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	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:



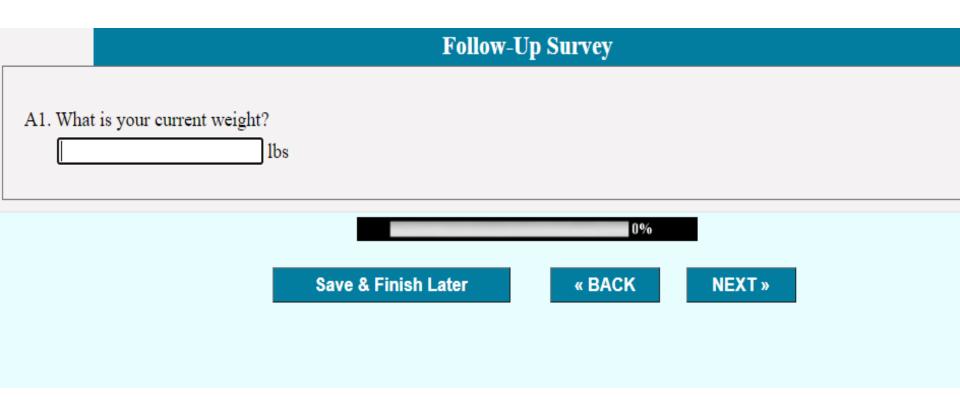
The Chronic Kidney Disease in Children (CKiD) Follow-Up Survey

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:	999001	
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				
A2. Wha	t is your current Height/Stature? ft in			
	Save & Finish Later « BACK NEXT »			

	F	Follow-Up Survey	
A3. Self-report Serum Creatinin mg/dL Don't	ne (SCr): t know		
	Save & Finish Late	er « BACK	NEXT »

	Follow-Up Survey	
A4. Are you currently anemic? Yes No (Skip to B1) Don't know (Skip to B1)		
	Save & Finish Later « BACK NEXT »	







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)

Save & Finish Later « BACK NEXT »

Transplantation: (continued ...)

B1a. How many kidney transplants have you had?

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

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

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)							
]	J <u>une</u>		Ju	ıly 201	3	4	August	
	Sun	Mon	Tue	Wed	Thu	Fri	Sat	
		<u>1</u>	2	<u>3</u>	4	<u>5</u>	<u>6</u>	
	7	<u>8</u>	<u>9</u>	<u>10</u>	<u>11</u>	<u>12</u>	<u>13</u>	
	<u>14</u>	<u>15</u>	<u>16</u>	<u>17</u>	<u>18</u>	<u>19</u>	<u>20</u>	
	<u>21</u>	<u>22</u>	<u>23</u>	<u>24</u>	<u>25</u>	<u>26</u>	<u>27</u>	
	<u>28</u>	<u>29</u>	<u>30</u>	<u>31</u>				

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

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)

On't know (Skip to C1)

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	
Deceased Donor:	
12%	
Save & Finish Later « BACK NEXT »	

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)

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)

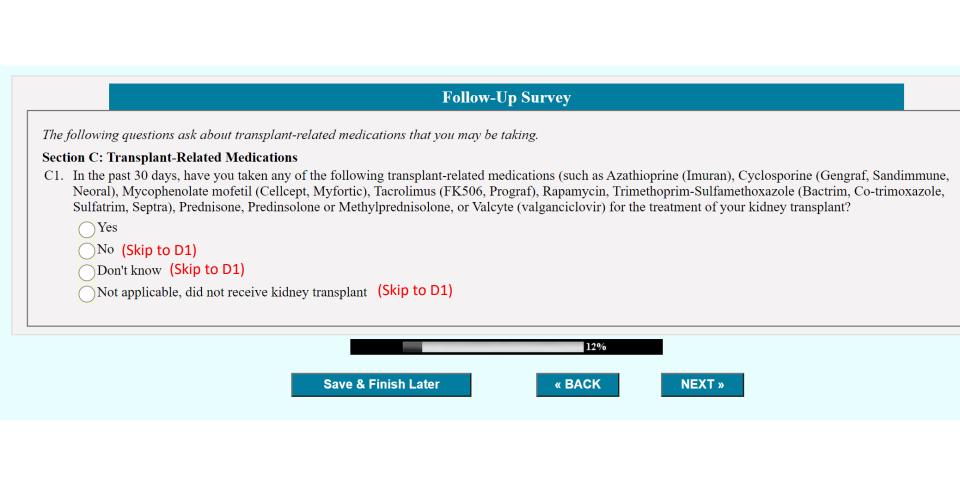
<u>June</u>	July 2013					August
Sun	Mon	Tue	Wed	Thu	Fri	Sat
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>
7	<u>8</u>	<u>9</u>	<u>10</u>	<u>11</u>	<u>12</u>	<u>13</u>
<u>14</u>	<u>15</u>	<u>16</u>	<u>17</u>	<u>18</u>	<u>19</u>	<u>20</u>
<u>21</u>	<u>22</u>	<u>23</u>	<u>24</u>	<u>25</u>	<u>26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

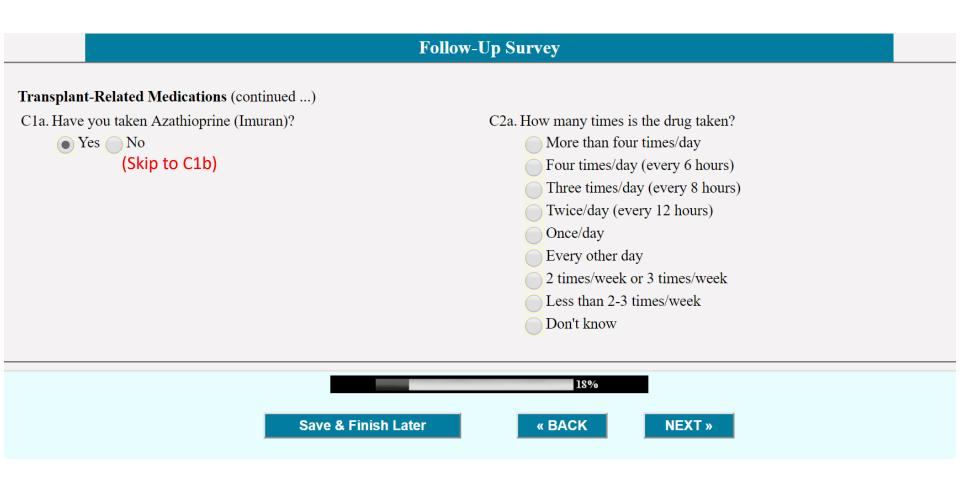
I Don't know/I'm not sure

56%

Save & Finish Later

« BACK





C1b. Have you taken Cyclosporine (Gengraf, Neoral, Sandimmune)?	C2b. How many times is the drug taken?
Yes No	More than four times/day
(Skip to C1c)	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

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

Transp	lant-R	elated	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

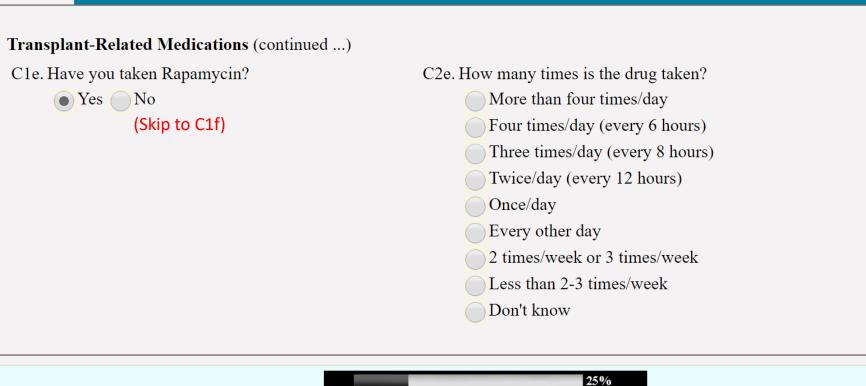
Less than 2-3 times/week

Oon't know

18%

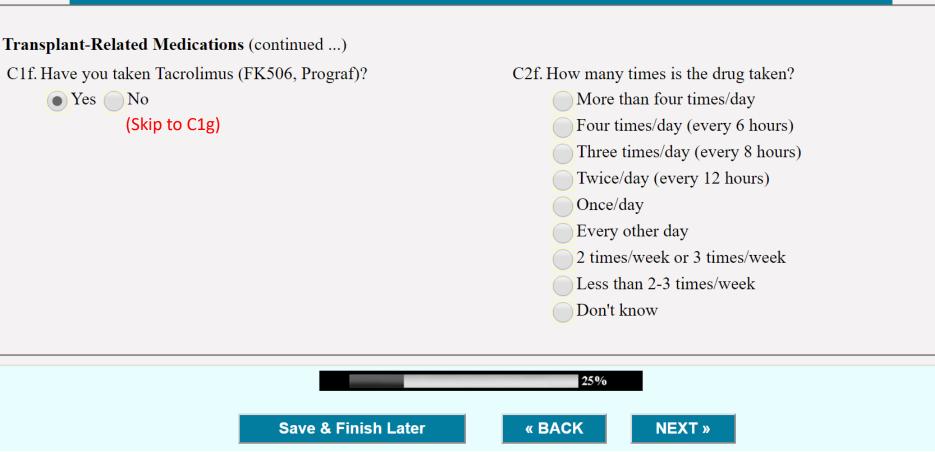
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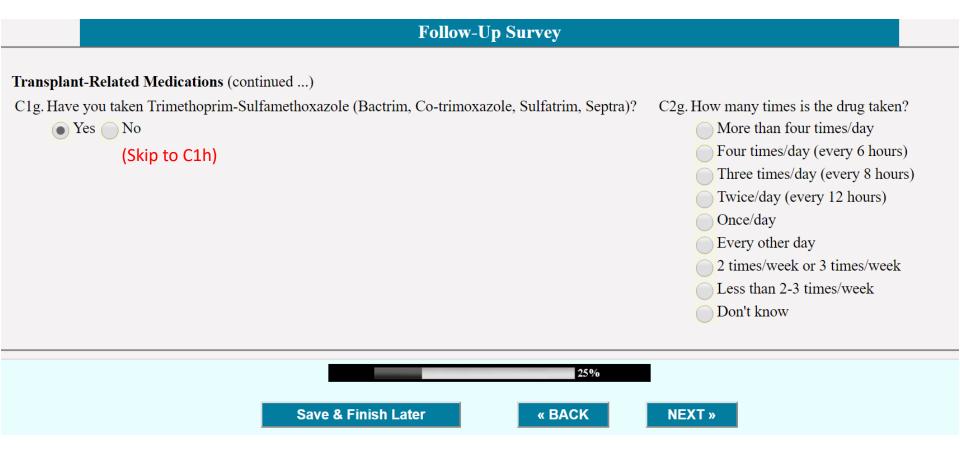
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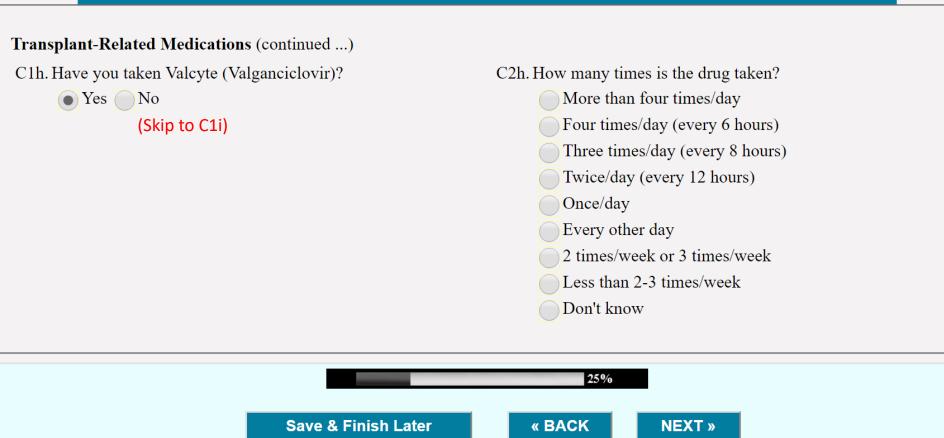


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« BACK







Follow-Up Survey Transplant-Related Medications (continued ...) C1i. Have you taken any other transplant related medication? C2i. How many times is the drug taken? Yes No (Skip to D1) More than four times/day Four times/day (every 6 hours) 1. Please specify the name of the drug: 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** »





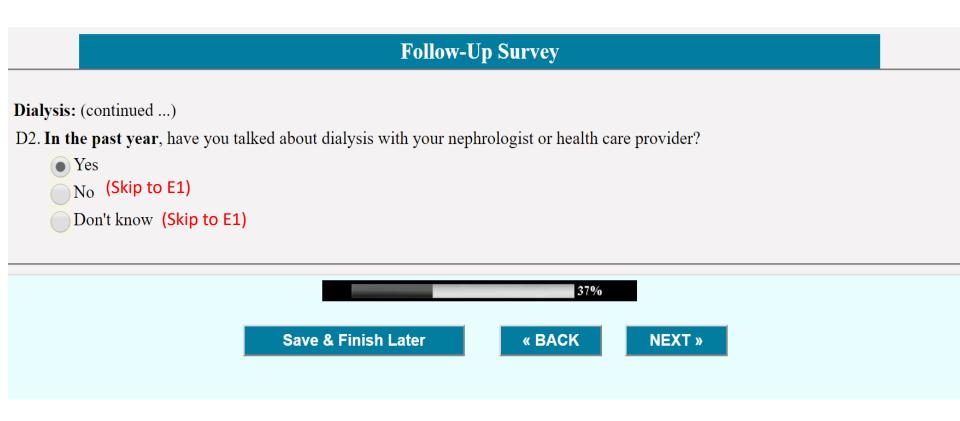
Dialysis: (continued ...)

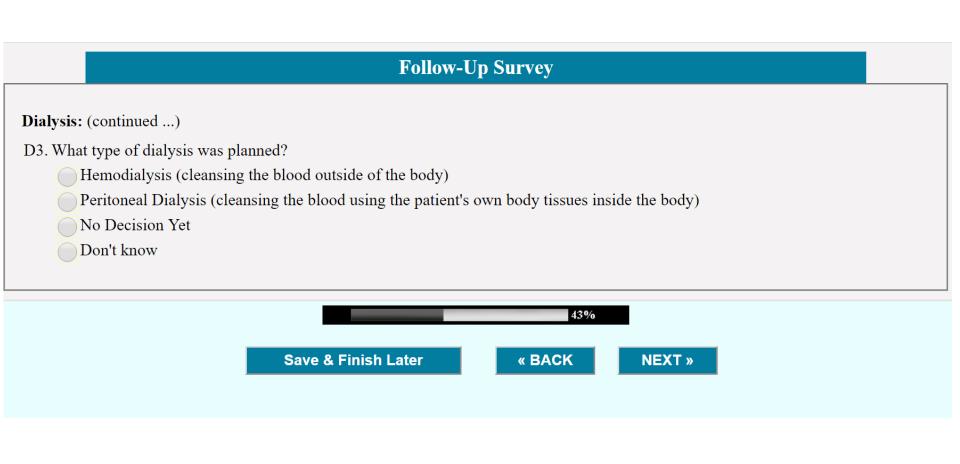
D1a. What type of dialysis did you use most recently:

- 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



	Follow-Up Survey
Pleas week If you August Sun M 5 12 19 26 I D1c. Are y	Most Recent Regularly Scheduled* Dialysis was Started or will start: see 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 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. a do not know the month or day, please enter the year. Otherwise, select "I Don't know/I'm not sure."
	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". Ono't know Not Applicable/Child is less than 5 years old and does not attend pre-school/pre-k	
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
Save & Finish Later « BACK NEXT »

E4.	• • • • • • • • • • • • • • • • • • • •	old at least half the time? A child is a person who is less than 18 years of age. Include spring, siblings, non-relatives. Include yourself if you are less than 18 years of age.
	Children Don't know	
	Which of the following children (under 18 years applicable.	of age) live in your primary household at least half the time? Include yourself, if
	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:	

Save & Finish Later

« BACK

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 No Don't know (If "Yes", "N/A" or "Don't Know", skip to E7)		
f. Unemployed not seeking work	Yes No No Don't know (If "Yes", "N/A" or "Don't Know", skip to E7)		
i. Are you self-employed?	Yes No Don't know		

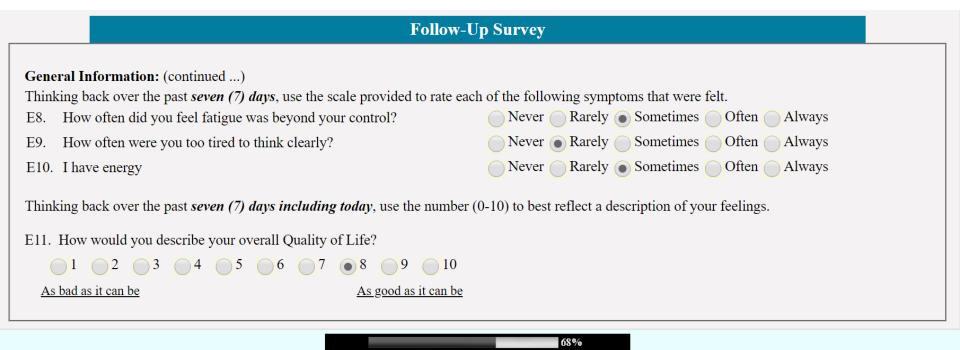
62%

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« BACK

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





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Save & Finish Later

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.

Save & Finish Later

68%

NEXT »

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Tonon op 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 be treated in the emergency room and then released the same day.	eing
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 2 Don't know	
68%	

Save & Finish Later

« BACK

4. 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?	

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 or MCHIP), dental insurance, and programs that help pay for medications. Yes No (If "Yes", skips to E17b)	, SCHIP
a. Please specify the reason why you do not have health insurance.	
Save & Finish Later « BACK NEXT »	

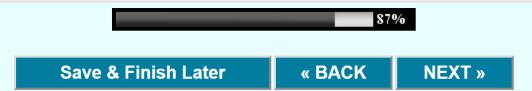
	Follov	v-Up Survey	
General Information: (continued)			
E17a. How long has it been since you last had AN	IY health insurance or coverag	ge?	
6 months or less	Any answe	r option skips to F1	
More than 6 months, but no more than	1 year ago		
More than 1 year, but no more than 3 y	ears ago		
More than 3 years			
Never had health insurance or coverage	e		
Don't know			
		75%	
	Save & Finish Later	« BACK	NEXT »
	Save & Finish Later	« BACK	NEAT »

Follow-Up Survey Section F: Medical History F1. In the past year, have you had a heart attack? Don't know Yes No 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% Save & Finish Later « BACK **NEXT** »

	Follow-Up Survey		
Medical History: (continued) The next question asks about diseases/illnesses that you may F5. In the past year, has a doctor or any other healthcare profes	ssional told you that you have any		
a. Diabetes Mellitus (Sugar diabetes, High Blood Sugar)b. Heart failure (congestive heart failure)	Yes No Don't know 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		
Save & Fini	sh Later « B	■ 81% BACK NEXT »	

Section G: Blood Pressure Medications
The next questions ask about the blood pressure medications that you may have taken in the past 30 days.

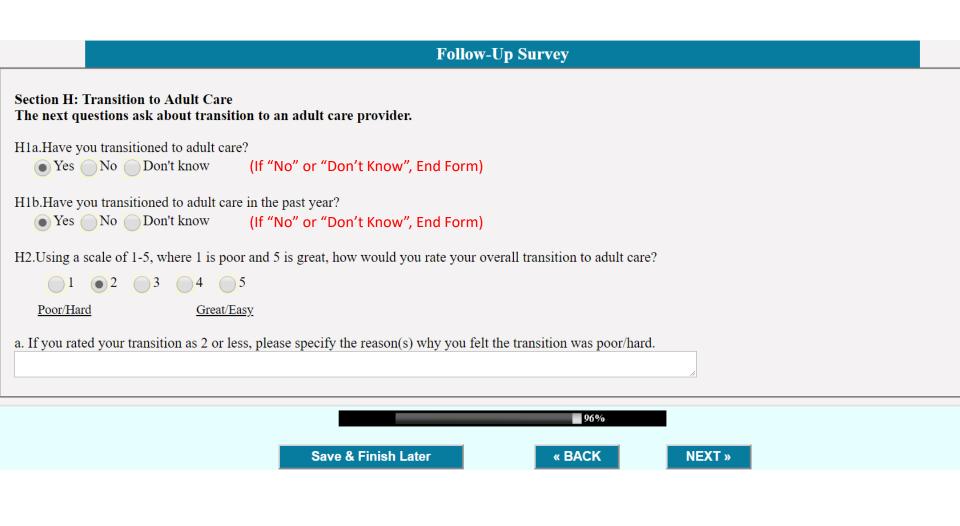
- G1. In the past 30 days, have you taken any blood pressure medications?
 - Yes No Don't know (If "No" or "Don't Know", skips to H1)
- G2. How many different blood pressure medications have you taken?



Follow-Up Survey				
Blood Pressure Medications (continued)				
<u>List of ACE Inhibitors</u>	List of Angiotensin Receptor Blockers (ARBs)			
Benazepril (Lotensin)	Candesartan (Atacand)			
Captopril (Capoten)	Irbesartan (Avapro)			
Enalapril (Vasotec)	Losartan (Cozaar)			
Fosinopril (Monopril)	Olmesartan (Benicar)			
Lisinopril (Prinivil, Zestril)	Telmisartan (Micardis)			
Quinapril (Accupril)	Valsartan (Diovan)			
Ramipril (Altace)				
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



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	
☐ B2.	Which donor option(s) has/have been discussed?	
D J.	• 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, Predinsolone 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	
Clg.	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	
☐ E17a.	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%