

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

Participant ID: ___ - ___ - _____

Follow-up Visit #: ___ ___ ___

Interviewer's Initials: ___ ___ ___

Date Form Completed: ___/___/_____ (MM/DD/YYYY)

Form Version: 0 8 / 0 1 / 1 3

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 (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: ___ ___/ ___ ___/ ___ ___ ___ ___

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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.....-8
 M M D D Y Y Y Y
 Don't Know/Not sure.....-8
 M M D D Y Y Y Y
 Don't Know/Not sure.....-8
 M M D D Y Y Y Y
 Don't Know/Not sure.....-8
 M M D D Y Y Y Y
 Don't Know/Not sure.....-8

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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