don't know

• Transplant Wait List/  
Deceased Donor:  Yes  No  Don't know

12%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplantation: (continued ...)

B4. Have you been listed for deceased donor transplantation, in other words, are you on a transplant waiting list?

- Yes
- No *(Skip to C1)*
- Don't know *(Skip to C1)*

50%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplantation: (continued ...)

B4a. Date activated on the waiting list:

*Please enter the date you were activated on the waiting list. If you do not know the month or day, please enter the year. Otherwise, select "I Don't know/I'm not sure".*

/  /  (mm/dd/yyyy)

| June | July 2013 |     |     |     |     | August |
|------|-----------|-----|-----|-----|-----|--------|
| Sun  | Mon       | Tue | Wed | Thu | Fri | Sat    |
|      | 1         | 2   | 3   | 4   | 5   | 6      |
| 7    | 8         | 9   | 10  | 11  | 12  | 13     |
| 14   | 15        | 16  | 17  | 18  | 19  | 20     |
| 21   | 22        | 23  | 24  | 25  | 26  | 27     |
| 28   | 29        | 30  | 31  |     |     |        |
|      |           |     |     |     |     |        |

I Don't know/I'm not sure

56%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

*The following questions ask about transplant-related medications that you may be taking.*

### Section C: Transplant-Related Medications

C1. In the past 30 days, have you taken any of the following transplant-related medications (such as Azathioprine (Imuran), Cyclosporine (Gengraf, Sandimmune, Neoral), Mycophenolate mofetil (Cellcept, Myfortic), Tacrolimus (FK506, Prograf), Rapamycin, Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra), Prednisone, Prednisolone or Methylprednisolone, or Valcyte (valganciclovir) for the treatment of your kidney transplant?

- Yes
- No (Skip to D1)
- Don't know (Skip to D1)
- Not applicable, did not receive kidney transplant (Skip to D1)

12%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1a. Have you taken Azathioprine (Imuran)?

Yes  No

(Skip to C1b)

C2a. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

18%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1b. Have you taken Cyclosporine (Gengraf, Neoral, Sandimmune)?

Yes  No

(Skip to C1c)

C2b. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

18%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1c. Have you taken Mycophenolate mofetil (Cellcept, Myfortic)?

Yes  No

(Skip to C1d)

C2c. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

18%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1d. Have you taken Prednisone, Prednisolone or Methylprednisolone?

Yes  No

(Skip to C1e)

C2d. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know



Save & Finish Later

« BACK

NEXT »



## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1e. Have you taken Rapamycin?

Yes  No

(Skip to C1f)

C2e. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1f. Have you taken Tacrolimus (FK506, Prograf)?

Yes  No

(Skip to C1g)

C2f. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1g. Have you taken Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra)?

Yes  No

(Skip to C1h)

C2g. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1h. Have you taken Valcyte (Valganciclovir)?

Yes  No

(Skip to C1i)

C2h. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Transplant-Related Medications (continued ...)

C1i. Have you taken any other transplant related medication?

Yes  No **(Skip to D1)**

1. Please specify the name of the drug:

C2i. How many times is the drug taken?

- More than four times/day
- Four times/day (every 6 hours)
- Three times/day (every 8 hours)
- Twice/day (every 12 hours)
- Once/day
- Every other day
- 2 times/week or 3 times/week
- Less than 2-3 times/week
- Don't know

25%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

*The following questions ask about dialysis that you may have had.*

### Dialysis:

D1. Have you ever been on dialysis?

- Yes
- No (Skip to D2)
- Don't know (Skip to D2)



Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Dialysis: (continued ...)

D1a. What type of dialysis did you use most recently:

- Hemodialysis (cleansing the blood outside of the body)
- Peritoneal Dialysis (cleansing the blood using the patient's own body tissues inside the body)
- Don't know

31%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Dialysis: (continued ...)

D1b. Date Most Recent Regularly Scheduled\* Dialysis was Started or will start:

*Please enter the date of your most recent "regularly scheduled" dialysis. For hemodialysis, please enter the date when you started treatments 2 or more days a week for at least 3 months. For peritoneal dialysis (PD), please enter the date when you started treatments 5 or more days a week for at least 3 months. If you do not know the month or day, please enter the year. Otherwise, select "I Don't know/I'm not sure."*

/  /  (mm/dd/yyyy)

| August |     |     | September 2021 |     |     | October |  |  |
|--------|-----|-----|----------------|-----|-----|---------|--|--|
| Sun    | Mon | Tue | Wed            | Thu | Fri | Sat     |  |  |
|        |     |     | 1              | 2   | 3   | 4       |  |  |
| 5      | 6   | 7   | 8              | 9   | 10  | 11      |  |  |
| 12     | 13  | 14  | 15             | 16  | 17  | 18      |  |  |
| 19     | 20  | 21  | 22             | 23  | 24  | 25      |  |  |
| 26     | 27  | 28  | 29             | 30  |     |         |  |  |
|        |     |     |                |     |     |         |  |  |

I Don't know/I'm not sure

D1c. Are you currently receiving regularly scheduled dialysis therapy?

- Yes (Skip to E1)  
 No  
 Don't know

31%

Save & Finish Later

« BACK

NEXT »



## Follow-Up Survey

**Dialysis:** (continued ...)

D2. **In the past year**, have you talked about dialysis with your nephrologist or health care provider?

- Yes
- No (Skip to E1)
- Don't know (Skip to E1)



Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

**Dialysis:** (continued ...)

D3. What type of dialysis was planned?

- Hemodialysis (cleansing the blood outside of the body)
- Peritoneal Dialysis (cleansing the blood using the patient's own body tissues inside the body)
- No Decision Yet
- Don't know

43%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Section E: General Information

E1. What is the highest grade or level of school that you have COMPLETED? **For example, if you are currently in the 12th grade, then enter “11”, or if you are currently in the 6th grade, then enter “5”. If you are a sophomore in college, then enter “13”. If you are completing this survey on behalf of a participant in the 1st grade, kindergarten or pre-school/pre-K, then enter “0”.**

Grade:

Don't know

Not Applicable/Child is less than 5 years old and does not attend pre-school/pre-k

50%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

**General Information:** (continued ...)

**The following questions ask about your primary household. The primary household is your parent/guardian's home in which you live at least half of the time. If you do 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.**

E2. How many adults live in your 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 yourself if you are 18 years of age or older.

Adults:   Don't know

E3. What is the status of the participant's primary household?

- Participant lives with at least one parent/guardian
- Participant has lived independently for less than 5 years
- Participant has lived independently for 5 years or more

56%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E4. How many children live in your primary household at least half the time? A child is a person who is less than 18 years of age. Include **all persons under 18 years of age**, including offspring, siblings, non-relatives. Include yourself if you are less than 18 years of age.

Children   Don't know

E5. Which of the following children (**under** 18 years of age) live in your primary household at least half the time? Include yourself, if applicable.

a. Biological Child of Participant (son/daughter)  Yes  No  Don't know

b. Step child/ Adopted child of participant  Yes  No  Don't know

c. Sibling  Yes  No  Don't know

d. Myself  Yes  No  Don't know

e. Other  Yes  No  Don't know (If "No" or "Don't Know", skip to E6)

i. Specify:

56%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E6. What is your current employment status?

- a. Working full-time (35 hours or more per week)  Yes  No  N/A  Don't know
- b. Working part-time (less than 35 hours per week)  Yes  No  N/A  Don't know
- c. Disability Income  Yes  No  N/A  Don't know
- d. Currently Enrolled Student  Yes  No  N/A  Don't know
- e. Unemployed but seeking work  Yes  No  N/A  Don't know (If "Yes", "N/A" or "Don't Know", skip to E7)
- f. Unemployed not seeking work  Yes  No  N/A  Don't know (If "Yes", "N/A" or "Don't Know", skip to E7)
- i. Are you self-employed?  Yes  No  Don't know

62%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E7. Have you started your menses (i.e. period)?

Yes  No  Don't know  Not Applicable / I am male (If "No", "Don't Know", "Not Applicable/I am male", skip to E8)

a. How old were you when you started your menses (i.e. period)?

years   Don't know

68%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

Thinking back over the past *seven (7) days*, use the scale provided to rate each of the following symptoms that were felt.

- E8. How often did you feel fatigue was beyond your control?  Never  Rarely  Sometimes  Often  Always
- E9. How often were you too tired to think clearly?  Never  Rarely  Sometimes  Often  Always
- E10. I have energy  Never  Rarely  Sometimes  Often  Always

Thinking back over the past *seven (7) days including today*, use the number (0-10) to best reflect a description of your feelings.

E11. How would you describe your overall Quality of Life?

- 1  2  3  4  5  6  7  8  9  10

As bad as it can be

As good as it can be

68%

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« BACK

NEXT »



## Follow-Up Survey

### General Information: (continued ...)

E12. In the past year, have you seen a healthcare provider/nephrologist? (Include any visits, including those in which you were well, sick, or visited the ER. Do not include times when you were hospitalized overnight).

Yes  No (If "Yes", skips to E13)

a. Please specify the reason why you have not seen a healthcare provider/nephrologist.

68%

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« BACK

NEXT »

## Follow-Up Survey

**General Information:** (continued ...)

**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.**

E13. In the past year, have you been hospitalized? Do not include overnight stays in the emergency room.

Yes  No  Don't know (If "No" or "Don't Know", skips to E14)

a. How many different times were you hospitalized during the past year?

times   Don't know

68%

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« BACK

NEXT »

## Follow-Up Survey

E14. In the past year, where have you gone to receive kidney clinical care?  
(Please circle "Yes" or "No" for EACH of the following places.)

a. A clinic or health care center

Yes  No

b. A private doctor's office

Yes  No

c. Hospital Outpatient Department

Yes  No

d. The emergency room

Yes  No (If "No", skips to E15)

1. How many times have you received care at the emergency room in the past year?

56%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E15. In the past year, have you had Urinary Tract Infections (UTI)?

Yes  No  Don't know (If "No" or "Don't Know", skips to E16)

a. How many different times did you have a UTI during the past year?

times   Don't know

E16. Do you 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 (If "Yes", skips to E17b)

a. Please specify the reason why you do not have health insurance.

68%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E17a. How long has it been since you 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

Any answer option skips to F1

75%

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« BACK

NEXT »

## Follow-Up Survey

### General Information: (continued ...)

E17b. In the past year, was there any time when you were not covered by ANY health insurance or coverage?

Yes  No (If "No", skips to F1)

E17c. In the past year, about how long were you without ANY health insurance or coverage?

months  weeks  days

75%

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« BACK

NEXT »

## Follow-Up Survey

### Section F: Medical History

F1. In the past year, have you had a heart attack?

Yes  No  Don't know

F2. In the past year, have you had a stroke?

Yes  No  Don't know

F3. In the past year, have you been diagnosed with angina (heart related chest pain)?

Yes  No  Don't know

F4. In the past year, have you been diagnosed with an irregular heart rhythm?

Yes  No  Don't know

14

81%

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« BACK

NEXT »

## Follow-Up Survey

**Medical History:** (continued ...)

**The next question asks about diseases/illnesses that you may currently have or developed in the past year.**

F5. In the past year, has a doctor or any other healthcare professional told you that you have any of the following diseases?

- a. Diabetes Mellitus (Sugar diabetes, High Blood Sugar)  Yes  No  Don't know
- b. Heart failure (congestive heart failure)  Yes  No  Don't know
- c. Passage of kidney stones  Yes  No  Don't know
- d. Leukemia  Yes  No  Don't know
- e. Lymphoma  Yes  No  Don't know
- f. Skin cancer  Yes  No  Don't know
- g. Other type of cancer  Yes  No  Don't know (If "No" or "Don't Know", skips to F5h)
- If other type, please specify:
- h. Anxiety  Yes  No  Don't know
- i. Depression  Yes  No  Don't know

81%

Save & Finish Later

« BACK

NEXT »



## Follow-Up Survey

### Section G: Blood Pressure Medications

The next questions ask about the blood pressure medications that you may have taken in the past 30 days.

G1. In the past 30 days, have you taken any blood pressure medications?

Yes  No  Don't know (If "No" or "Don't Know", skips to H1)

G2. How many different blood pressure medications have you taken?

87%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Blood Pressure Medications (continued ...)

#### List of ACE Inhibitors

Benazepril (Lotensin)

Captopril (Capoten)

Enalapril (Vasotec)

Fosinopril (Monopril)

Lisinopril (Prinivil, Zestril)

Quinapril (Accupril)

Ramipril (Altace)

#### List of Angiotensin Receptor Blockers (ARBs)

Candesartan (Atacand)

Irbesartan (Avapro)

Losartan (Cozaar)

Olmesartan (Benicar)

Telmisartan (Micardis)

Valsartan (Diovan)

G3. Are you taking any ACE/ARB? Please refer to the medication list above for examples of ACE/ARB.

Yes  No  Don't know (If "No" or "Don't Know", skips to H1)

G4. How many different ACE/ARBs are you taking?

93%

Save & Finish Later

« BACK

NEXT »

## Follow-Up Survey

### Section H: Transition to Adult Care

The next questions ask about transition to an adult care provider.

H1a. Have you transitioned to adult care?

Yes  No  Don't know (If "No" or "Don't Know", End Form)

H1b. Have you transitioned to adult care in the past year?

Yes  No  Don't know (If "No" or "Don't Know", End Form)

H2. Using a scale of 1-5, where 1 is poor and 5 is great, how would you rate your overall transition to adult care?

1  2  3  4  5

Poor/Hard

Great/Easy

a. If you rated your transition as 2 or less, please specify the reason(s) why you felt the transition was poor/hard.

96%

Save & Finish Later

« BACK

NEXT »

The participant will see this page if they click on “**Save & Finish Later**” at any point during the survey:



**The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey**

**INCOMPLETE**

We thank you for your time spent taking this survey. Your record is not completed.

When you are ready to complete this survey, please click on the link that was sent to you.

**EXIT**

On this Confirmation Page, the participant can update their response to any question. They can check the box to the left of the question they want to change and then click “Update”:

### Confirmation page

Please review **ALL** of your answers prior to clicking "**SUBMIT**". By clicking submit, you acknowledge that you answered the questions honestly and to the best of your ability. We will not compensate participants who knowingly provide false responses.

If you would like to change any of your responses, please check the box to the left of the question you want to change and click "**UPDATE**". After you click update, you will be able to change the response for the question you selected, and then navigate back to this confirmation page by clicking "**NEXT**". If you need to update more than one question, you can select the other question(s) that need to be updated once you're back on this confirmation page and repeat this process.

#### Section A: General Info.

- A1. What is your current weight? **120 lbs**
- A2. What is your current Height/Stature? **5 ft 4 in**
- A3. Self-report Serum Creatinine (SCr): **0.3 mg/dL**
- A4. Are you currently anemic? **Yes**
- A4a. Self-report Hemoglobin (Hgb): **19 g/dL**
- A4b. Self-report Hematocrit (HCT): **50 %**



## (Confirmation Page, continued)

If the participant does not want to change any responses, they can move forward with clicking “Submit”:

### Section B: Transplantation

- B1. Have you ever had a kidney transplant? **Yes**
- B1a. How many kidney transplants have you had? **One**
- B1b. Was your most recent kidney transplant from a living relative, a living non-relative, or from a deceased donor?  
**Living Donor - Related**
- B1c. Date of Most Recent Kidney Transplant: **I Don't know/I'm not sure**
- B1d. When you see your doctor about your kidney transplant, how does he/she say it's doing? If you have more than one kidney transplant, please answer based on your most recent transplant.  
**My kidney is OK but I might need another transplant or dialysis in the near future (in 1 year or so)**
- B2. **In the past year**, have you talked about kidney transplant with your nephrologist or health care provider? **Yes**
- B3. Which donor option(s) has/have been discussed?
  - Living Donor: **No**
  - Transplant Wait List/Deceased Donor: **No**
- B4. Have you been listed for deceased donor transplantation, in other words, are you on a transplant waiting list? **Yes**
- B4a. Date activated on the waiting list: **I Don't know/I'm not sure**

### Section C: Transplant-Related Medications

- C1. In the past 30 days, have you taken any of the following transplant-related medications (such as Azathioprine (Imuran), Cyclosporine (Gengraf, Sandimmune, Neoral), Mycophenolate mofetil (Cellcept, Myfortic), Tacrolimus (FK506, Prograf), Rapamycin, Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra), Prednisone, Prednisolone or Methylprednisolone, or Valcyte (valganciclovir) for the treatment of your kidney transplant? **Yes**
- C1a. Have you taken Azathioprine (Imuran)? **No**
- C1b. Have you taken Cyclosporine (Gengraf, Neoral, Sandimmune)? **No**
- C1c. Have you taken Mycophenolate mofetil (Cellcept, Myfortic)? **No**
- C1d. Have you taken Prednisone, Prednisolone or Methylprednisolone? **No**
- C1e. Have you taken Rapamycin? **No**
- C1f. Have you taken Tacrolimus (FK506, Prograf)? **No**
- C1g. Have you taken Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra)? **No**
- C1h. Have you taken Valcyte (Valganciclovir)? **No**
- C1i. Have you taken any other transplant related medication? **No**
- C1i. 1. Please specify the name of the drug:

(Confirmation Page, continued)

If the participant does not want to change any responses, they can move forward with clicking “Submit”:

#### Section D: Dialysis

- D1. Have you ever been on dialysis? **Yes**
- D1a. What type of dialysis did you use most recently: **Peritoneal Dialysis (cleansing the blood using the patient's own body tissues inside the body)**
- D1b. Date Chronic\* Dialysis Started: **I Don't know/I'm not sure**
- D1c. Are you currently receiving regularly scheduled dialysis therapy? **Yes**
- D2. **In the past year, have you talked about dialysis with your nephrologist or health care provider? No**

#### Section E: General Information

- E1. What is the highest grade or level of school that you have **COMPLETED**? For example, if you are currently in the 12th grade, then enter “11”, or if you are currently in the 6th grade, then enter “5”. If you are a sophomore in college, then enter “13”. If you are completing this survey on behalf of a participant in the 1st grade, kindergarten or pre-school/pre-K, then enter “0”. **11 Grade**
- E2. How many adults live in your 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 yourself if you are 18 years of age or older. **1 Adults**
- E3. What is the status of the participant's primary household? **Participant has lived independently for 5 years or more**
- E4. How many children live in your primary household at least half the time? A child is a person who is less than 18 years of age. Include **all persons under 18 years of age**, including offspring, siblings, non-relatives. Include yourself if you are less than 18 years of age. **Don't know**

(Confirmation Page, continued)

If the participant does not want to change any responses, they can move forward with clicking “Submit”:

E6. What is your current employment status?

- a. Working full-time (35 hours or more per week) **No**
- b. Working part-time (less than 35 hours per week) **No**
- c. Disability Income **No**
- d. Currently Enrolled Student **No**
- e. Unemployed but seeking work **No**
- f. Unemployed not seeking work **No**

E7.a a. How old were you when you started your menses (i.e. period)? **years**

E8. How often did you feel fatigue was beyond your control? **Never**

E9. How often were you too tired to think clearly? **Never**

E10. I have energy **Never**

E11. How would you describe your overall Quality of Life? **10**

E12. In the past year, have you seen a healthcare provider/nephrologist? (Include any visits, including those in which you were well, sick, or visited the ER. Do not include times when you were hospitalized overnight). **Yes**

E13. In the past year, have you been hospitalized? Do not include overnight stays in the emergency room. **No**

E15. In the past year, have you had Urinary Tract Infections (UTI)? **No**

E16. Do you 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**

E17.a. How long has it been since you last had ANY health insurance or coverage? **Never had health insurance or coverage**

E17b. In the past year, was there any time when you were not covered by ANY health insurance or coverage? **Yes**

E17c. In the past year, about how long were you without ANY health insurance or coverage? **5 months**



## (Confirmation Page, continued)

If the participant does not want to change any responses, they can move forward with clicking “Submit”:

### Section F: Medical History

- F1. In the past year, have you had a heart attack? **No**
- F2. In the past year, have you had a stroke? **No**
- F3. In the past year, have you been diagnosed with angina (heart related chest pain)? **No**
- F4. In the past year, have you been diagnosed with an irregular heart rhythm? **No**

### Section G: Blood Pressure Medications

- G1. **In the past 30 days**, have you taken any blood pressure medications? **Yes**
- G2. How many different blood pressure medications have you taken? **2**
- G3. Are you taking any ACE/ARB? Please refer to the medication list above for examples of ACE/ARB. **No**
- G4. How many different ACE/ARBs are you taking?

### Section H: Transition to Adult Care

- H1a. Have you transitioned to adult care? **No**
- H2. Using a scale of 1-5, where 1 is poor and 5 is great, how would you rate your overall transition to adult care? **0**
- H2. a. If you rated your transition as 2 or less, please specify the reason(s) why you felt the transition was poor/hard.

100%

« BACK

SUBMIT »

The participant will see this page after they submit their completed survey:



## The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey

Thank you for completing the web-based follow-up survey.  
You will be compensated for your time. We greatly  
appreciate your participation!

**Thanks again!**

100%