

Condition-Specific Data Entry Instructions for RaDaR

The following instructions indicate which tabs should be filled in for each cohort of patients on RaDaR.

If you have Patient View at your site you must get the patient added to PV and enable PV extraction on their renal system record to ensure that the data flows into RaDaR.

For any queries please contact: **Garry.King@renalregistry.nhs.uk**.

ADPKD

Please fill in the following tabs for ADPKD patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Co-morbidities
- Genetics
- Family History
- Renal Imaging
- Liver Imaging
- Liver Disease

If applicable

- Kidney Transplants
- Liver Transplants
- Dialysis
- Nephrectomies
- Nutrition

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Alports

Please fill in the following tabs for Alport Syndrome patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Clinical Picture

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

ADTKD/FUAN

Please fill in the following tabs for ADTKD/FUAN patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Co-morbidities
- Genetics
- Family History
- Clinical Picture

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

aHUS

Please fill in the following tabs for aHUS patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Co-morbidities
- Family History

If applicable

- Dialysis
- Plasmapheresis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

APRT-D

Please fill in the following tabs for APRT-D patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Co-morbidities
- Renal Imaging
- Pathology

If applicable

- Dialysis
- Plasmapheresis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

ARPKD/NPHP

Please fill in the following tabs for ARPKD/NPHP patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis – please select either ARPKD or NPHP

Strongly Recommended

- Co-morbidities
- Genetics
- Family History
- Fetal Anomaly Scans
- Renal Imaging
- Liver Imaging
- Liver Diseases
- Nutrition

If applicable

- Kidney Transplants
- Liver Transplants
- Nephrectomies
- Dialysis

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

BK Nephropathy

Detailed PDF instructions available to download from <https://tinyurl.com/BK-Neph-data> or on request from Melanie.Dillon@renalregistry.nhs.uk

Calciphylaxis

Please fill in the following tabs for Calciphylaxis patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Clinical Picture
- Co-morbidities
- Family History
- Renal Imaging

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Cystinosis

Please fill in the following tabs for Cystinosis patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Renal Imaging

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Cystinuria

Please fill in the following tabs for Cystinuria patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Renal Imaging

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Dent Disease & Lowe Syndrome

Please fill in the following tabs for Dent & Lowe patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Clinical Picture
- Genetics
- Family History
- Renal Imaging

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Fabry Disease

Please fill in the following tabs for Fabry Disease patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Renal Imaging

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Fibromuscular Dysplasia

Please fill in the following tabs for Fibromuscular Dysplasia patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Renal Imaging

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

HNF1-B

Please fill in the following tabs for HNF1-b patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Fetal Anomaly Scans
- Renal Imaging
- Clinical Pictures
- Pathology

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Stec HUS

Please fill in the following tabs for Stec-HUS patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Co-morbidities
- Pathology

If applicable

- Dialysis
- Plasmapheresis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Hyperoxaluria

Please fill in the following tabs for Hyperoxaluria patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Renal Imaging
- Clinical Pictures

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

IgA Nephropathy

Please fill in the following tabs for IgA Nephropathy patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Clinical Picture
- Genetics
- Family History

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

INS & NephroS

Detailed PDF instructions available to download from <https://tinyurl.com/NephrosDatav4>
or on request from Melanie.Dillon@renalregistry.nhs.uk

MGRS

A Crib Sheet of the conditions that are included in the MGRS cohort is available to download from <https://tinyurl.com/mgrs-crib-sheet> or on request from Melanie.Dillon@renalregistry.nhs.uk

Please fill in the following tabs for MGRS patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis – specific diagnosis to be selected

Strongly Recommended

- Pathology
- Family History
- Comorbidities

If applicable

- Hospitalisations
- Plasmapheresis
- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results – fill in gaps manually

MPGN

Detailed PDF instructions available to download from <https://tinyurl.com/MpgnData> or on request from Melanie.Dillon@renalregistry.nhs.uk

Membranous Nephropathy

Please fill in the following tabs for Membranous Nephropathy patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Pregnancy

Please fill in the following tabs for Pregnancy and CKD patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis - please only put 'Pregnancy' if there is no other appropriate option, and put the EDTA Renal Diagnosis in the Comorbidity tab so we know what the additional renal disease is

Strongly Recommended

- Pregnancies
- Fetal Ultrasounds

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Pure Red Cell Aplasia

Please fill in the following tabs for Pure Red Cell Aplasia patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Retroperitoneal Fibrosis

Please fill in the following tabs for Retroperitoneal Fibrosis patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Family History

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Tuberous Sclerosis

Please fill in the following tabs for Tuberous Sclerosis patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Co-morbidities
- Genetics
- Family History
- Renal Imaging

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Tubulopathy (formally Hypokalaemic Alkaloses)

Please fill in the following tabs for Tubulopathy patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Genetics
- Family History
- Clinical Features
- Co-morbidities
- Renal Imaging

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results

Vasculitis

Please fill in the following tabs for Vasculitis patients:

Compulsory

- Demographics
- Consent
- Consultants
- Primary Diagnosis

Strongly Recommended

- Comorbidities
- Family History
- Renal Imaging
- Pathology

If applicable

- Dialysis
- Kidney Transplants

Transferred from Patient View if the patient is registered with both systems

- Medications
- Lab Results