Chronic Kidney Disease in Children Cohort Study (CKiD)

PFU01: PHONE/IN-PERSON FOLLOW-UP INTERVIEW
QUESTION BY QUESTION SPECIFICATIONS

**General Instructions:**

The Phone/In-Person Follow-up Interview form (PFU01) allows the study to obtain important information on study participants who no longer attend clinical visits. The PFU01 contains questions about vital status, transplantation, and dialysis. If patient death is known, do not contact the family to do a phone/in-person interview.

1. Use the correct form version.
2. All dates should be recorded in the MM/DD/YYYY format unless otherwise noted. For dates that must be completed on the form, if the participant cannot remember the exact month (and day), probe for the season. Use “15” for the day if the specific day cannot be recorded. Probe for the season and assign the month as follows:
   - Summer = July = 07
   - Fall = October = 10
   - Winter = January = 01
   - Spring = April = 04

   Interviewers should have an appropriate calendar available to aid the participant in determining dates. Record as much date information as can be obtained. If the month or day is unknown, indicate the year. Otherwise, indicate “Don't know/not sure”.

3. For questions containing an open-ended specify box linked to the response “other,” interviewers must print responses exactly in the words of the respondent.

**Follow the skip patterns as they appear on the form.**

4. If a participant declines to answer a certain question, document -7 to the right of the response choice(s). For the missing data, document -9 to the right of the response choices. Also document any reasons for missing data, such as the question was accidentally skipped.

**PRE-INTERVIEW QUESTIONS**

5. Record the participant's I.D. number or affix label in space provided.

6. The interviewer (study coordinator) should record the PIP number (e.g., 01, 02) the participant is completing. For example, if this is the first PIP survey that the participant is completing, then document 01. If it is the second PIP survey, then document 02 and so on. If there is any confusion, the interviewer should bring this to the attention of their clinical coordinating center project director for clarification before completing the form.
7. Record the interviewer’s initials. Example: K I D

8. Record the date the form is completed - the month, day and year. Example: 03/01/2007.

9. The form version is pre-printed. Use the form version dated 03/01/14.

SECTION A: VITAL STATUS

A1. Record the date of interview – the month, day and year. Example: 03/01/2014.

A2. Indicate the vital status of the participant by choosing “Alive” (Code 1), “Deceased” (Code 2), or “Unknown” (Code 3). If a patient’s death is previously known, do not contact the family. If vital status is “alive”, then skip to A5. If vital status is “unknown” because attempts to contact the participant were unsuccessful, skip to A4. If the family was contacted but refused to partake in the interview, choose “Contacted but refused interview” (Code 4) and END the interview.

A3. Record the date of participant’s death – month, day, and year.

For sub-question “i”, specify the cause of death by choosing one of the options provided. If the cause of death is unknown, circle “98” or not listed circle “99.”

A4. Indicate whether or not the following methods of contact were used to locate or reach the participant. Please circle “Yes” “No” or “Don’t Know” for each of the following.

- Home number
- Work number
- Family contact
- Social contact
- Other method

If “Yes” (Code 1) is selected for “Other Method”, please specify the method used in the space provided. Otherwise, proceed to question A4i.

For sub-question “i”, record the date the first attempt was made to contact the participant.

For sub-question “ii”, record the number of times attempt was made to contact the participant.

For sub-question “iii”, record the date the last attempt was made to contact the participant.

A5. Indicate the individual reporting vital status of the participant as participant, mother, father, relative or acquaintance. The individual identified should be the person being interviewed, or the person who provides the vital status. If a relative (other than a parent) or an acquaintance reports vital status, choose code 4 and specify the relationship between this individual and the participant. If vital status is obtained via a method not specified (e.g. seeing the participant in clinic, notice via chart record), please select “Other Method” (Code 5) and specify the method used in the space provided.
SECTION B: RENAL REPLACEMENT THERAPY

B1. Record whether or not the child has ever had a kidney transplant by circling “Yes” (Code 1), “No” (Code 2) or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, skip to B2.

For sub-question “a”, record the number of transplants the child has had by circling “One” (Code 1), “Two” (Code 2), “Three or more” (Code 3) or “Don’t know” (Code -8).

For sub-question “b” record if the most recent kidney transplant was from a living related donor, a living non-related donor, or a deceased donor.

For sub-question “c” record the date of the participant’s most recent transplant – the month, day, and year.

For sub-question “d”, record whether the participant’s doctor discussed how well the child’s kidney was functioning by circling “The kidney function is good/excellent” (Code 1), “The kidney is OK but (name of child) might need another transplant in the near future (in 1 year or so)” (Code 3), “The kidney is not working well and (name of child) is on dialysis” (Code 2), or “Don’t know” (Code -8). If the participant indicates “The kidney function is good/excellent” or “Don’t know” and then skip to B5.

B2. Record whether or not the family talked about the kidney transplant with the child’s nephrologist or health care provider in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, skip to B5.

B3. Indicate whether or not the child has discussed the following donor options. Please circle “Yes” “No” or “Don’t Know” for each of the following.

- Living Donor
- Transplanted Waitlist/Decease Donor

B4. Record whether or not the child has been listed for a deceased donor transplant (i.e., is the child on a transplant waiting list by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, skip to B5.

For sub-question “a”, record the date of the child was put on the waiting list (i.e., indicated the date the child was activated on the waiting list).

B5. Record whether or not the child has ever been on dialysis by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, skip to B6.

For sub-question “a”, record what type of dialysis the child used most recently by circling “Hemodialysis (cleansing the blood outside of the body)” (Code 1), “Peritoneal Dialysis (cleansing the blood using his/her own body tissues inside the body)” (Code 2) or “Don’t know” (Code -8).

For sub-question “b”, record the date of the most recent dialysis started.

For sub-question “c”, record whether the child is currently on dialysis by circling “Yes” (Code 1), “No” (Code 2) or “Don’t know” (Code -8). If participant selects “Yes”, END the interview.
B6. Record whether or not the family talked about dialysis with the child’s nephrologist or health care provider in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, END the interview.

B7. Record what type of dialysis was planned by circling “Hemodialysis (cleansing the blood outside of the body)” (Code 1), “Peritoneal Dialysis (cleansing the blood using his/her own body tissues inside the body)” (Code 2), “No decision yet” (Code 9), or “Don’t know” (Code -8).