Phone/In-Person Follow-Up Interview Form (PFU01)

Participant ID: ___ - ____ - ______

PIP #: ____ ____ (Must match the number recorded on the PFU02 form)

Interviewer's Initials: ____ ____ ____

Date Form Completed: ____/____/________ (MM/DD/YYYY)

Form Version: 0 3 / 0 1 / 1 8

INDICATE PERSON COMPLETING THE FORM

Child/young adult............................	1
Parent or other adult........................	2
Both (Parent and Child/young adult)	3

Section A: Vital Status

A1. Date of Interview/Vital Status Determination: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

A2. What is the vital status of the participant? Circle only one answer.

Alive...	1	**(Skip to Question A5)**
Deceased*...	2	
Unknown...	3	**(Skip to Question A4)**
Alive/Contacted but refused interview........	4	**(END FORM HERE)**

***Note: If patient death is known, do not contact family.**

A3. Date of Participant's Death: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

A3i. Cause of Death (Please use code from list provided): ___ ___ **(END FORM HERE)**

A4. If vital status is unknown, what methods of contact were used to locate or reach the participant?
(Please circle "Yes", "No" or "Don't Know" for EACH of the following methods below)

	Yes	No	Don't Know
Home Number	1	2	-8
Work Number	1	2	-8
Family Contact	1	2	-8
Social Contact	1	2	-8
Other Method	1	2 **(Skip to A4i)**	-8 **(Skip to A4i)**

Specify other method used: ______________________

A4i. Date of first attempt to contact participant: ___ ___/ ___ ___/ ___ ___ ___ ___

A4ii. Number of times attempted to contact participant: ___

A4iii. Date of last attempt to contact participant: ___ ___/ ___ ___/ ___ ___ ___ ___

Phone/In-Person Follow-Up Interview Form (PFU01)

A5. Who reported the vital status of the participant (i.e., who participated in the interview or provided information about the vital status)?

Participant.. 1
Mother... 2
Father... 3
Relative or Acquaintance.......................... 4
i. Please specify relationship: ________________________________
Other Method...................................... 5
i. Please specify **OTHER method**: ________________________________

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Sections B – D: Renal Replacement Therapy

Section B: Transplantation

B1. Has (*name of participant*) ever had a kidney transplant?

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

B1a. How many transplants has (*name of participant*) had?

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

B1b. Was (*name of participant*)'s most recent kidney transplant from a living related, 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 Transplant: ___ ___/ ___ ___/ ___ ___ ___ ___ (M M D D Y Y Y Y)
Indicate the date of the most recent transplant. If the month or day is unknown, indicate the year. Otherwise, indicate "Don't Know/Not Sure."
Don't Know/Not sure………………-8

B1d. When you see *(name of participant)*'s doctor about their kidney transplant, how does he/she say it's doing? If he/she has had more than one kidney transplant please answer based on their most recent transplant.

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

Phone/In-Person Follow-Up Interview Form (PFU01)

B2. **In the past year**, have you talked about kidney transplant with (*name of participant*)'s 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?
(Please circle "Yes", "No" or "Don't Know" for EACH of the following)

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

B4. Has (*name of participant*) been listed for deceased donor transplantation, in other words, is *(name of participant)* on a transplant waiting list?

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

B4a. Date active on the waiting list:

Indicate the date he/she was activated on the waiting list. If the month or day is unknown, indicate the year. Otherwise, indicate "Don't Know/Not Sure."

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

Don't Know/Not sure……….…….-8

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Section C: Transplant-Related Medications

C1. **In the past 30 days,** has (*name of participant*) taken any of the following transplant-related medications (such as Azathioprine (Imuran), Cyclosporine (Sandimmune, Neoral), Mycophenolate mofetil (Cellcept), Tacrolimus, (FK506, Prograf), Trimethoprim-Sulfamethoxazole (Bactrim, Sulfatrim, Septra), Prednisone, Methylprednisolone) for the treatment of their kidney transplant?

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

	Medication (Brand Name and/or Generic)	Yes	No		C2. How **times** is the drug taken?
C1a.	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.	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.	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
C1d.	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

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Medication **(Brand Name and/or Generic)**	Yes	No	C2. How **times** is the drug taken?	
C1e. 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. 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. 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
C1h. 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. Other transplant related medication 1. 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

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Section D: Dialysis

D1. Has (*name of participant*) ever been on dialysis?

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

D1a. What type of dialysis did (*name of participant*) use most recently:

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

D1b. Date Most Recent Regularly Scheduled* Dialysis was started: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

Don't Know/Not Sure………………-8

Indicate the start date of the most recent "regularly scheduled" dialysis.

For hemodialysis, indicate the date when participant started treatments 2 or more days/week for at least 3 months.

For peritoneal dialysis (PD), indicate the date when participant started treatments 5 or more days a week for at least 3 months.

If the month or day is unknown, indicate the year. Otherwise, indicate "Don't Know/Not Sure."

D1c. Is (*name of participant*) currently receiving regularly scheduled dialysis therapy?

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

D2. **In the past year,** have you discussed dialysis with (*name of participant*)'s nephrologist or health care provider?

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

D3. What type of dialysis was planned?

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

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Section E: General Information

E1. What is the **highest** grade or level of school that (*name of participant*) has COMPLETED? **For example, if the participant is currently in the 12th grade, then enter "11", or if the participant is currently in the 6th grade, then enter "5". In addition, if the participant is in the 1st grade, kindergarten or pre-school/pre-K, then enter "0" or if participant is a sophomore in college, then enter "13".**

___ ___Grade

Don't Know………………..…………………..…… -8

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

The following questions ask about the participant's primary household. The primary household is the parent/guardian's home in which the participant lives at least half of the time. If the participant does 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 the 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 participant if 18 years of age.

___ ___ adults

Don't Know………………..…………………..…… -8

E3. Which of the following adults (18 years of age or older) live in the primary household at least half the time? Include the participant, if applicable. **(Circle "Yes", "No" or "Don't Know" for EACH of the following.)**

	Yes	No	Don't Know
a. Birth Mother…………	1	2	-8
b. Birth Father…………	1	2	-8
c. Step Mother/ Adoptive Mother…………	1	2	-8
d. Step Father/ Adoptive Father…………	1	2	-8
e. Participant…………	1	2	-8
f. Spouse/domestic partner…………	1	2	-8
g. Other…………	1	2 **(Skip to E4)**	-8 **(Skip to E4)**

i. Specify: _________________________

E4. How many children live in the 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 participant if less than 18 years of age.

___ ___ children

Don't Know………………..…………………..…… -8

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

E5. Which of the following children (**under** 18 years of age) live in the primary household at least half the time? Include the participant, if applicable. **(Circle "Yes", "No" or "Don't Know" for EACH of the following.)**

	Yes	No	Don't Know
a. Biological Child of Participant (son/daughter)......	1	2	-8
b. Step child/ Adopted child of participant...............	1	2	-8
c. Sibling..	1	2	-8
d. Participant...	1	2	-8
e. Other..	1	2 **(Skip to E6)**	-8 **(Skip to E6)**

i. Specify: ___________________________

E6. What is the current employment status of (*name of participant*)?
(Circle "Yes", "No", "Not applicable (N/A)" or "Don't Know" for EACH of the following.)

	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)**

i. Is (*name of participant*) self-employed?

Yes.. 1
No.. 2
Don't Know.. -8

E7. Has (*name of participant*) started her menses (i.e. period)?

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

a. How old was she when she started her menses (i.e. period)?

___ ___ years
Don't Know.. -8

Phone/In-Person Follow-Up Interview Form (PFU01)

Thinking back over the past ***seven (7) days***, use the scale provided to rate each symptom that was felt.

	Item	Never	Rarely	Sometimes	Often	Always
E8.	How often did (*name of participant*) feel fatigue was beyond his/her control?	1	2	3	4	5
E9.	How often was (*name of participant*) too tired to think clearly?	1	2	3	4	5
E10.	(*name of participant*) has 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 (*name of participant*) describe 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, has (*name of participant*) seen a healthcare provider/nephrologist? (Include well child visits, sick visits and ER visits. **Do not include** times when (name of participant) was hospitalized overnight).

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

a. Specify the reason why *(name of participant)* has not seen a healthcare provider/nephrologist.

____

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, has (*name of participant*) 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 was (*name of participant*) hospitalized during the past year?

___ ___ times
Don't Know……………………………………………... -8

Phone/In-Person Follow-Up Interview Form (PFU01)

E14. In the past year, has (*name of participant*) had Urinary Tract Infections (UTI)?

Yes………………………..……………………….. 1
No……………………………………………..……… 2 **(Skip to E15)**
Don't Know……………………..……………………. -8 **(Skip to E15)**

a. How many different times did (*name of participant*) have a UTI during the past year?

___ ___ times
Don't Know……………………….....………… -8

E15. Does (*name of participant*) currently have any kind of health insurance or health care coverage? This includes both private and public insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.

Yes …………………………………………….......... 1 **(Skip to E16b)**
No …………..………..………………………........ 2

a. Specify the reason why *(name of participant)* does not have health insurance.

____

E16a. How long has it been since (name of participant) 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)**

E16b. In the past year, was there any time when (name of participant) was not covered by ANY health insurance or coverage?

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

E16c. In the past year, about how long was (name of participant) without ANY health insurance or coverage?

____ ____ 1 = months 2 = weeks 3 = days

Phone/In-Person Follow-Up Interview Form (PFU01)

Sections F: Medical History

F1. In the past year, has (*name of participant*) had a heart attack?

Yes.. 1
No.. 2
Don't Know.. -8

F2. In the past year, has (*name of participant*) had a stroke?

Yes.. 1
No.. 2
Don't Know.. -8

F3. In the past year, has (*name of participant*) been diagnosed with angina (heart related chest pain)?

Yes.. 1
No.. 2
Don't Know.. -8

F4. In the past year, has (*name of participant*) been diagnosed with an irregular heart rhythm?

Yes.. 1
No.. 2
Don't Know.. -8

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

The next question asks about diseases/illnesses that (*name of participant*) may currently have or has developed in the past year.

F5. In the past year, has a doctor or any other healthcare professional told you that (name of participant) has any of the following diseases? **(Circle "Yes", "No" or "Don't Know" for EACH of the following.)**

		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	1	2 **(Skip to F5h)**	-8 **(Skip to F5h)**
	If other type, please specify ______________________________			
h.	Anxiety	1	2	-8
i.	Depression	1	2	-8

Section G: Blood Pressure Medications

The next questions ask about the blood pressure medications taken in the past 30 days

G1. **In the past 30 days,** has (*name of participant*) 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 has (*name of participant*) 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. Is (*name of participant*) taking any ACE/ARB?
- Yes………………………..……………………….. 1
- No……………………………………………..……. 2 **(Skip to H1)**
- Don't Know……………………..……………………. -8 **(Skip to H1)**

G4. How many different ACE/ARBs is (*name of participant*) taking? ___ ___

Participant ID: ___ - ___ - ______
PIP #: ____________
Date Form Completed:___/___/_____
(MM/DD/YYYY)

Phone/In-Person Follow-Up Interview Form (PFU01)

Section H: Transition to Adult Care

The next questions ask about transition to adult care provider.

H1a. Has (*name of participant*) transitioned to adult care?
- Yes…………………………………………………….. 1
- No…………………………………………………….. 2 **(END)**
- Don't Know……………………………………………. -8 **(END)**

H1b. Has (name of participant) transitioned to adult care in the past year?
- Yes…………………………………………………….. 1
- No…………………………………………………….. 2 **(END)**
- Don't Know……………………………………………. -8 **(END)**

Using a scale of 1 – 5, where 1 is poor and 5 is great, rate the transition from pediatric to adult care.

	Poor/Hard				Great/Easy
H2. How would (*name of participant*) rate the overall transition to adult care?	1	2	3	4	5

a. If score is less than or equal to 2, specify reason(s) (*name of participant*) felt the transition was poor/hard.

____