RaDaR Training

Checklist

- Introduction
- Site set-up / Sign-posting
- Radar site file
- Rarerenal.org website
- Recruitment Process (consent and database)

Introduction

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.

Site set-up / Signposting

- Study roles / Delegation Log
- RaDaR accounts

Identify

Recruit

Enter

RaDaR Site File (PDF)

- Protocol & Recruitment Guidelines
- Ethics and Regulatory Approvals
- Patient Information Sheets & Consent Forms
- Local Research Team
- Screening & Enrolment
- Study Contact Details

Rarerenal.org

Identify Clinics / retrospectively on clinical system

- Patient Information
- Clinical Information
- Rare Disease Groups
- Registry (RaDaR)
    - Recruitment Resources
        - **Inclusion/exclusion criteria (ctrl-F to search for keywords)**
- Recruitment
- News
- Glossary

Recruitment Process

Recruit   Consent

- Recruit/consent patient - Face to Face or Remote (telephone/postal / *e-consent).
- Ask at this point, specific research questions, if required by cohort, e.g. RDG "CKD due to Genetic Factors in people of African ancestry" requires family ethnic origin info which is not typically available on clinical systems.
- https://renal.org/rare-renal/criteria-and-consent

Enter   RaDaR Database   https://nwww.radar.nhs.uk/

- **Compulsory**: patient demographic information, email, primary diagnosis and date.
- Add Confirmed by Gene Test, Biochemistry, Clinical picture or Biopsy
- With **Biopsy you must indicate Yes or No**. If Yes, "Please, fill biopsy details on pathology tab" (you can paste in report in Histological Summary field but please remove patient identifiable information.
- Add patient's consultant
- Notify renal IT system admin of patient NHS number to switch on data feed (results/meds)
- Add specific data recommended by rare disease cohort…

Add specific data recommended by rare disease cohort

Please check and add specific data that is strongly recommended for that rare disease cohort.

The green 'cohort info button' in patient record will show you which pages require data (see Alport info button right)
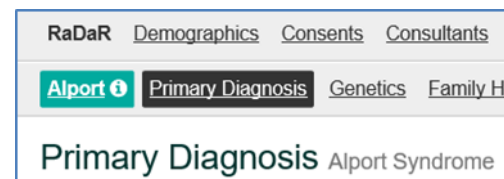
Alports

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 renal system

- Medications
- Lab Results

Specific rare disease group (RDG) data instructions

How to recruit a patient to RaDaR

RaDaR

Step One - Consent

1. Download appropriate Patient Information Sheets (PIS) from **RareRenal.org** and give to patient

2. Inform patient about RaDaR

3. Download consent forms from **RareRenal.org**. These should be printed with Hospital / Trust letterheads

4. Obtain consent from patient. This can be done by post or face-to-face

5. Copies of consent form for patient and medical record to be retained in the local site file.

Step Two - Data Entry

1. Log in to **https://nww.radar.nhs.uk**

2. Go to the **Patients** tab and click on **Recruit Patient**

3. Enter the required details and click **Search**. Enter the patient's details manually if their record is not found

4. Select the appropriate **Renal Unit** and **Cohort** (Rare Disease Group /diagnosis)

5. Confirm that the patient has been consented by selecting the **Consent** check box

6. If the patient needs to be added to another **Cohort** (e.g. NephroS), this can be done via the **Cohorts** tab at the top of the next screen

7. Click on the green **Cohort** tab for condition-specific data entry instructions. Fill in the **Demographics, Primary Diagnosis and Consultant** tabs as a minimum for all patients. More data is always appreciated.

8. For every patient who is recruited onto RADAR it is **important** that you make them known to the administrator of your Renal IT System to enable the patient's **Medications and Results data to flow into RADAR automatically**. A switch needs to be 'set to extraction' on the renal system. A chain link icon appearing next to patient number in RaDaR site list indicates an established link.

9. Check the data is correct. If any changes are required please notify your Renal IT Manager so that alterations can be made at source

Websites

www.rarerenal.org public information about rare kidney diseases

https://nww.radar.nhs.uk patient registry for professional access via NHS computers

Any queries please contact: **nbn-tr.RADAR@nhs.net**