Web-based Follow-Up Survey Questions (WFU01)

Form Version: 0 1 / 0 1 / 2 5

WEB # (automated): ____ ____

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 (automated): ___ - ____ - _____

Birthday: ____/____/_____ (MM/DD/YYYY)

Date of Survey Entry (automated): ____/____/_____ (MM/DD/YYYY)

A1. What is your current weight?

a. ___ ___ ___ . ___ **(lbs)**

A2. What is your current Height/Stature?

a. ___ **(ft)**___ ___ **(in)**

A3. Self-report Serum Creatinine (SCr): |___| . |___| |___| (mg/dL)

Don't Know**……..……...** -8

A4. Are you currently anemic?

Yes**……..……** 1

No**…….……** 2 **(Skip to B1)**

Don't Know**…….** -8 **(Skip to B1)**

a. Self-report Hemoglobin (Hgb): |___|___| . |___| (g/dL)

Don't Know……..……... -8

b. Self-report Hematocrit (HCT): |___|___| . |___| (%)

Don't Know**……..……...** -8

Web-based Follow-Up Survey Questions (WFU01)

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

Section B: Transplantation

B1. Have you ever had a kidney transplant?

Yes……	1	
No……	2	**(Skip to B2)**
Don't Know……	-8	**(Skip to B2)**

B1a. How many kidney transplants have you had?

One……	1
Two……	2
Three or More……	3
Don't Know……	-8

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

Living Donor – Related……	1
Living Donor – Not Related……	2
Deceased Donor……	3
Don't Know……	-8

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."

___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

I Don't know/I'm not sure……-8

Web-based Follow-Up Survey Questions (WFU01)

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.

The kidney function is good/excellent……....	1	**(Skip to C1)**
The kidney is OK but I might need another transplant or dialysis in the near future (in 1 year or so)…..……...……	3	
The kidney is not working well and I am on dialysis……..	2	
Don't know/I'm not sure..……..……..……	-8	**(Skip to C1)**

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

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

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

	Yes	No	Don't Know
Living Donor	1	2	-8
Transplant Wait List/Deceased Donor	1	2	-8

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

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

a. Date listed on the Inactive Waitlist: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

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

I Don't know/I'm not sure……..……-8

b. Date listed on the Active Waitlist: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

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."

I Don't know/I'm not sure……..……-8

Web-based Follow-Up Survey Questions (WFU01)

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, Predinsolone or Methylprednisolone, or Valcyte (valganciclovir) for the treatment of your kidney transplant?

Yes..... 1
No..... 2 **(Skip to D1)**
Don't Know..... -8 **(Skip to D1)**
Not applicable, did not receive kidney transplant -1 **(Skip to D1)**

Medication **(Brand Name and/or Generic)**	Yes	No	C2. How many **times** is the drug taken?
C1a. Have you taken Azathioprine (Imuran)?	1	2 **(skip to C1b)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1b. Have you taken Cyclosporine (Gengraf, Neoral, Sandimmune)?	1	2 **(skip to C1c)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1c. Have you taken Mycophenolate mofetil (Cellcept, Myfortic)?	1	2 **(skip to C1d)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8

Web-based Follow-Up Survey Questions (WFU01)

Medication **(Brand Name and/or Generic)**	Yes	No	C2. How **times** is the drug taken?
C1d. Have you taken Prednisone, Prednisolone or Methylprednisolone?	1	2 **(skip to C1e)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1e. Have you taken Rapamycin?	1	2 **(skip to C1f)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1f. Have you taken Tacrolimus (FK506, Prograf)?	1	2 **(skip to C1g)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1g. Have you taken Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra)?	1	2 **(skip to C1h)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8

Web-based Follow-Up Survey Questions (WFU01)

Medication **(Brand Name and/or Generic)**	Yes	No	C2. How **times** is the drug taken?
C1h. Have you taken Valcyte (Valganciclovir)?	1	2 **(skip to C1i)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8
C1i. Have you taken any other transplant related medication? 1. Please specify the name of the drug: _____	1	2 **(skip to D1)**	More than four times/day..... 1 Four times/day (every 6 hours)..... 2 Three times/day (every 8 hours)..... 3 Twice/day (every 12 hours)..... 4 Once/day..... 5 Every other day..... 6 2 times/week or 3 times/week..... 7 Less than 2-3 times/week..... 8 Don't Know..... -8

Web-based Follow-Up Survey Questions (WFU01)

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

Section D: Dialysis

D1. Have you ever been on dialysis?

Yes……..…….. 1
No……..…….. 2 **(Skip to D2)**
Don't Know…….…… -8 **(Skip to D2)**

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

Hemodialysis (cleansing the blood outside of the body)… 1
Peritoneal Dialysis (cleansing the blood using the patient's own body tissues inside the body)……..……. 2
Don't Know……..…….. -8

D1b. Date Chronic* Dialysis Started: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

I Don't Know/I'm Not Sure……..……-8

For hemodialysis, please enter indicate the date when you started 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."

D1c. Are you currently receiving regularly scheduled dialysis therapy?

Yes……..…….. 1 **(SKIP TO E1)**
No……..…… 2
Don't Know……..…….. -8

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

Yes……..…….. 1
No……..…… 2 **(SKIP TO E1)**
Don't Know……..…….. -8 **(SKIP TO E1)**

D3. What type of dialysis was planned?

Hemodialysis (cleansing the blood outside of the body)…. 1
Peritoneal Dialysis (cleansing the blood using the patient's own body tissues inside the body)……..…..…. 2
No Decision yet……. 9
Don't Know……..……..…… -8

Web-based Follow-Up Survey Questions (WFU01)

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…… -8

Not Applicable/Child is less than 5 years old and does not attend pre-school/pre-k…… -1

E2. What is your current relationship status?

Single…… 1
Married…… 2
Non-Married partner…… 3

E3. Who do you identify as your primary support system? **(Check "Yes", "No" or "Don't Know" for EACH of the following)**

	Yes	No	Don't Know
a. Parent/legal guardian/caregiver.....	1	2	-8
b. Spouse/Partner.....	1	2	-8
c. Other family member(s).....	1	2	-8
d. Friend.....	1	2	-8
e. Colleague/Co-worker.....	1	2	-8

The following questions ask about your household.

E4. How many people live in the household at least half the time?

___ ___ people
Don't Know…… -8

E5. What is your current living status/arrangement? **(Select "Yes", "No" or "Don't Know" for EACH of the following.)**

	Yes	No	Don't Know
a. Live Alone.....	1	2	-8
b. Live with at least one parent/legal guardian……..	1	2	-8
c. Live with other family member.....	1	2	-8
d. Live with spouse/significant other/partner.....	1	2	-8
e. Live with roommate.....	1	2	-8

Web-based Follow-Up Survey Questions (WFU01)

E6. What is your current employment status?

	Yes	No	N/A	Don't Know
Working full-time (35 hours or more per week).....	1	2	-1	-8
Working part-time (less than 35 hours per week).....	1	2	-1	-8
Disability Income.....	1	2	-1	-8
Currently Enrolled Student.....	1	2	-1	-8
Unemployed but seeking work.....	1 **(skip to E7)**	2	-1 **(skip to E7)**	-8 **(skip to E7)**
Unemployed not seeking work.....	1 **(skip to E7)**	2	-1 **(skip to E7)**	-8 **(skip to E7)**

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

Yes..... 1
No..... 2 **(Skip to E8)**
Don't Know..... -8 **(Skip to E8)**
Not Applicable / I am male..... -1 **(Skip to E8)**

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

___ ___ years
Don't Know..... -8

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

Item	Never	Rarely	Sometimes	Often	Always
E8. How often did you feel fatigue was beyond your control?	1	2	3	4	5
E9. How often were you too tired to think clearly?	1	2	3	4	5
E10. I have energy	1	2	3	4	5

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

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..... 1 **(Skip to E13)**
No..... 2

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

_____

Web-based Follow-Up Survey Questions (WFU01)

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…….. 1
No…….. 2 **(Skip to E14)**
Don't Know…….. -8 **(Skip to E14)**

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

___ ___ times
Don't Know…….. -8

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	1	2	
b.	A private doctor's office	1	2	
c.	Hospital Outpatient Department	1	2	
d.	Urgent care	1	2	
e.	The emergency room	1	2	**(Skip to E15)**

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

___ ___

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

Yes…….. 1
No…….. 2 **(Skip to E16)**
Don't Know…….. -8 **(Skip to E16)**

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

___ ___ times
Don't Know…….. -8

E16. In the past year, has your health insurance changed?

Yes …….. 1
No …….. 2

Web-based Follow-Up Survey Questions (WFU01)

E17. Do you currently have any kind of health insurance or health care coverage? This includes both private and government/state insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.

Yes ……..... 1 **(Skip to E19)**
No ……..……..……..……..... 2

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

_____

E18. How long has it been since you last had ANY health insurance or coverage?

6 months or less……..…. 1 **(Skip to F1)**
More than 6 months, but no more than 1 yr ago…….. 2 **(Skip to F1)**
More than 1 year, but no more than 3 years ago……... 3 **(Skip to F1)**
More than 3 years…… 4 **(Skip to F1)**
Never had health insurance or coverage……. 5 **(Skip to F1)**
Don't know…… -8 **(Skip to F1)**

E19. Do you have private insurance?

Yes……..……..…. 1
No……..…..... 2

a. Do you or your family members pay for any of the insurance premium?

Yes……..……..…. 1
No……..…..... 2

E20. Do you have government/state (Medicaid, SCHIP, MCHIP) insurance?

Yes……..……..…. 1
No……..…..... 2

E21. In the past year, was there any time when you were not covered by ANY health insurance or coverage?

Yes……..……..…. 1
No……..…..... 2 **(Skip to F1)**

E22. In the past year, about how long were you without ANY health insurance or coverage?

____ ____ 1 = months 2 = weeks 3 = days

Web-based Follow-Up Survey Questions (WFU01)

Sections F: Medical History

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

Yes…… 1
No…… 2
Don't Know…… -8

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

Yes…… 1
No…… 2
Don't Know…… -8

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

Yes…… 1
No…… 2
Don't Know…… -8

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

Yes…… 1
No…… 2
Don't Know…… -8

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?

		Yes	No	Don't Know
a.	Diabetes Mellitus (Sugar diabetes, High Blood Sugar)	1	2	-8
b.	Heart failure (congestive heart failure)	1	2	-8
c.	Passage of kidney stones	1	2	-8
d.	Leukemia	1	2	-8
e.	Lymphoma	1	2	-8
f.	Skin cancer	1	2	-8
g.	Other type of cancer If other type, please specify _____	1	2 **(Skip to F5h)**	-8 **(Skip to F5h)**
h.	Anxiety	1	2	-8
i.	Depression	1	2	-8

Web-based Follow-Up Survey Questions (WFU01)

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……	1	
No……	2	**(Skip to H1)**
Don't Know……	-8	**(Skip to H1)**

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

List of ACE Inhibitors	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……	1	
No……	2	**(Skip to H1)**
Don't Know……	-8	**(Skip to H1)**

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

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……	1	
No……	2	**(End Form)**
Don't Know……	-8	**(End Form)**

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

Yes……	1	
No……	2	**(End Form)**
Don't Know……	-8	**(End Form)**

Web-based Follow-Up Survey Questions (WFU01)

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?

Poor/Hard				Great/Easy
1	2	3	4	5

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

_____

H3a. Using a scale of 1 – 5, where 1 is not at all satisfied and 5 is very satisfied, how would you rate your overall satisfaction **with your adult nephrology provider/team**?

Not at all satisfied				Very satisfied
1	2	3	4	5

b. If you rated your satisfaction as 2 or less, please specify the reason(s) why you are unsatisfied.

_____

H4. Is your current **nephrology** provider/team considered?

Private practice (doctor's office not part of a hospital or university) 1
Affiliated (part) with a hospital or a university…….. 2
Don't Know……. -8

H5. In the past year, where have you gone to receive your nephrology care?

Provide the name and address of your **nephrology** care provider/team.

Name of Provider: _____

Location (Address): _____

H6. In the past year, when you went for **nephrology care**, did you usually (more than half of the time) see the same health care provider or group of providers for your **nephrology** medical appointments?

Yes……. 1
No……. 2
Don't Know……. -8

[INSERT CONFIRMATION PAGE AT THE END]