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 9 / 1 5 / 2 1

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: ___ ___/ ___ ___/ ___ ___ ___ ___

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

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**: ________________________________

A6. What is your current weight?

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

A7. What is your current Height/Stature?

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

A8. Self-report Serum Creatinine (SCr): |___| **.** |___| |___| (mg/dL)
Don't Know………………..………... -8

A9. Is (*name of participant*) 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

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

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

Sections B – Kidney 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:
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."

___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y
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 or dialysis 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)**
Not applicable, did not receive kidney transplant	-1	**(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

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	2	**(skip to D1)**	More than four times/day…………………	1
				Four times/day (every 6 hours)……………	2
1. Specify the name of the drug:				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

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 or will start:

___ ___/ ___ ___/ ___ ___ ___ ___
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? <u>An adult</u> 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? <u>A child</u> 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

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 (1-10) to best reflect a description of your feelings.

		1	2	3	4	5	6	7	8	9	10
E11.	How would (*name of participant*) describe overall Quality of Life	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, where has (*name of participant*) gone to receive kidney clinical care? **(Please circle "Yes" or "No" for EACH of the following places.)**

	Yes	No	
a. A clinic or health care center	1	2	
b. A private doctor's office	1	2	
c. Hospital Outpatient Department	1	2	
d. The emergency room	1	2	**(Skip to E15)**

1. How many times has (name of participant) received care at the emergency room in the past year?

___ ___

E15. In the past year, has (*name of participant*) 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 (*name of participant*) have a UTI during the past year?

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

E16. 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 E17b)**
No ………………………………………………… 2

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

____

E17a. 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)**

E17b. 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)**

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

E17c. In the past year, about how long was (name of participant) without ANY health insurance or coverage?

____ ____ 1 = months 2 = weeks 3 = days

Section 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

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	

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

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

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? ___ ___

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	**(Skip to Section I)**
Don't Know…………………………………………	-8	**(Skip to Section I)**

H1b. Has (name of participant) transitioned to adult care in the past year?

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

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.

____

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

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

Section I: COVID-19 Illness Information

I1. a. Did you receive a laboratory confirmed diagnosis of COVID-19 in the past year?

Yes………………………………………… 1 **(Skip to I1c)**
No………………………………………… 2

b. Did your doctor or healthcare provider tell you that you had a suspected case of COVID-19 in the past year?

Yes………………………………………… 1
No………………………………………… 2 **(Skip to J1)**

c. What was the date of the confirmed diagnosis or the date that you were told you had a suspected case of COVID-19? (If specific date is unknown, please provide month and year)

Date: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

Don't know……………………… -8

d. Did you have contact with a confirmed case of COVID-19?

Yes………………………………………… 1
No………………………………………… 2 **(Skip to I2)**

e. Was the contact within 14 days of the suspected or confirmed COVID-19 illness?

Yes………………………………………… 1
No………………………………………… 2
Don't know…………………………………… -8

f. At the time of the your suspected or confirmed COVID-19 illness, did you and an individual with a confirmed case of COVID-19 live in the same household?

Yes………………………………………… 1
No………………………………………… 2

I2. a. Are you currently sick with COVID-19?

Yes………………………………………… 1
No………………………………………… 2 **(Skip to I2c)**

b. Number of days since symptom onset

____________ **(Skip to J1)** Don't know……… -8 **(Skip to J1)**

c. Total length of illness (if recovered)

___ ___ 1 = day(s) 3 = month(s)
2 = week(s) -8 = don't know

Not recovered/Not applicable………. -1

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Section J: COVID-19 Impact

J1. Due to COVID-19, in the past week, how often…

		Not at all	1-2 days	3-4 days	5-7 days
a.	Have you felt nervous, anxious, or on edge?	1	2	3	4
b.	Have you felt depressed?	1	2	3	4
c.	Have you felt lonely?	1	2	3	4
d.	Have you felt hopeful about the future?	1	2	3	4
e.	Have you had physical reactions, such as sweating, trouble breathing, nausea or a pounding heart, when thinking about your experience with the novel coronavirus (COVID-19) pandemic?	1	2	3	4

Please indicate if you agree or disagree with the following statements.

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly agree
J2.	I am very worried about getting the coronavirus.	1	2	3	4	5
J3.	I am very worried about my family/friends getting the coronavirus.	1	2	3	4	5
J4.	I am very worried about giving someone else the coronavirus.	1	2	3	4	5
J5.	I have a hard time sleeping because of the coronavirus.	1	2	3	4	5
J6.	I have had difficulties concentrating because of the coronavirus.	1	2	3	4	5
J7.	Thinking about the coronavirus makes me very anxious.	1	2	3	4	5
J8.	I am feeling overwhelmed by the coronavirus.	1	2	3	4	5

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

Section K: COVID-19 Impact

The novel coronavirus (COVID-19) pandemic has impacted people in different ways. The following series of questions ask you to rate whether and how much the COVID-19 pandemic has changed various aspects of your life since around March 1, 2020.

K1. Have your daily routines changed since March 1, 2020? Daily routines are activities like your work, school, social and religious activities or other ways you normally spend your time.

No, I have had no changes to my routines... 0
Yes, I have had mild changes to a few of my routines... 1
Yes, I have had moderate changes across several of my routines................................ 2
Yes, I have had severe changes across most or all of my routines............................... 3

K2. Has your household income changed since March 1, 2020?

No, there have been no changes to my household incomes.. 0
Yes, there have been small changes, but I am able to meet all my needs and pay bills....... 1
Yes, there have been moderate changes and I made cuts, but I am able to meet basic needs and pay bills.. 2
Yes, there have been severe changes and I am unable to meet basic needs or pay bills..... 3

K3. Has your access to food changed since March 1, 2020?

No, my access to food has not changed.. 0
Yes, I have had enough food, but difficulty getting to the store or finding items.................. 1
Yes, I have occasionally been without food or good quality foods.................................. 2
Yes, I have frequently been without enough food.. 3

K4a. Have you been eating more food than usual since March 1, 2020?

No, there have been no changes, or I have been eating slightly less than usual................ 0
Yes, I have been eating slightly more than usual.. 1
Yes, I have been eating more frequently 2
Yes, I have been eating much more frequently.. 3

K4b. Have you been eating more processed food than usual since March 1, 2020?

No, there have been no changes, or I have been eating slightly less than usual................ 0
Yes, I have been eating slightly more than usual.. 1
Yes, I have been eating more processed foods than usual.. 2
Yes, I have been eating a significantly less healthy diet.. 3

K5. Has your normal physical activity changed since March 1, 2020?

No, I do not normally exercise.. 0
No, I have been exercising with the same frequency and intensity as I usually do............. 1
Yes, I have been exercising regularly, but with less intensity than usual.......................... 2
Yes, I have not been exercising regularly as usual, but the intensity is the same as usual.... 3
Yes, I have been not exercising at all and I am very sedentary...................................... 4

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K6. Has your access to medical health care changed since March 1, 2020?

No, I have not tried to access care, or I haven't needed care since March 1, 2020…………	0
No, there have been no changes to my medical health care………………………………………	1
Yes, I have had mild changes, such as appointments moved to telehealth instead of in-person visits………………………………………………………………………………	2
Yes, I have had moderate changes, such as delays in my appointments or getting prescriptions with some impact on my health……………………………………………………	3
Yes, I have had severe changes; I have been unable to access needed care with impact on my health………………………………………………………………………………	4

K7. Has access to extended family and trusted friends changed since March 1, 2020?

No, there has been no change……………………………………………………………………	0
Yes, there has been mild changes. I continued to visit with social distancing, made phone calls or connected through social media…………………………………………………	1
Yes, there has been moderate changes, with loss of contact with some friends and family, but not all………………………………………………………………………………	2
Yes, there has been severe changes; with loss of contact with all of my friends and family...	3

K8. Overall, considering all the possible ways your life may have been impacted by the COVID-19 pandemic, how much has the pandemic impacted your day-to-day life?

It has not impacted my life at all………………………………………………	0
It has impacted my life a little…………………………………………………	1
It has moderately impacted my life……………………………………………	2
It has extremely impacted my life………………………………………………	3
Refused to answer………………………………………………………………	-7

Section L: COVID-19 Socialization Questions

The next series of questions about your experiences with your neighbors and in your neighborhood since the COVID-19 pandemic (March 1, 2020). Please indicate whether you agree or disagree with the following statements.

		Agree	Disagree
L1.	I can count on people in my neighborhood to help me if I'm sick………………………	1	2
L2.	My neighbors would go to the store for me if I'm sick…………………………………...	1	2

The next series of questions ask about social distancing measures and other activites to reduce exposure to COVID-19. Not applicable (NA) means you typically do not participate in these activities.

		Yes	No	NA
L3.	Since social distancing measures have been put in place in your city, have your neighbors			
a.	Checked in on you to see if you needed anything?	1	2	-1
b.	Helped each other with things like grocery shopping or running errands to minimize their risk for COVID-19?	1	2	-1
c.	Worked together to take care of each other?	1	2	-1

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L4.	What actions have you taken to reduce your risk of exposure to COVID-19 since March 1, 2020?	Yes	No	NA
a.	Washing hands and/or using sanitizer frequently………………………………………	1	2	-1
b.	Staying at least 6 feet away from others………………………………………………	1	2	-1
c.	Avoiding large gatherings……………………………………………………………	1	2	-1
d.	Not going out to restaurants or bars…………………………………………………	1	2	-1
e.	Cancelled planned travel……………………………………………………………	1	2	-1
f.	Wearing a face mask…………………………………………………………………	1	2	-1
g.	Not shaking hands or touching people………………………………………………	1	2	-1
h.	Staying home when I am sick…………………………………………………………	1	2	-1
i.	Not going to work or working remotely (when working is possible)………………	1	2	-1
j.	Not going to school (when attending school is possible)…………………………	1	2	-1
k.	Not going to church or faith services (when church holds in-person services)………	1	2	-1
l.	Avoiding public transportation………………………………………………………	1	2	-1
m.	Wiping down surfaces with disinfectant……………………………………………	1	2	-1
n.	Ordering groceries for delivery/curb-side pickup…………………………………	1	2	-1
o.	Following government guidelines or rules to stay at home and limiting contacts with other people…………………………………………………………………	1	2	-1
p.	Placed under full quarantine by local authorities…………………………………	1	2	-1

L5. Did you receive any recommendations from a healthcare provider about reducing your risk of exposure to COVID-19?

		Yes	No
a.	My primary care doctor…………………………………………………	1	2
b.	My nephrologist…………………………………………………………	1	2
c.	Another provider…………………………………………………………	1	2

END FORM