

## 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. Note that this number must match the number recorded on the PFU02 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 **09/15/2021**.

## SECTION A: VITAL STATUS

- A1. Record the date of interview – the month, day and year. Example: **03/01/2017**.
- 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 “Alive/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.
- A6. Record the participant’s self-reported weight in pounds (lbs).
- A7. Record the participant’s self-reported height in feet and inches.
- A8. Record the participant’s self-reported serum creatinine (SCr) measurement. If serum creatinine is unknown select “Don’t Know” (Code -8).

- A9. Record whether or not the participant is currently anemic by circling “Yes” (Code 1), “No” (Code 2) or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, **skip to B1**.
- A9a. Record the participant’s self-reported hemoglobin. If hemoglobin is unknown select “Don’t Know” (Code -8).
- A9b. Record the participant’s self-reported hematocrit. If hematocrit is unknown select “Don’t Know” (Code -8).

## SECTION B: TRANSPLANTATION

- B1. Record whether or not the participant 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 participant 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 participant’s kidney was functioning by circling “The kidney function is good/excellent” (Code 1), “The kidney is OK but (*name of participant*) might need another transplant or initiate dialysis in the near future (in 1 year or so)” (Code 3), “The kidney is not working well and (*name of participant*) 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 C1**.

- B2. Record whether or not the family talked about the kidney transplant with the participant’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 C1**.

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

- Living Donor
- Transplanted Waitlist/Deceased Donor

- B4. Record whether or not the participant has been listed for a deceased donor transplant (i.e., is the participant 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 C1**.

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

## SECTION C: TRANSPLANT-RELATED MEDICATIONS

- C1. Record whether or not the participant has taken any of the listed transplant-related medication in the past 30 days for the treatment of their kidney transplant by circling “Yes” (Code 1), “No” (Code 2) or “Don’t know” (Code -8). If participant has not had a kidney transplant, then select “Not Applicable” (Code -1). If participant selects “No”, “Don’t know” or “Not Applicable”, **skip to Section D**.
- C1a. Record whether or not the participant has taken Azathioprine (Imuran) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1b**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1b. Record whether or not the participant has taken Cyclosporine (Gengraf, Neoral, Sandimmune) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1c**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1c. Record whether or not the participant has taken Mycophenolate mofetil (Cellcept, Myfortic) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1d**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1d. Record whether or not the participant has taken Prednisone, Prednisolone or Methylprednisolone in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1e**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1e. Record whether or not the participant has taken Rapamycin in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1f**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1f. Record whether or not the participant has taken Tacrolimus (FK506, Prograf) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1g**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).

- C1g. Record whether or not the participant has taken Trimethoprim-Sulfamethoxazole (Bactrim, Co-trimoxazole, Sulfatrim, Septra) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1h**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1h. Record whether or not the participant has taken Valcyte (Valganciclovir) in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). If participant selects “No”, **skip to C1i**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).
- C1i. Record whether or not the participant has taken any other transplant related medication in the past 30 days by circling “Yes” (Code 1), “No” (Code 2). For sub-question C1i1, specify the name of the drug in the space provided. If participant selects “No”, **skip to D1**. If yes, proceed to C2 and document how many times the drug was taken by circling more than 4 times/day (Code 1), four times/day (Code 2), three times/day (Code 3), twice/day (Code 4), once/day (Code 5), every other day (Code 6), 2 times/week or 3 times/week (Code 7), less than 2-3 times/week (Code 8) or Don’t know (-8).

#### **SECTION D: DIALYSIS**

- D1. Record whether or not the participant 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 D2**.

For sub-question “a”, record what type of dialysis the participant 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 that the most recent “regularly scheduled” dialysis started or will start. For hemodialysis, indicate the date when the participant started 2 or more days/week for at least 3 months. For peritoneal dialysis (PD), indicate the date when the participant started treatments 5 or more days a week for at least 3 months.

For sub-question “c”, record whether the participant is currently receiving regularly scheduled dialysis therapy by circling “Yes” (Code 1), “No” (Code 2) or “Don’t know” (Code -8). If participant selects “Yes”, **skip to Section E**.

- D2. Record whether or not the family talked about dialysis with the participant’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 Section E**.

- D3. 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).

### SECTION E: GENERAL INFORMATION

- E1. Record the highest grade or level of school that the participant has completed. For example, the participant is currently in the 12<sup>th</sup> grade, then enter “11”, or if the participant is currently in the 6<sup>th</sup> grade, then enter “5”. In addition, if the participant is in the 1<sup>st</sup> grade, kindergarten or pre-school/pre-K, then enter “0”. If participant is a sophomore in college, then enter “13”. If grade is unknown, circle “Don’t Know” (Code -8). Example:   1     1   grade (this value corresponds to 12<sup>th</sup> grade).
- E2. 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. This question is asked to determine the number of adults living in the primary household, at least half the time. Adults are defined as all persons at least 18 years or older. Record the number of persons living in the household that are at least 18 years or older. Include participant if 18 years of age.
- E3. This question is asked to obtain more details about the adults who live in the primary household at least half the time. Remember adults are all persons at least 18 years of age or older. Include the participant, if applicable. Circle “Yes” (Code 1) for each relationship the respondent mentions. Circle “No” (Code 2) if the respondent does not mention that particular relationship. Circle either “Yes” (Code 1), “No” (Code 2) or “Don’t Know” (Code -8) for each response option. **PROBE:** “Any others?” until all relationships have been established and specify those relationships. If there are transient household visitors (“Sometimes his/her father shows up”), code only those people *currently* living in the primary household.  
If “Other” person lives in the household, specify in D5i. Otherwise **skip to E4.**
- E4. This question is asked to determine the number of children living in the primary household, at least half the time. Children are defined as all persons who are less than 18 years old. Record the number of persons living in the household that are less than 18 years old. Include participant if less than 18 years of age.
- E5. This question is asked to obtain more details about the children who live in the primary household at least half the time. Remember children are all persons who are less than 18 years old. Include the participant, if applicable. Circle “Yes” (Code 1) for each relationship the respondent mentions. Circle “No” (Code 2) if the respondent does not mention that particular relationship. Circle either “Yes” (Code 1), “No” (Code 2) or “Don’t Know” (Code -8) for each response option.  
If “Other” person lives in the household, specify in D5i. Otherwise **skip to E6.**

- E6. Record the current employment status of the participant by responding “Yes”, “No” or “Don’t Know” for each employment category. If not applicable or don’t know, then circle “N/A (Code -1)” or “Don’t know (Code -8), and **skip to E7**. If participant is working full-time or part-time; indicate whether they are self-employed in sub question E6i
- E7. Record if the participant has started her menses in the past year by circling “Yes” (Code 1), “No” (Code 2) or “Don’t Know” (Code -8). If “No” or “Don’t Know” is selected, skip to **E8**. If participant is male, select “Not applicable/participant is male” and skip to E8 **PROBE: Period**
- E7a. Record the age of the participant when she started her first period. If unknown, select “Don’t Know” (Code -8).  
Example:   1     3   years of age
- E8. On a scale of 1 (never) to 5 (always), ask the participant to rate how often they felt fatigue beyond their control over the past 7 days.
- E9. On a scale of 1 (never) to 5 (always), ask the participant to rate how often they were too tired to think clearly over the past 7 days.
- E10. On a scale of 1 (never) to 5 (always), ask the participant to rate their energy over the past 7 days.
- E11. On a scale of 1 (as bad as it can be) to 10 (as good as it can be), ask the participant to rate their overall quality of life over the past 7 days.
- E12. Record whether or not in the past year the participant saw a healthcare provider, nephrologist or group of providers for his/her medical appointments in the past year. Circle “Yes” (Code 1), “No” (Code 2), or “Don’t Know (Code -8). All types of visits which are **NOT** associated with CKiD should be included, such as well participant visits, sick visits and ER visits. **Do not include** times when the participant was hospitalized overnight.  
  
If no, complete sub-question E12a and specify the reason they have not seen a healthcare provide/nephrologist. Otherwise, **skip to E13**.
- E13. Record whether or not the participant was hospitalized in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). **Do not include overnight stays in the emergency room**. If participant selects “No” or “Don’t know”, **skip to E14**.
- E13a. Record the number of different times the participant was hospitalized in the past year. If unknown, select “Don’t Know”.  
  
Example:   0     2   times

- E14. The purpose of this question is to establish the type of facility or facilities where the participant has gone to receive kidney clinical care in the past year. In this series, the participant must provide a “Yes” (Code 1) or “No” (Code 2) for each response option in sub-questions a-d.
- a-c Record whether or not the participant has been to a clinic/health care center, a private doctor’s office, or a hospital outpatient department in the past year by circling “Yes” (Code 1) or “No” (Code 2).
- d. Record whether or not the participant has been to the emergency room by circling “Yes” (Code 1) or “No” (Code 2). If participant selects “No”, **Skip to E15**. If participant selects “Yes” proceed to question **E14d1**.
1. Record the number of times the participant has received care at the emergency room during the last year. Example: 0 4.
- E15. Indicate whether or not the participant has had Urinary Tract Infections in the past year. If “No” or “Don’t know” is selected, **skip to E16**.
- E15a. Record the number of different times the participant had a UTI in the past year. If unknown, select “Don’t Know”.
- Example: 0 2 times
- E16. The purpose of this question is to determine whether the participants are currently with or without health insurance. The participant must select “Yes” (Code 1) or “No” (Code 2). If participant responds “No”, **skip to E17b**. Ensure that the participant considers all types of insurance listed before responding.
- PROBE: “Please include both private and public insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.**
- If no, complete sub-question E15a and specify the reason they do not have health insurance. Otherwise, **skip to E17b**.
- E17a. Some families may not currently have insurance coverage. The purpose of this question is to determine how long it has been since the family has had ANY coverage. Participant must select one of the options: “6 months or less” (Code 1), “More than 6 months, but now more than 1 yr ago” (Code 2), “More than 1 year, but no more than 3 years ago” (Code 3), “More than 3 years” (Code 4), “Never had health insurance or coverage” (Code 5), or “Don’t Know” (Code -8). For all answer options, **skip to F1**.
- E17b. The purpose of this question is to determine if the family has had a lapse in insurance coverage in the past year. Participant must select “Yes” (Code 1) or “No” (Code 2). If participant selects “No”, **skip to F1**.
- E17c. Some families may have a lapse in insurance coverage in the past year. The purpose of this question is to determine the length of time the family was uncovered. Participant must indicate the length of time the family has been uninsured and circle months, weeks or days.



## SECTION F: MEDICAL HISTORY

- F1. Record whether or not the participant has had a heart attack in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8).
- F2. Record whether or not the participant has had a stroke in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8).
- F3. Record whether or not the participant has had angina (heart related chest pain) in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8).
- F4. Record whether or not the participant has had an irregular heart rhythm in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8).
- F5. This question asks about diseases/illnesses that the participant may currently have or has developed in the past year. For each disease in F5a-i, record whether a doctor or any other healthcare professional told the participant that they had the disease listed in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t Know” (Code -8) for each disease listed. For sub-question F5g, if “Yes” is selected, please specify the type of cancer. Otherwise, **skip to F5h**.

## SECTION G: BLOOD PRESSURE MEDICATIONS

- G1. Record whether or not the participant has taken any blood pressure medication in the past 30 days by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, **skip to H1**.
- G2. Record the number of different blood pressure medication the participant has taken the past 30 days.  
Example: \_0\_ \_2\_
- G3. Record whether or not the participant has taken any ACE/ARB medications in the past 30 days by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, **skip to H1**.
- G4. Record the number of different ACE/ARBs the participant has taken the past 30 days.  
Example: \_0\_ \_2\_

## SECTION H: TRANSITION TO ADULT CARE

- H1a. Record whether or not the participant has transitioned to adult care by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “No” or “Don’t know”, **skip to Section I**.
- H1b. Record whether or not the participant has transitioned to adult care 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 Section I**.
- H2. On a scale of 1 (Poor/Hard) to 5 (Great/Easy), ask the participant to rate their overall transition from pediatric to adult care.  
If the score is less than or equal to 2, complete sub-question H2a and specify the reason the participant felt the transition was poor/hard. Otherwise, **skip to Section I**.

## SECTION I: COVID-19 ILLNESS INFORMATION

- I1a. Record whether or not the participant has received a laboratory confirmed diagnosis of COVID-19 in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “yes”, **skip to I1c**.
- I1b. Record whether or not a doctor or other health care provider told the participant that they had a suspected case of COVID-19 in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8). If participant selects “no”, **skip to J1**.
- I1c. Record the date of the participant’s confirmed diagnosis or suspected case of COVID-19 – the month, day, and year.
- I1d. Record whether or not the participant had contact with someone who had a confirmed diagnosis of COVID-19 by circling “Yes” (Code 1), or “No” (Code 2). If participant selects “no”, **skip to I2**.
- I1e. Record whether or not the participant had contact within the past 14 days with someone who had a suspected or confirmed diagnosis of COVID-19 in the past year by circling “Yes” (Code 1), “No” (Code 2), or “Don’t know” (Code -8).
- I1f. Record whether or not the participant lived in the same household as someone who had a confirmed diagnosis of COVID-19 by circling “Yes” (Code 1), or “No” (Code 2).
- I2a. Record whether or not the participant is currently sick with COVID-19 by circling “Yes” (Code 1), or “No” (Code 2). If participant selects “no”, **skip to I2c**.
- I2b. Record the number of days since the symptom onset and **skip to J1**.
- I2c. Record the total length of illness (if recovered). If the participant has not recovered, then circle “Not recovered/Not applicable”

## SECTION J: COVID-19 IMPACT

- J1. On a scale of 1 (not at all) to 4 (5-7 days), ask the participant to indicate how often they felt each of the following in the past 7 days:
- a. nervous, anxious or on edge
  - b. depressed
  - c. lonely
  - d. hopeful about the future
  - e. physical reactions, such as sweating, trouble breathing, nausea or a pounding heart, when thinking about your experience with the novel coronavirus (COVID-19) pandemic
- J2. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I am very worried about getting the coronavirus.”

- J3. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I am very worried about my family/friends getting the coronavirus.”
- J4. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I am very worried about giving someone else the coronavirus”.
- J5. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I have a hard time sleeping because of the coronavirus.”
- J6. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I have had difficulties concentrating because of the coronavirus.”
- J7. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “Thinking about the coronavirus makes me very anxious.”
- J8. On a scale of 1 (strongly disagree) to 5 (strongly agree), ask the participant to rate their agreement with the statement “I am feeling overwhelmed by the coronavirus.”

**SECTION K: COVID-19 IMPACT**

- K1. Record whether or not the participant’s daily routine has changed since March 1, 2020 by circling “No, I have had no changes” (Code 0), “Yes, I have had mild changes” (Code 1), “Yes, I have had moderate changes” (Code 2) or “Yes, I have had severe changes” (Code 3).
- K2. Record whether or not the participant’s household income has changed since March 1, 2020 by circling “No, there have been no changes” (Code 0), “Yes, there have been small changes” (Code 1), “Yes, there have been moderate changes” (Code 2) or “Yes, there have been severe changes” (Code 3).
- K3. Record whether or not the participant’s access to food has changed since March 1, 2020 by circling “No, access has not changed” (Code 0), “Yes, I have had enough food but difficulty getting to stores” (Code 1), “Yes, I have occasionally been without food or good quality food” (Code 2) or “Yes, I have frequently been without enough food” (Code 3).
- K4a. Record whether or not the participant’s has been eating more food than usual since March 1, 2020 by circling “No, I have had no changes or eating slightly less than usual” (Code 0), “Yes, I have been eating slightly more” (Code 1), “Yes, I have been eating more frequently” (Code 2) or “Yes, I have been eating much more frequently” (Code 3).

- K4b. Record whether or not the participant's has been eating more processed food than usual since March 1, 2020 by circling "No, I have had no changes or eating slightly less than usual" (Code 0), "Yes, I have been eating slightly more" (Code 1), "Yes, I have been eating more processed food than usual" (Code 2) or "Yes, I have been eating a significantly less healthy diet" (Code 3).
- K5. Record whether or not the participant's normal physical activity has changed since March 1, 2020 by circling "No, I do not normally exercise" (Code 0), "Yes, I have been exercising with the same frequency and intensity as I usually do" (Code 1), "Yes, I have been exercising regularly, but with less intensity than usual" (Code 2), "Yes, I have not been exercising regularly as usual, but the intensity is the same as usual" (Code 3), or "Yes, I have been not exercising at all and I am very sedentary" (Code 4).
- K6. Record whether or not the participant's access to medical health care changed since March 1, 2020 by circling "No, I have not tried to access care or I haven't needed care" (Code 0), "No there have been no changes to medical health care" (Code 1), "Yes, I have mild changes" (Code 2), "Yes, I have moderate changes" (Code 3) or "Yes, I have had severe changes" (Code 4).
- K7. Record whether or not the participant's access to extended family and trusted friends changed since March 1, 2020 by circling "No there have been no changes" (Code 0), "Yes, I have mild changes" (Code 1), "Yes, I have moderate changes" (Code 2) or "Yes, I have had severe changes" (Code 3).
- K7. Record the participant's overall perception of the impact of the COVID-19 pandemic on their day-to-day life by circling "It has not impacted my life at all" (Code 0), "It has not impacted my life a little" (Code 1), "It has not moderately impacted my life" (Code 2), "It has not extremely impacted my life (Code 3)" or "Refused to answer" (Code -7).

### **SECTION L: SOCIALIZATION QUESTIONS**

- L1. Ask the participant to rate their agreement with the statement "I can count on people in my neighborhood to help me if I'm sick" by circling "Agree" (Code 1) or "Disagree" (Code 2).
- L2. Ask the participant to rate their agreement with the statement "My neighbors would go to the store for me if I'm sick" by circling "Agree" (Code 1) or "Disagree" (Code 2).
- L3. Since social distancing measure have been put in place, record the participant's response to the following questions regarding their neighbors by circling "Yes (Code 1), "No" (Code 2) or "Not applicable" (Code -1).
- a. Checked in on you to see if you needed anything?
  - b. Helped each other with things like grocery shopping or running errands to minimize their risk for COVID-19?
  - c. Worked together to take care of each other?

- L4. Ask the participant what action have they taken to reduce risk of exposure to COVID-19 since March 1 2020 and record the participant's response by circling "Yes (Code 1), "No" (Code 2) or "Not applicable" (Code -1).
- a. Washing hands and/or using sanitizer frequently
  - b. Staying at least 6 feet away from others
  - c. Avoiding large gatherings
  - d. Not going out to restaurants or bars
  - e. Cancelled planned travel
  - f. Wearing a face mask
  - g. Not shaking hands or touching people
  - h. Staying home when I am sick
  - i. Not going to work or working remotely (when working is possible)
  - j. Not going to school (when attending school is possible)
  - k. Not going to church or faith services (when church holds in-person services)
  - l. Avoiding public transportation
  - m. Wiping down surfaces with disinfectant
  - n. Ordering groceries for delivery/curb-side pickup
  - o. Following government guidelines or rules to stay at home and limiting contacts with other people
  - p. Placed under full quarantine by local authorities
- L5. Record whether the participant received any recommendations from a healthcare provider about reducing risk of exposure to COVID-19 by circling "Yes (Code 1), "No" (Code 2).
- a. My primary care doctor
  - b. My nephrologist
  - c. Another provider