

**Supplementary Table 2.** List of key performance and outcome indicators (KPIs) in ERKReg Registry

General
Time (months) from 1 <sup>st</sup> symptom to diagnosis: Median (IQR)
Time (months) from referral to diagnosis: Median (IQR)
% hereditary disease patients with any genetic screening
% hereditary disease patients with NGS screening (panel, WES)

Glomerulopathies
% patients with hereditary glomerulopathies with genetic screening
% patients with multidrug resistant NS with comprehensive genetic screening
% normotensive patients (CKD1-3)
% patients with office blood pressure in target range
% patients with immunological glomerulopathies in clinical remission
% patients with persistent proteinuria who receive RAS antagonist therapy
% patients with hereditary and multidrug resistant NS on conservative treatment who are prescribed RAS antagonist therapy
% adult patients with statin therapy
% adult patients with LDL cholesterol <100 mg/dl
% children with steroid sensitive idiopathic nephrotic syndrome who are obese
% children with steroid sensitive idiopathic nephrotic syndrome with height < 3rd percentile

Tubulopathies & metabolic nephropathies
% patients with hereditary nephropathy with genetic confirmation
% children (<16y) with normal length/height SDS
% patients with renal tubular acidosis maintaining normal serum bicarbonate
% cystinosis patients in whom at least one cystine blood level has been obtained during the past 12 months
% cystinosis patients with leukocyte cystine level < 1 nmol/mg protein
% cystinuria patients free of new stones in past 12 months
% Fabry disease patients with at least one proteinuria measurement in past 12 months
% Bartter/Gitelman patients with serum K > 2.5 mmol/l

Thrombotic microangiopathies
% new-onset HUS patients with complete initial diagnostics pediatric: ADAMTS13, STEC stool culture, Shigatoxin PCR adult: ADAMTS13 only
% aHUS patients with genetic/autoantibody screening (NGS, CFH autoantibodies)

Structural kidney disorders
% ADPKD patients with genetic screening
% ADPKD patients with at least one total kidney volume measurement by MRI
% normotensive ADPKD patients (CKD1-4) by office BP
% ADPKD patients screened for intracranial aneurysm when family history is positive
% TSC patients treated with mTOR inhibitors for indication AML>3 cm
% TSC patients treated with mTOR inhibitors for neurological indication (SEGA/Epilepsy)
% VHL patients with children or planning a pregnancy offered prenatal genetic counseling
% VHL patients with regular audiology assessment (every 2 years, starting at age 5)

CAKUT, ciliopathies & obstructive uropathies
% familial cystic disease patients with genetic screening
% patients with PUV detected by prenatal ultrasound
Mean (SD) of febrile UTIs in past 12 months in OUP / VUR patients

Pediatric CKD 3-5
% children (<16y) with height > 3rd percentile
% children (1-16y) with height < 3rd percentile on growth hormone therapy
% children with BMI < 5th percentile
% Children < 3 years with BMI < 5th percentile receiving enteral feeds
% patients with office systolic BP < 75th percentile
% patients with office systolic BP < 50th percentile
% patients with hemoglobin > 11 g/dl
Serum phosphorus in normal range for age
% patients with serum bicarbonate > 20 mmol/L

Pediatric dialysis
% children (<16y) with height > 3rd percentile
% children (1-16y) with height < 3rd percentile on growth hormone therapy
% children with BMI < 5th percentile
Children < 3 years with BMI < 5th percentile receiving enteral feeds
Serum phosphorus in normal range for age
% patients with hemoglobin > 11 g/dl
% patients with serum bicarbonate > 20 mmol/L
PD peritonitis rate

Pediatric transplantation
% children with pre-emptive transplantation
% children (<16y) with height > 3rd percentile
% children (1-16y) with height < 3rd percentile on growth hormone therapy
% normotensive children (by office BP)
% patients with hemoglobin > 10 g/dl
% patients without severe metabolic acidosis
% patients with biopsy proven rejection