

Study Number: _____

Phenotype	
Serology features. Select all that apply. Only select those features that pre-date renal failure - if known	
<input type="checkbox"/> NONE <input type="checkbox"/> Unknown (add details below) <input type="checkbox"/> Yes but not in this list (add details below) <input type="checkbox"/> Nephrolithiasis <input type="checkbox"/> Calcium oxalate nephrolithiasis <input type="checkbox"/> Renal salt wasting <input type="checkbox"/> Renal sodium wasting <input type="checkbox"/> Renal potassium wasting <input type="checkbox"/> Renal magnesium wasting <input type="checkbox"/> Impaired renal uric acid clearance <input type="checkbox"/> Renal chloride wasting	<input type="checkbox"/> Renal calcium wasting <input type="checkbox"/> Renal phosphate wasting <input type="checkbox"/> Renal hypophosphatemia <input type="checkbox"/> Increased renal tubular phosphate reabsorption <input type="checkbox"/> Decreased renal tubular phosphate excretion <input type="checkbox"/> Parathormone-independent increased renal tubular calcium reabsorption <input type="checkbox"/> Low alkaline phosphatase of renal origin (HPO term – select “yes but not in this list” and add details below if not on the lists)
Please add details if unknown:	
List any other serological or biochemical findings not listed above: <i>DO NOT copy and paste reports here. These should be scanned and uploaded in the Upload document instrument</i>	
Urinalysis findings. Select all that apply only select those features that pre-date renal failure - if known	
<input type="checkbox"/> NONE <input type="checkbox"/> Unknown <input type="checkbox"/> Yes but not in this list (add details below) <input type="checkbox"/> No Proteinuria <input type="checkbox"/> Proteinuria <input type="checkbox"/> Mild proteinuria <input type="checkbox"/> Moderate proteinuria <input type="checkbox"/> Nephrotic range proteinuria <input type="checkbox"/> Low-molecular-weight proteinuria <input type="checkbox"/> No hematuria <input type="checkbox"/> Hematuria <input type="checkbox"/> Macroscopic hematuria <input type="checkbox"/> Microscopic hematuria <input type="checkbox"/> Abnormality of the renal tubule <input type="checkbox"/> Renal tubular dysfunction/Renal tubular defect <input type="checkbox"/> Proximal tubulopathy/Proximal renal tubule defect <input type="checkbox"/> Global proximal tubulopathy <input type="checkbox"/> Non-acidotic proximal tubulopathy <input type="checkbox"/> Proximal renal tubular acidosis	<input type="checkbox"/> Bicarbonate-wasting renal tubular acidosis <input type="checkbox"/> Generalized distal tubular acidosis <input type="checkbox"/> Distal renal tubular acidosis <input type="checkbox"/> Renal tubular acidosis <input type="checkbox"/> Renal Fanconi syndrome <input type="checkbox"/> Renal aminoaciduria <input type="checkbox"/> Reduced ratio of renal calcium clearance to creatinine clearance <input type="checkbox"/> Parathormone-independent increased renal tubular calcium reabsorption <input type="checkbox"/> Increased renal tubular phosphate reabsorption <input type="checkbox"/> Decreased renal tubular phosphate excretion <input type="checkbox"/> Renal tubular lysine transport defect <input type="checkbox"/> Calcium oxalate nephrolithiasis <input type="checkbox"/> Abnormality of renal resorption <input type="checkbox"/> Impaired renal concentrating ability Impaired urinary acidification (HPO term - select “yes but not in this list” and add details below if not on the lists)

Please add details if unknown:	
List any other urinalysis findings not listed above: <i>DO NOT copy and paste reports here. These should be scanned and uploaded in the Upload document instrument</i>	
Imaging findings. Select all that apply only select those features that pre-date renal failure - if known	
<input type="checkbox"/> NONE <input type="checkbox"/> Unknown (add details below) <input type="checkbox"/> Yes but not in this list (add details below) <input type="checkbox"/> Hyperechogenic kidneys <input type="checkbox"/> Absence of renal corticomedullary differentiation <input type="checkbox"/> Reduced renal corticomedullary differentiation <input type="checkbox"/> Abnormal renal corticomedullary differentiation <input type="checkbox"/> Bilateral normal kidney length <input type="checkbox"/> Bilateral renal atrophy <input type="checkbox"/> Unilateral normal kidney length <input type="checkbox"/> Unilateral renal atrophy <input type="checkbox"/> Nephrocalcinosis <input type="checkbox"/> Nephrolithiasis <input type="checkbox"/> No renal cysts <input type="checkbox"/> Solitary renal cyst <input type="checkbox"/> Renal cyst/Cystic kidney disease <input type="checkbox"/> Renal corticomedullary cysts <input type="checkbox"/> Renal cortical cysts <input type="checkbox"/> Multiple small medullary renal cysts <input type="checkbox"/> Multiple renal cysts <input type="checkbox"/> Polycystic kidney dysplasia/Enlarged polycystic kidneys <input type="checkbox"/> Enlarged kidney <input type="checkbox"/> Cystic renal dysplasia <input type="checkbox"/> Multicystic kidney dysplasia/Multicystic dysplastic kidney <input type="checkbox"/> Renal duplication/supernumerary <input type="checkbox"/> Kidney Duplicated collecting system	<input type="checkbox"/> Horseshoe kidney <input type="checkbox"/> Ectopic kidney/Displaced kidney <input type="checkbox"/> Crossed fused renal ectopia/Ectopic kidney with fusion <input type="checkbox"/> Pelvic kidney <input type="checkbox"/> Abnormal localization of kidney Renal malrotation <input type="checkbox"/> Bilateral renal dysplasia <input type="checkbox"/> Unilateral renal dysplasia <input type="checkbox"/> Unilateral renal hypoplasia <input type="checkbox"/> Bilateral renal hypoplasia <input type="checkbox"/> Bilateral renal agenesis <input type="checkbox"/> Unilateral renal agenesis <input type="checkbox"/> Duplication of renal pelvis <input type="checkbox"/> Partially duplicated kidney <input type="checkbox"/> Abnormality of the renal pelvis <input type="checkbox"/> Dilatation of the renal pelvis <input type="checkbox"/> Fetal pyelectasis/Fetal renal pelvic dilatation <input type="checkbox"/> Renal angiomyolipoma <input type="checkbox"/> Abnormal renal artery morphology <input type="checkbox"/> Abnormality of renal cortex morphology <input type="checkbox"/> Abnormality of renal calyx morphology <input type="checkbox"/> Abnormal renal morphology <input type="checkbox"/> Renal medullary pyramid hypoplasia <input type="checkbox"/> Dilatation of renal calices <input type="checkbox"/> Renal diverticulum <input type="checkbox"/> Abnormality of the renal medulla (HPO term - select "yes but not in this list" and add details below if not on the lists)
Please add details if unknown:	
List any other imaging findings not listed above: <i>DO NOT copy and paste reports here. These should be scanned and uploaded in the Upload document instrument</i>	
Biopsy findings. Select all that apply only select those features that pre-date renal failure - if known	

<input type="checkbox"/> NONE <input type="checkbox"/> Unknown (add details below) <input type="checkbox"/> Yes but not in this list (add details below) <input type="checkbox"/> Immunofluorescence not performed <input type="checkbox"/> Electron Microscopy not performed <input type="checkbox"/> Tubular atrophy <input type="checkbox"/> Tubulointerstitial fibrosis <input type="checkbox"/> Renal fibrosis <input type="checkbox"/> Renotubular dysgenesis <input type="checkbox"/> Renal cortical atrophy <input type="checkbox"/> Renal cortical microcysts <input type="checkbox"/> Multiple glomerular cysts <input type="checkbox"/> Abnormality of renal glomerulus morphology <input type="checkbox"/> Glomerulopathy <input type="checkbox"/> Glomerulosclerosis <input type="checkbox"/> Focal segmental glomerulosclerosis <input type="checkbox"/> Glomerulonephritis <input type="checkbox"/> Membranoproliferative glomerulonephritis <input type="checkbox"/> Membranous nephropathy <input type="checkbox"/> Minimal change glomerulonephritis <input type="checkbox"/> Diffuse mesangial sclerosis	<input type="checkbox"/> Global glomerulosclerosis <input type="checkbox"/> Crescentic glomerulonephritis <input type="checkbox"/> Nephrocalcinosis <input type="checkbox"/> Nephritis <input type="checkbox"/> Thickening of the glomerular basement membrane <input type="checkbox"/> Glomerular subendothelial electron-dense deposits <input type="checkbox"/> Tubular basement membrane disintegration <input type="checkbox"/> Thin glomerular basement membrane <input type="checkbox"/> Diffuse glomerular basement membrane lamellation <input type="checkbox"/> Renal juxtaglomerular cell hypertrophy/hyperplasia <input type="checkbox"/> IgA deposition in the glomerulus <input type="checkbox"/> Glomerular C3 deposition <input type="checkbox"/> Renal amyloidosis <input type="checkbox"/> Abnormal renal corpuscle morphology <input type="checkbox"/> Abnormal glomerular capillary morphology <input type="checkbox"/> Abnormal morphology of Bowman capsule (HPO term - select "yes but not in this list" and add details below if not on the lists)
Please add details if unknown:	
List any other biopsy findings not listed above: <i>DO NOT copy and paste reports here. These should be scanned and uploaded in the Upload document instrument</i>	
Other general/non-specific renal features. Select all that apply	
<input type="checkbox"/> NONE <input type="checkbox"/> Unknown (add details below) <input type="checkbox"/> Yes but not in this list (add details below) <input type="checkbox"/> Abnormality of the kidney Nephropathy <input type="checkbox"/> Abnormality of the renal collecting system <input type="checkbox"/> Abnormality of renal excretion	<input type="checkbox"/> Abnormal renal morphology <input type="checkbox"/> Abnormal renal physiology <input type="checkbox"/> Renal cell carcinoma <input type="checkbox"/> Acute kidney injury (HPO term - select "yes but not in this list" and add details below if not on the lists)
Please add details if unknown:	
List any other renal specific findings not listed above. <i>DO NOT copy and paste reports here. These should be scanned and uploaded in the Upload document instrument</i>	
Non-renal clinical phenotype	
Are there any non-renal phenotypic features?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Audiology	<input type="checkbox"/> Yes <input type="checkbox"/> No

Features: _____ _____	
Ophthalmology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Endocrinology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Gastroenterology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Skeletal	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Cardiology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Respiratory	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Neurology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Dermatology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Haematology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Immunology	<input type="checkbox"/> Yes <input type="checkbox"/> No

Features: _____ _____	
Oncology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Reproductive	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Developmental/Learning/Behavioural issues	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Dysmorphology	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Other non-renal features	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Growth parameters	<input type="checkbox"/> Yes <input type="checkbox"/> No
Features: _____ _____	
Age at which CKD first diagnosed	
<input type="checkbox"/> Unknown	<input type="checkbox"/> between 5 years and 18 years
<input type="checkbox"/> < 2 years	<input type="checkbox"/> between 18 years and 30 years
<input type="checkbox"/> between 2 years and 5 years	<input type="checkbox"/> > 30 years
Age when first saw renal physician/nephrologist	
<input type="checkbox"/> Unknown	<input type="checkbox"/> between 5 years and 18 years
<input type="checkbox"/> < 2 years	<input type="checkbox"/> between 18 years and 30 years
<input type="checkbox"/> between 2 years and 5 years	<input type="checkbox"/> > 30 years
Stage of CKD when first diagnosed	
<input type="checkbox"/> Unknown	<input type="checkbox"/> Stage 3 chronic kidney disease
<input type="checkbox"/> Stage 1 chronic kidney disease	<input type="checkbox"/> Stage 4 chronic kidney disease
<input type="checkbox"/> Stage 2 chronic kidney disease	<input type="checkbox"/> Stage 5 chronic kidney disease
Age at which eGRF < 15 (CKD 5)	

<input type="checkbox"/> Unknown	<input type="checkbox"/> between 5 years and 18 years
<input type="checkbox"/> < 2 years	<input type="checkbox"/> between 18 years and 30 years
<input type="checkbox"/> between 2 years and 5 years	<input type="checkbox"/> > 30 years
Age at which eGFR < 15 (CKD 5) <i>In months and years</i> _____	
Current RRT	
<input type="checkbox"/> None, CKD5 - Pre RRT	<input type="checkbox"/> Peritoneal dialysis
<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> Transplant (answer below)
Previous RRT	
<input type="checkbox"/> None/same as current	<input type="checkbox"/> Peritoneal dialysis
<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> Transplant
Age commenced RRT?: _____ <i>Enter whole number only. If dialysis not commenced NA</i>	
Transplant(s)	
<input type="checkbox"/> Yes, more than one <input type="checkbox"/> Yes, only one <input type="checkbox"/> No	Number of previous transplants, not including current transplant <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
Year of current transplant: _____ <input type="checkbox"/> donor brain death <input type="checkbox"/> donor cardiac death <input type="checkbox"/> living related donor <input type="checkbox"/> living non-related donor	Year of previous transplant: _____ <input type="checkbox"/> donor brain death <input type="checkbox"/> donor cardiac death <input type="checkbox"/> living related donor <input type="checkbox"/> living non-related donor
Year of first of 3 or more transplants: _____	Reason for failure of previous transplant: _____
Source of first of 3 or more transplants: <input type="checkbox"/> donor brain death <input type="checkbox"/> donor cardiac death <input type="checkbox"/> living related donor <input type="checkbox"/> living non-related donor	Reason for failure of first of 3 or more transplants:
Year of other transplants where 4 or more: _____	Source of other transplants where 4 or more and reason for failure: _____
Medicine	
Past Medical Conditions: _____ _____	
Medications	
Medication Allergies: _____ _____	
Current Medications	

How many prescription medications is the patient currently taking? _____
Medication: _____ Dose: _____ <i>*Option for multiple entries</i>
Non-Script Medications
How many non-prescription medications is the patient currently taking? _____ <i>Include over the counter, traditional Chinese medication etc</i>
Medication: _____ Dose: _____ <i>*Option for multiple entries</i>