|  |  |  |
| --- | --- | --- |
| **Glomerular Filtration Rate** | | |
| 1Serum Creatinine |  |  |
| 1Serum Cystatin C |  |  |
| Measured GFR |  | (Includes Iohexol, Iothalamate, CrEDTA) |
| 1Estimated GFR |  | Use eGFR with highest accuracy and precision in SCD. |
| Assume these are collected: Sex1, Race1, Height1, BMI1, Potassium2, Bicarbonate2, BUN2 | | |
| **Biomarkers of Kidney Injury** | | |
| 1Urine Albumin |  |  |
| 1Urine Creatinine |  | KDIGO definition to define AKI |
| 1 Urine Albumin/Creatinine |  | KDIGO definition and protocol for collection of urine |
| 3KIM-1 |  |  |
| 3NAG |  |  |
| 3NGAL(neutrophil gelatinase-associated lipocalin or lipocalin-2) |  |  |
| 3B2M (Beta-2 Microglobulin) |  |  |
| 3Nephrocheck (based on TIMP-2 and IGFBP7) |  |  |
| 3MCP-1 |  |  |
| 3Nephrin |  |  |
| 1Daily Urine Output |  | KDIGO definition to define AKI |
| **Renal Imaging** | | |
| **Ultrasound** |  |  |
| 3Right Kidney Size |  |  |
| 3Left Kidney Size |  |  |
| 3Echogenicity Right |  |  |
| 3Echogenecity Left |  |  |
| 3Papillary necrosis Right |  |  |
| 3Papillary necrosis Left |  |  |
| **MRI** |  |  |
| 3Kidney R2\* |  |  |
|  |  |  |
| **Urine Concentrating Ability** | | |
| 3Urine Specific Gravity | Need to document water deprivation (yes/no) |  |
| 3Urine Osmole | Need to document water deprivation (yes/no) |  |
| 3Serum Osmole |  |  |
|  |  |  |
| **Enuresis** | | |
| 3Nocturnal Eneuresis | Age of patient.  History of enuresis |  |
| 3Daytime Eneuresis | Age of patient.  History of enuresis |  |
| **Hypertension** | | |
| 1Systolic Blood Pressure |  | Use recommended standards for measuring blood pressure |
| 1Diastolic Blood Pressure |  |
| 324 hour systolic blood pressure |  |  |
| 324 hour diastolic blood pressure |  |  |
| 3Nocturnal systolic blood pressure | BP  % readings elevated: |  |
| 3Nocturnal diastolic blood pressure | BP  % readings elevated: |  |
| 3Daytime systolic blood pressure |  |  |
| 3Daytime diastolic blood pressure |  |  |
| 3Nocturnal systolic dip |  |  |
| 3Nocturnal diastolic dip |  |  |
| **Urinalysis** | | |
| 2Specific gravity |  |  |
| 2pH |  |
| 2Blood |  |  |
| 2Glucose |  |  |
| 2Protein |  |  |

Below are guidelines/recommendations for the appropriate collection, measuring, and/or interpreting common data elements. If these guidelines/recommended are update after the development of the CURE-SCI, please refer to the most recent version.

Acute Kidney Injury definitions

<https://kdigo.org/guidelines/acute-kidney-injury/>

<https://kdigo.org/wp-content/uploads/2016/10/KDIGO-2012-AKI-Guideline-English.pdf>

Albuminuria Standards

<https://kdigo.org/guidelines/ckd-evaluation-and-management/>

Blood Pressure Standards

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5678635/pdf/main.pdf>

<https://www.ahajournals.org/doi/10.1161/CIR.0000000000000596>

Instructions:

This document contains the common data elements (CDEs) recommended for use in sickle cell disease to assess renal function. There are Core (required by all sickle cell studies) elements which should be required of all sickle cell genetic research studies. There is also the classification of Supplemental-High Recommended and Exploratory data elements on this document.

Some of the Core elements include assessment serum creatinine, estimated GFR using the CKD-EPI formula and assessment of renal complication with the AKI guidelines that include urine, creatinine, urine albumin/creatinine, and daily urine outcome. Other Core elements related to monitoring hypertension. Supplemental-Highly recommended elements of the urinalysis as outlined. There are Exploratory items related to some urine biomarkers, ambulatory blood pressure reading, ultrasound readings, MRI findings, enuresis and urine concentrating ability.

1 Core

2 Supplemental-Highly Recommended

3 Exploratory