CKiD Chronic Kidney Disease in Children Cohort Study (CKiD)
QUESTION BY QUESTION SPECIFICATIONS
REF: REFUSAL/NON-PARTICIPATION FORM

THIS FORM MUST BE DATA ENTERED

General Instructions:

1.) This form is to be completed for each **eligible** patient (a patient who meets the eligibility criteria), who has refused to participate in the study (CKiD) OR if the site does not recruit (approach) the family/patient for study participation. **This form should NOT be completed for participants who are ineligible for study participation.**

2.) The form version is pre-printed. Be sure that you are using the current version (03/01/25) and that all unused, outdated versions have been discarded.

Upper Left Corner: **SITE MUST ASSIGN ID NUMBER FOR EACH FORM COMPLETED.**

Enter the Cohort, Site and Local ID number. Sites must enter "4" in the first box for participants who are recruited during the 4th wave of recruitment.The next two digits indicate the site number. Values between "01" and "49" are reserved for clinical sites coordinated by the midwest clinical coordinating center, and "50" to "99" for clinical sites coordinated by the eastcoast clinical coordinating center. In the 5 last digits, sites must assign all patients a local ID number. The local ID number should be at least 3 digits in length. It can be 5 digits from the part of the patient's medical record or some other commonly used number at the site. **The Local ID is NOT the KID #.**

Upper Right Corner: Enter the initials of the person completing the form. The person who is interviewing the potential participant must document his/her initials.

Question 1: Record the date the potential participant refused to participate in the CKiD cohort study.

Question 2: Sites must have a documented year of birth.

Question 3: Site must document the participant's sex that was assigned at birth.

Question 4. Site must document the participant's KRT status. If KRT naïve (i.e., the participant has not initiated dialysis or transplant), then check "KRT Naïve" (Code 1). If participant's most recent KRT status is that they had a transplant, check "Transplant" (Code 2). If participant's most recent KRT status is dialysis, check "Dialysis" (Code 3) and skip to question 5.

Question 4a: Sites must document the most recent estimated GFR based on the U25eGFR.

Question 5: Sites must document the primary diagnosis category. Use Table 1 to identify the primary diagnosis category for each listed primary diagnosis.

TABLE 1: PRIMARY DIAGNOSIS CLASSIFICATION

	PRIMARY DIAGNOSIS	DIAGNOSIS CATEGORY	CODE
51)	Aplastic/hypoplastic/dysplastic kidneys	Non-GN (Urologic/Cystic/Hereditary)	**2**
65)	Branchio-oto-Renal Disease/Syndrome	Non-GN (Urologic/Cystic/Hereditary)	**2**
15)	Chronic glomerulonephritis	Glomerulonephritis (GN)	**1**
20)	Congenital nephrotic syndrome	Glomerulonephritis (GN)	**1**
62)	Congenital Urologic Disease (Bilateral Hydronephrosis)	Non-GN (Urologic/Cystic/Hereditary)	**2**
54)	Cystinosis	Non-GN (Other)	**3**
23)	Denys-Drash syndrome	Glomerulonephritis (GN)	**1**
24)	Diabetic nephropathy	Glomerulonephritis (GN)	**1**
12)	Familial nephritis (Alport's)	Glomerulonephritis (GN)	**1**
10)	Focal segmental glomerulosclerosis	Glomerulonephritis (GN)	**1**
40)	Glomerular Other: _____	Glomerulonephritis (GN)	**1**
11)	Hemolytic uremic syndrome	Glomerulonephritis (GN)	**1**
19)	Henoch Schonlein nephritis	Glomerulonephritis (GN)	**1**
17)	Idiopathic cresentic glomerulonephritis	Glomerulonephritis (GN)	**1**
13)	IgA Nephropathy (Berger's)	Glomerulonephritis (GN)	**1**
57)	Medullary cystic disease/juvenile nephronophthisis	Non-GN (Urologic/Cystic/Hereditary)	**2**
16)	Membranoproliferative glomerulonephritis Type I	Glomerulonephritis (GN)	**1**
21)	Membranoproliferative glomerulonephritis Type II	Glomerulonephritis (GN)	**1**
18)	Membranous nephropathy	Glomerulonephritis (GN)	**1**
80)	Non-Glomerular Other: _____	Non-GN (Other)	**3**
50)	Obstructive uropathy	Non-GN (Urologic/Cystic/Hereditary)	**2**
61)	Oxalosis	Non-GN (Urologic/Cystic/Hereditary)	**2**
64)	Perinatal Asphyxia	Non-GN (Other)	**3**
60)	Polycystic kidney disease (Autosomal dominant)	Non-GN (Urologic/Cystic/Hereditary)	**2**
53)	Polycystic kidney disease (Autosomal recessive)	Non-GN (Urologic/Cystic/Hereditary)	**2**
55)	Pyelonephritis/Interstitial nephritis	Non-GN (Urologic/Cystic/Hereditary)	**2**
52)	Reflux nephropathy	Non-GN (Urologic/Cystic/Hereditary)	**2**
56)	Renal infarct	Non-GN (Other)	**3**
22)	Sickle cell nephropathy	Glomerulonephritis (GN)	**1**
58)	Syndrome of agenesis of abdominal musculature	Non-GN (Urologic/Cystic/Hereditary)	**2**
14)	Systemic immunological disease (including SLE)	Glomerulonephritis (GN)	**1**
63)	Vactrel or Vater Syndrome	Non-GN (Other)	**3**
59)	Wilms' tumor	Non-GN (Other)	**3**

Question 6: Sites must have a documented race.

Question 7: Sites must have a documented Hispanic or Latino/a origin.

Question 8: Sites must document whether a patient/family who was screened/identified as eligibile for CKiD study participation was asked to participate (approached by the site.) If yes (Code 1) then proceed to question 6a. Otherwise, if the family was NOT approached/recruited for study participation, check No (Code 2) and skip to Question 9.

Question 8a: Specify the reason for the participant's refusal (i.e., disinterest, confidentiality concerns, ect.)

Question 9: *This question should be completed ONLY if the family was NOT recruited/approached by site for study participation (response to question 8 was "No".)*

Specify the reason for the patient/family was not recruited (i.e., patient too ille, family has problems complying with clinical visits.)

Question 10: Site must record whether a KID was assigned. If a KID was assigned the site must circle "yes" and **document the KID in questions 10a**. If the site assigned a KID and the family/patient does not agree to participate in the study (i.e., does not provide written consent/assent), the site must inform their CCC and that KID ID should not be reused.