

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

Participant ID:                    \_\_\_ - \_\_\_ - \_\_\_\_\_

PIP #:                                    \_\_\_ \_\_\_

Interviewer's Initials:            \_\_\_ \_\_\_ \_\_\_

Date Form Completed:            \_\_\_/\_\_\_/\_\_\_\_\_ (MM/DD/YYYY)

Form Version:                      0     3   /   0     1   /   1     4  

INDICATE PERSON	Child/young adult.....	1
COMPLETING THE FORM	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)**
- 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 <b>(Skip to A4i)</b>	-8 <b>(Skip to A4i)</b>

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: \_\_\_\_ - \_\_\_\_ - \_\_\_\_

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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: \_\_\_\_\_

### Section B: Renal Replacement Therapy

#### Transplantation:

B1. Has (*name of child*) 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 child*) had?

One..... 1

Two..... 2

Three or More..... 3

Don't Know..... -8

B1b. Was (*name of child*)'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.....-8"*

*Don't Know/Not Sure."*

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B1d. When you see (*name of child*)'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 B5)**  
 The kidney is OK but (*name of child*) might need another transplant in the near future (in 1 year or so)..... 3  
 The kidney is not working well and (*name of child*) is on dialysis 2  
 Don't Know..... -8 **(Skip to B5)**

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

- Yes..... 1  
 No..... 2 **(Skip to B5)**  
 Don't Know..... -8 **(Skip to B5)**

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

- Yes..... 1  
 No..... 2 **(Skip to B5)**  
 Don't Know..... -8 **(Skip to B5)**

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

**Dialysis:**

B5. Has (*name of child*) ever been on dialysis?

- Yes..... 1  
 No..... 2 **(Skip to B6)**  
 Don't Know..... -8 **(Skip to B6)**

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- B5a. What type of dialysis did (*name of child*) 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

- B5b. Date Most Recent Dialysis was started: \_\_\_\_ \_\_\_\_/\_\_\_\_ \_\_\_\_/\_\_\_\_ \_\_\_\_ \_\_\_\_
- M M D D Y Y Y Y
- Indicate the date of the most recent dialysis started. If the month or day is unknown, indicate the year. Otherwise, indicate "Don't Know/Not Sure."*
- Don't Know/Not Sure.....-8

- B5c. Is (*name of child*) on dialysis right now?
- Yes..... 1 **(END FORM HERE)**
  - No..... 2
  - Don't Know..... -8

- B6. **In the past year**, have you discussed dialysis with your/your child's nephrologist or health care provider?
- Yes..... 1
  - No..... 2 **(END FORM HERE)**
  - Don't Know..... -8 **(END FORM HERE)**

- B7. What type of dialysis was planned?
- Hemodialysis (cleansing the blood outside of the body).... 1
  - Peritoneal Dialysis cleansing the blood using his/her on body tissues inside the body)..... 2
  - No Decision yet..... 9
  - Don't Know..... -8