Chronic Kidney Disease in Children Cohort Study (CKiD)
QUESTION BY QUESTION SPECIFICATIONS
REACH DATA COLLECTION FORM

Reaching **E**quity for **A**dults and **CH**ildren (REACH) in Transplant is a CKiD Ancillary Study with a goal to enhance understanding of racial and ethnic disparities in access to kidney transplantation in children with CKD.

Eligible participants:

- Age at time of first episode of renal replacement therapy (RRT) between 1 to 24 years (inclusive).
- Data needed for eGFR accessible in electronic health record prior to the RRT episode.

List of eligible participants will be provided by the CKiD CCCs. The REACH Data Collection Form should be completed for each eligible participant and returned to the CCC for data entry.

SECTION A: General Information

A1. Record the participant's I.D. number or affix label in the space provided.

A2. The form version is pre-printed. Use the form version dated 03/15/21.

A3. Record the date the form is completed – the month, day, and year.

A4. Record the initials of the person completing the form.

SECTION B: Dialysis and Kidney Transplantation Information

B1. Record if the participant ever started dialysis by circling "Yes" (Code 1) or "No" (Code 2). This includes if dialysis was initiated before or after kidney transplant. If "No" is selected, then **Skip to B4.**

B2. Record the date the participant started dialysis – the month, day, and year.

B3. Record the type of dialysis the participant initiated by circling "In-center hemodialysis" (Code 1), "Home hemodialysis" (Code 2), or "Peritoneal dialysis" (Code 3).

B4. Record if the participant was put on the waitlist for a kidney transplant by circling "Yes" (Code 1) or "No" (Code 2). If "No" is selected, then **Skip to B8**.

B5. Record the date of waitlist registration.

B6. Record if the participant was made active on the waitlist by circling "Yes" (Code 1) or "No" (Code 2). If "No" is selected, then **Skip to B8**.

B7. Record the date the participant was made active on the waitlist.

B8. Record if the patient received a kidney transplant by circling “Yes” (Code 1) or “No” (Code 2). If “No” is selected, then **Skip to C1**.

B9. Record the date the participant received the kidney transplant. If more than one transplant, record the date of the first kidney transplant.

B10. Record the kidney donor type by circling “Living” (Code 1), “Deceased” (Code 2), or “Unknown” (Code -8). If “Deceased” or “Unknown, then **Skip to C1**.

B11. Record the living donor’s relationship to the participant by circling the corresponding code. “Parent” – biological parent only (Code 1); “Sibling” – biological sibling only, including half-sibling (Code 2); “Other family member” – biological family members only, including Aunt/Uncles/Cousins/Grandparents (Code 3); “Non-related but known to the recipient (e.g. neighbor friend, co-workers, member of faith community)” – including step-parents and step-siblings (Code 4); “Directed, altruistic (e.g. saw on billboard)” – living non-related donor who wants to donate to a specific unfamiliar person (Code 5); “Non-directed, altruistic (e.g. I’ll donate to anyone)” – living non-related donor who wants to donate to anyone (Code 6); “Unknown” (Code 8).

SECTION C: Lab Values

Data collected should be for the **initial** RRT event. For example:

- If the participant had a kidney transplant & then started dialysis after the transplant occurred, document data that pertains to the kidney transplant date which would be the initial RRT event.
- If the participant initiated dialysis prior to transplant, then document data that pertains to the date dialysis was initiated.

The term “**preemptive transplant**” refers to a kidney transplant that occurred as initial RRT therapy and no dialysis was initiated prior to the transplant.

C1 Record serum creatinine at the time of dialysis initiation or preemptive kidney transplant. Use the most recent lab result **prior** to RRT.

C2. Record height at the time of dialysis initiation or preemptive kidney transplant.

C3. Record the participant’s blood type by circling “A” (Code 1), “B” (Code “2”), “O” (Code 3), or “AB” (Code 4).

Sensitization is captured by panel reactive antibody (PRA) questions.

Record the most recent PRA information **prior** to transplant.

PRA scores are often found on HLA Reports completed by an Immunogenetics Laboratory. Further questions about finding PRA information can be directed to site PI or REACH coordinator at CHOP.

If your site has Class I PRA and Class II PRA reported separately (**preferred**), record that data and skip calculated PRA (cPRA). If your site only reports cPRA, skip Class I PRA and Class II PRA and record cPRA.

C4. Record the PRA class I score. If "Not Available", the circle -8.

C5. Record the PRA class II score. If "Not Available", the circle -8. If PRA class I & II were documented, then **Skip to D1**.

C6. Record the calculated PRA score.

SECTION D- SECTION I:
6, 12, 18, 24, 30, and 36 months prior to RRT

Collect data at specific 6 month intervals going backwards 3 years from the date of initial RRT.

Initial RRT (dialysis or preemptive transplant) is the anchor date (timepoint 0). Each section is for a specific timepoint prior to initial RRT: 6 months before RRT (Section D), 12 months before RRT (Section E), 18 months before RRT (Section F), 24 months before RRT (Section F), 30 months before RRT (Section H), and 36 months before RRT (Section I).

It may be helpful to use an Excel file with a formula that calculates the timepoints of interest based on the date of initial RRT (available upon request).

Data may not fall exactly on each interval. Ideally, we want 2 timepoints each year spaced as far apart as possible.

Laboratory values/vital signs should only be collected from **outpatient visits** (not during emergency room visits or inpatient hospitalizations)

If multiple results are available document the result / date closest to the exact time point relative to the date of initial RRT.

1. Record if clinical data is available at the specified timepoint by circling "Yes" (Code 1) or "No" (Code 2). If "No" is selected, **Skip to the next Section**.

2. Record serum creatinine result at the specified timepoint.

3. Record the date of serum creatinine at the specified timepoint.

4. Record height at the time of serum creatinine result at the specified timepoint. Height should be collected as close to the date of serum creatinine as possible.

5. Record systolic blood pressure at the specified timepoint.

6. Record diastolic blood pressure at the specified timepoint.

7. Record date of blood pressure measurement at the specified timepoint.

The goal is to have **one** of the proteinuria values for each timepoint, but this can be collected several different ways. Below are some guidelines:

- Urine creatinine should be recorded whenever available.
- For proteinuria, urine albumin is preferred; if not available, urine protein is preferred. Both urine albumin and urine protein are preferred **only** when urine creatinine is also available.
- If individual urine albumin or urine protein values are not available, but the ratios are reported, record that information and label whether it is an urine albumin: creatinine ratio or urine protein: creatinine ratio
- If none of these are available, protein by urine dipstick is the last choice.
- It is preferred that urine be collected on same date as the date of serum creatinine/ height. However, if there is only a urine dipstick on the date of serum creatinine/ height, but there is a urine albumin or urine protein within 2 months of the serum creatinine/ height, record the urine albumin or urine protein instead of the urine dipstick.

8. Record urine creatinine at the specified timepoint. Circle Code -8 if "Not available"

9. Record urine albumin at the specified timepoint. **Skip to 13** if result available and recorded. Circle Code -8 if "Not available"

10. Record urine protein at the specified timepoint. **Skip to 13** if result available and recorded. Circle Code -8 if "Not available"

11. Record urine albumin: creatinine or urine protein: creatinine ratio at the specified timepoint. If not available circle Code -8, and **Skip to 12.**

    a. Record the type of ratio by circling "Urine albumin : creatinine ratio" (Code 1) or "Urine protein : creatinine ratio" (Code 2). **Skip to 13**

12. Record urine protein dipstick at the specified timepoint by circling "Negative" (Code 1), "Trace" (Code 2), "1+ (30mg/dL)" (Code 3), "2+ (100mg/dL)" (Code 4), "3+ (300mg/dL) or greater" (Code 5).

13. Record the date of the urine result at the specified timepoint.

Section J: Weight for Participants less than 5 years old at time of RRT

Weight should be collected for participants that were less than 5 years of age at time of RRT (dialysis or preemptive transplant) for each time point (0, 6, 12, 18, 24, 30, and 36 months prior to RRT)

J1. Record if the participant was less than 5 years of age at time of RRT (dialysis or preemptive transplant by circling "Yes" (Code 1) or "No" (Code 2). If "No" is selected, **END FORM**.

J2. - J8. Record weight (in kilograms) at the specified timepoint. Weight should be collected as close to the date of serum creatinine as possible (dates used in the previous sections). Data may not fall exactly on each interval. Ideally, we want 2 timepoints each year spaced as far apart as possible.