UK Kidney Association

RaDaR
Registry of Rare Kidney Diseases

Training

1. UK Rare Renal Registry (RaDaR)

Signposting

- Who is this training for?
- Site Principal Investigators, Research Nurses and other staff who will identify, consent and collect data from renal, genetic and other related departments
- For those new to RaDaR or refresher training.
- Acquaint staff with the rare renal registry, systems and processes.
- Study roles / delegation log / radar database accounts
- Training is in 3 parts. This is part 1.

1. UK Rare Renal Registry (RaDaR)

2. Rare Renal Website

3. Data Entry

Introduction to RaDaR

The purpose of the **National Registry of Rare Kidney Diseases** (RaDaR; rare disease registry) is to facilitate translational and epidemiological research into rare kidney diseases by setting up and maintaining a comprehensive clinical database in partnership with Rare Disease Groups.

RaDaR provides an infrastructure to capture both generic and disease-specific clinical information and to collate longitudinal information. Patients and clinicians can view information about the conditions covered by RaDaR on **RareRenal.org**, which links closely with RaDaR.

Database

Rarerenal.org Website

The Registry

- Radar first recruited in 2010
- With over **33,000 patients** recruited from **109 sites** across the UK, it is the largest rare kidney disease registry in the world.
- 230 active database users at any given time
- Average 250 recruited patients per month

Site File and Website documents

- Protocol & Recruitment Guidelines
- Ethics and Regulatory Approvals
- Patient Information Sheets & Consent Forms
- Delegation log to record study roles such as identification, consent and data entry at each site

Training Themes

Identification

Recruitment

Data Entry

Identification

- Rarerenal.org Information portal for clinicians
- Inclusion & Exclusion list
- 33 Cohorts
- >100 conditions
- Newly diagnosed in clinics
- Search List with keyword search (ctrl-F)
- Search hospital clinical system with keywords
- Any queries, ask cohort lead via RaDaR team.

RaDaR Inclusion and Exclusion Criteria

Diagnosis	Cohort	Inclusion Criteria	Exclusion Criteria	Date of Diagnosis
Hypertensive kidney disease	CKD-Africa Genes	People of African or Afro-Caribbean ancestry with CKD (KDIGO definition), >18 years	Known cause of Kidney disease	Date that clinical diagnosis was first made
Hyperuricaemic Nephropathy (Primary/Familial Hyperuricaemic nephropathy) **Medullary cystic kidney disease**	ADTKD	Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD; previously known as FUAN) Familial juvenile hyperuricaemic nephropathy Familial gouty nephropathy Familial urate nephropathy Familial interstitial nephropathy Uromodulin-associated nephropathy Medullary cystic kidney disease (type I or II)	None stated	Date that genetic confirmation was received
IgA Nephropathy	IgA Nephropathy	Biopsy proven IgA Nephropathy plus proteinuria >0.5g/ day or eGFR<60ml/min	All forms of secondary IgA nephropathy, including Henoch Schonlein purpura	Date of renal biopsy
Isolated autosomal dominant hypomagnesemia, Glaudemans type	Tubulopathy	Isolated autosomal dominant hypomagnesemia Genetically confirmed homozygous pathogenic variant in KCNA1	None stated	Date that clinical diagnosis was first made

Recruitment

- To recruit from as many sites as possible (geographically diverse)
- To recruit into as many cohorts as possible (including smaller groups)
- Some sites specialise in certain cohorts (e.g. genetic, paediatric centres)
- Informed consent
- Electronic consent
- Re-consent (upgrade from 2017 consent)
- Retention – Transition from Paediatrics to Adult consent
- **Rarerenal.org** Information portal for patients

Data Entry

- Aim is to get as complete data as possible for each cohort across all sites
- Rare conditions – every item of data counts
- Data completeness and accuracy - reporting
- Staff can improve the existing patient dataset even before recruiting
- 76% of patients have lab results via a data feed.
- Some blood tests are not sent via data feed and need manual entry
- Compulsory fields
- Generic information
- Cohort-specific requirements
- Genetic and Pathology Reports to support diagnosis