

Issue Eleven, Autumn 2017

The National Registry of Rare Kidney Diseases (RaDaR) is a Renal Association initiative designed to pull together information from patients with certain rare kidney diseases. This will give a better understanding of how these illnesses affect people and will also speed up research. Recruitment to RaDaR is now open to all UK hospitals, both adult and paediatric.

15,000th RaDaR Patient Recruited!

The 15,000th UK RaDaR patient was recruited on the 10th October 2017. The landmark patient was an Alport Syndrome recruit from Kent and Canterbury hospital. This is a fantastic achievement and a testament to all the hard work and support that the 87 currently recruiting hospitals have given to the project over the years. Many thanks to you all.



Our overall recruitment target is 25,000 patients so we still have a way to go but with over 500 new patients recruited each month we are well on track to archive this by the current study end date of December 2019.

Patient View Linkage

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. If you have any questions about this please contact: Fiona.Braddon@nhs.net

Patient Transition

Paediatric sites - please tell the adult hospital that the patient is moving to that they have been recruited to RaDaR so that they can be re-consented as an adult. If you do not know where are moving to please let the central RaDaR team know so we can investigate.

Top Recruiting Adult Sites	Recruits
London Royal Free	762
London Evelina & Guys	683
Glasgow Queen Elizabeth	582
Lister Hospital, Stevenage	577
Nottingham City Hospital	563

Top Recruiting Paediatric Sites	Recruits
Birmingham	374
Nottingham	166
Leeds	153
Manchester	143
Southampton	142

RaDaR is generously supported by:



RaDaR Ethics Amendment Approved

The latest RaDaR amendment has now been approved by Ethics. The main changes concern clarification that **RaDaR consent covers Patient View sign-up**, subject to local availability, and that patients consent to being **contacted directly** by a member of the central RaDaR team and/or their Rare Disease Group Lead regarding information events or further research studies.

The amendment also allows for **data linkage to other registries**, including the Hospital Episode Statistics (HES) and Office for National Statistics (ONS) databases. This will enable a far more comprehensive RaDaR data-set than is currently available with manual data entry. It will also allow for longitudinal follow-up of patients who have previously consented to condition-specific research studies, or who do so in the future.

Copies of the new Consent forms and Patient Information sheets have been sent to all current sites and are also available from the **Criteria and Consent** page of **Rare Renal** - www.rarerenal.org/radar-registry/criteria-and-consent

Please note that as RaDaR is a registry rather than a clinical trial, additional HRA approvals are not needed. The amendment is therefore all approved and ready to be implemented. If you have any queries about the amendment please contact Melanie.Dillon@RenalRegistry.nhs.uk

Patient View Logins

In the RaDaR Site File we include a template letter to provide patients with their login to Patient View. This letter is optional and not version controlled. It can be replaced with the sites' own standard letter for providing PV logins, which are usually sent out by the PV administrator. If the template letter is used, the example of setting the patient's password as their DOB is not ideal as it is easy to guess. We recommend that the PV system-generated password is used instead.

Renal Association Guidelines

The Renal Association produce guidance on best practice in the management of patients with kidney disease. The current editions of the Guidelines can be found at www.renal.org/guidelines.

Several new guidelines are currently in preparation which are relevant to RaDaR:

- Recommendations for monitoring children and young people with or at risk of ADPKD
- Medical management of stone disease
- Pregnancy and renal disease



For more information please visit www.renal.org/guidelines/recent-activity

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st November 2017** when there were **15,419** UK patients in RaDaR from **87 hospitals**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	3761
ADTKD/FUAN	√	√	121
aHUS	√		158
Alport Syndrome	√	√	522
APRT-D	√		6
ARPKD	√	√	162
Calciophylaxis	√	√	27
Cystinosis	√		112
Cystinuria	√		342
Dent Disease & Lowe Syndrome	√	√	47
Fabry Disease	√		27
Fibromuscular Dysplasia	√		15
HNF1-B	√	√	59
Stec HUS	√		110
Hyperoxaluria	√		95
Hypokalaemic Alkaloses	√	√	232
IgA Nephropathy	√	√	2009
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	754
Membranous Nephropathy	√		1428
Nephrotic Syndrome	√	√	2226
Pregnancy & Chronic Kidney Disease	√	√	357
Pure Red Cell Aplasia	√		4
Retroperitoneal Fibrosis	√		78
Tuberous Sclerosis	√		74
Vasculitis	√		2763

If you are having problems with recruitment or in getting your site set-up please contact:

Melanie Dillon - Melanie.Dillon@renalregistry.nhs.uk