Chronic Kidney Disease in Children Cohort Study (CKiD)
QUESTION BY QUESTION SPECIFICATIONS
Neonatal History Form (NH)

The goal of this form is to document specific information about perinatal health within the first 90 days of life.

If the information cannot be found in the participant's medical chart please use "-8" indicating the information is unknown or not available.

Email the completed form to your respective CCC.

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SECTION A: GENERAL INFORMATION

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

A2. The study coordinator should record the last CKiD visit number (e.g., 01, 02, 03 or 04) completed by the participant. If there is any confusion regarding the last visit completed by the participant, the site should check the Nephron Follow-up report or bring this to the attention of their clinical coordinating center project director for clarification before completing the form.

A3. The form version is pre-printed. Use the form version dated **12/01/21**.

A4. Record the date the form is completed – the month, day, and year

A5. Record the initials of the person completing the form.

SECTION B: Birth History

B1. Record if medical record information is available and accessible for the participant to complete this form. If "Yes" then circle 1, otherwise circle 2 for "No". If "No" is selected, **END the form here.**

B2. Record the participant's weight at birth in grams.

B3. Record the participant's head circumference at birth in centimeters.

B4. Record the participant's length at birth in centimeters.

B5. Record the gestational age of the participant by circling the number that corresponds to the gestational age range of the participant.

B6. Record the APGAR Score for the participant at the given time points. If the APGAR Score is not available for the given time point, circle -8 for "Unknown/Not Assigned". Often, APGAR scores are only recorded for some time points (e.g. 1 min and 5 min).

SECTION C: Prenatal History

C1. Record if congenital anomalies (birth defects, congenital disorders, or congenital malformations) were diagnosed prenatally (occurring or existing prior to birth). If "Yes" circle 1, if "No" circle 2, and if "Unknown" circle -8.

C2. Record if there were any fetal antenatal (prior to birth) conditions of the participant. If "Yes" circle 1, if "No" circle 2, and if "Unknown" circle -8. If "No" or "Unknown", **Skip to D1.**

    a. Record if there were any fetal anomalies (abnormalities) including anomalies related to CNS (Central Nervous System), abdominal, cardiovascular, renal, or respiratory. If "Yes" then circle 1, otherwise circle 2 for "No".

    b. Record if there was any fetal distress prior to birth. If "Yes" then circle 1, otherwise circle 2 for "No".

c. Record if there was Intrauterine Growth Restriction (IUGR). If "Yes" then circle 1, otherwise circle 2 for "No".
d. Record if there were any other fetal or placental conditions prior to birth. If "Yes" then circle 1, otherwise circle 2 for "No".

SECTION D: NICU

D1. Record if the participant was hospitalized in a NICU during the first 90 days of life. NICU includes ICN (Intensive Care Nursery) and all levels of NICU (Neonatal Intensive Care Unit) care. If "Yes" then circle 1, if "No" then circle 2, and if "Unknown" then circle -8. If "No" or "Unknown", **Skip to E1.**

D2. Record what type of respiratory support was needed on admission to the NICU. Circle the code that corresponds to the type of respiratory support needed on admission: no respiratory support needed (code 1); Hood/NC(Nasal Cannula) or O (Oxygen) (code 2); nasal continuous positive airway pressure (NCPAP)/continuous positive airway pressure (CPAP) (code 3); EET (Endotracheal Tube) or V (Ventilation) including tracheostomy or LMA (Laryngeal Mask Airway) (code 4); Unknown (Code -8)

D3. This question pertains to the first blood pressure obtained on admission to the NICU.
a. Record the systolic blood pressure or if not recorded then circle -8 "Unknown"
b. Record the diastolic blood pressure or if not recorded then circle -8 "Unknown".
c. Record the mean blood pressure if recorded in chart note. If not recorded then circle -8 for "Unknown".

D4. Record if any treatment or prescription was required during transport to the NICU, or during the first hour of Admission to the NICU. If "Yes" then circle 1, if "No" then circle 2, and if "Unknown" then circle -8. If "No" or "Unknown", **Skip to D5**.
a. Record if inhaled nitric oxide was required during transport to NICU or during the first hour of admission to the NICU. If "Yes" then circle 1, otherwise circle 2 for "No".
b. Record if the participant was intubated and ventilated (through ETT (Endotracheal Tube), Trach (Tracheostomy), or LMA (Laryngeal Mask Airway)) during transport or during the first hour of admission to the NICU. If "Yes" then circle 1, otherwise circle 2 for "No".
c. Record if continuous vasoactive agents (e.g. pressors) were required during transport or during the first hour of admission to the NICU. If "Yes" then circle 1, otherwise circle 2 for "No".
d. Record if paralysis by neuromuscular blockage was required during transport of during the first hour of admission to the NICU. If "Yes" then circle 1, otherwise circle 2 for "No".

D5. Record the initial NICU disposition (Neonatal Intensive Care Unit Discharge Plan). The word "Home" includes Foster Care or Medical Foster Care. If the participant was "Discharged from NICU to Home" circle 1 and **Skip to E1**. If the participant was "Transferred out of initial NICU to another NICU at another Institution" then circle 2. If the participant was "Transferred out of NICU to Nursery or other inpatient setting" then circle 3, and **Skip to E1**.

D6. Record the date the participant transferred out of initial NICU to a different NICU.

SECTION E: First 90 Days of Life

E1. Record what problems the participant had during the first 90 days of life, including at NICU or Nursery stay. For each problem listed record "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). "a. AKI" refers to Acute Kidney Injury. If "Yes" is circled for Question E1.p. "Other", specify below for Question E1.p1..

E2. Record if respiratory treatment was required during the participants first 90 Days of Life including NICU or Nursery stay. Circle the corresponding code: Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "No" or "Unknown", **Skip to E3**.
   a. Record if Endotracheal Tube/Ventilation was required during participants first 90 days of life. If "Yes" then circle 1, otherwise circle 2 for "No".
   b. Record if epinephrine was required during the participants first 90 days of life. If "Yes" then circle 1, otherwise circle 2 for "No".
   c. Record if cardiac compressions were required during the participants first 90 days of life. If "Yes" then circle 1, otherwise circle 2 for "No".

E3. Record if the participant had seizures during the first 90 days of life including NICU or Nursery stay. If the participant had no seizures, then circle 1. If the participant had seizures confirmed by EEG (Electroencephalogram) or aEEG (Amplitude-integrated Electroencephalography), then circle 2. If the participant had seizures suspected clinically, but not confirmed by EEG, then circle 3. If the seizure status of the participant was unknown, then circle -8.

E4. Record if the participant had sepsis (i.e. Positive Blood Culture) in the NICU, Nursery Stay or within the first 90 days of life. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8).

SECTION F: Growth and Nutrition

Growth and nutrition information is very important during a child's first 90 days of life. The 3 time points in this section (Admission, 2 Weeks, and 3 Months) used to collect growth and nutrition information does not have to directly correspond to the time point listed below. (e.g. If information at 2 weeks (Question F2) is not available, but information is available at 3 weeks and is prior to the third time point (3 Months), the information for 3 weeks can be used for Question F2.)

F1. Record if growth and nutrition information is available for the participant at the time of birth admission to the NICU or Nursery. If "Yes" then circle 1, otherwise circle 2 for "No" and **Skip to F2.**
   a. Record the date that corresponds to the growth and nutrition information that was collected for the participant at the time of Admission to the NICU or Nursery.
   b. Record the participant's weight in grams at admission
   c. Record the participant's head circumference in centimeters at admission
   d. Record the participant's length in centimeters at admission
   e. Record the participant's type of nutrition at admission. If "Enteral", then circle 1. If "Parenteral" (e.g. TPN) then circle 2. If "No Feeds/TPN"at admission then circle 3. If "Parenteral" or "No Feeds/TPN" then **Skip tot F2**.
   f. Record the route of feeds at admission. If "Oral" then circle 1, if "Gastric (NG/GT)" (i.e. nasogastric tube or gastric tube) then circle 2, if "Transpyloric (NJ/GJ)" (i.e. naso-jejunal or gastro-jejunal tube) circle 3.

F2. Record if growth and nutrition information is available for 2 weeks after birth admission to NICU or Nursery. If "Yes" then circle 1, otherwise circle 2 for "No" and **Skip to F3.**
   a.-f. These questions are similar to the questions under F1, but pertain to the 2 week growth and nutrition marker.

F3. Record if growth and nutrition information is available for 3 months after birth admission to NICU or Nursery. If "Yes" then circle 1, otherwise circle 2 for "No" and **Skip to G1.**
   a.-f. These questions are similar to the questions under F1, but pertain to the 3 month growth and nutrition marker.

SECTION G: Imaging

G1. Record if neonatal imaging was completed during the participant's first 90 days of life. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "No" or "Unknown", then **Skip to H1**.

G2. Record if the patient had a renal or bladder US (ultrasound) during the first 90 days of life. If the participant had a normal renal or bladder ultrasound, then circle 1. If the participant had an abnormal renal or bladder ultrasound, then circle 2. If the participant did not have a renal or bladder ultrasound, circle 3 and **Skip to G3.**
   a. Record the date of the renal or bladder ultrasound.

G3. Record if the participant had a Head ultrasound or Head CT Scan. If the participant had a normal head ultrasound or CT scan, then circle 1. If the participant had an abnormal head ultrasound or CT scan, then circle 2. If the participant did not have a head ultrasound or CT scan, then circle 3.

G4. Record if the participant had an initial Head MRI during the first 90 days of life. If the participant had a normal Head MRI, then circle 1. If the participant had an abnormal Head MRI, then circle 2. If the participant did not have a Head MRI, circle 3 and **Skip to H1.**
   a. Record the date of the initial Head MRI.

G5. Record if the participant had a Final Head MRI during the first 90 days of life. If the participant had a normal Head MRI, then circle 1. If the participant had an abnormal Head MRI, then circle 2. If the participant did not have a Head MRI, circle 3 and **Skip to H1.**
   a. Record the date of the final Head MRI

SECTION H: Surgery

H1.   Record if the participant had any surgeries during the first 90 days of life including NICU, or Nursery Stay. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "No" or "Unknown", **Skip to I1.**
   a.   Record the date of the first surgery during the participant's first 90 days of life.
   b.   Record the organ system of the first surgery during the participant's first 90 days of life (e.g. renal, cardiovascular, digestive).
   c.   Record the surgery procedure of the first surgery during the participant's first 90 days of life (e.g. nephrectomy, hernia repair, biopsy).
   d.   Record the surgery approach of the first surgery during the participant's first 90 days of life (e.g. open, endoscopic).

H2.   Record if the participant had two or more surgeries during the first 90 days of life including NICU, or Nursery Stay. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "No" or "Unknown", **Skip to I1.**
   a.-d.   These questions are similar to questions under H1, but correspond to the second surgery the participant had during the first 90 days of life.

H3.   Record if the participant had three or more surgeries during the first 90 days of life including NICU, or Nursery Stay. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "No" or "Unknown", **Skip to I1.**
   a.-d.   These questions are similar to questions H1. and H2., but correspond to the third surgery the participant had during the first 90 days of life.

SECTION I: Discharge

I1.   Record the date of initial discharge from NICU or Nursery Stay to home. If the participant was transferred from the birth institution to another institution, record the date the patient was discharged to home. The word "Home" includes Foster Care or Medical Foster Care.
I2.   Record the discharge weight of the participant in grams.
I3.   Record the discharge head circumference in centimeters.
I4.   Record the discharge length in centimeters.
I5.   Record if laboratory results are available for the participant within the first 90 days of life including NICU, or Nursery Stay, which are also nearest to the discharge date. If "Yes" then circle 1, otherwise circle 2 for "No" and **END the form here**.
I6.   Record the serum creatinine laboratory value in mg/dL.
I7.   Record the Urea Nitrogen (BUN) laboratory value in mg/dL.
I8.   Record the date of laboratory values were collected.

SECTION J: Maternal History

J1.   Record the age of the participant's biological mother at birth.
J2.   Record if assisted reproductive technology (including fertility meds and/or procedures) were used. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8).
J3.   Record if biological mother received pre-natal care. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8).
J4.   Record if the biological mother had any Substance Use History. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "Yes" then proceed to sub-questions a-d, otherwise circle 2 for "No" or -8 for "Unknown" and **skip to J5**.
J5.   Record if the biological mother had any Antenatal Conditions. Circle the corresponding code: "Yes" (Code 1), "No" (Code 2), or "Unknown" (Code -8). If "Yes" then proceed to sub-questions a-d, otherwise circle 2 for "No" or -8 for "Unknown" and **END the form here**.