

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.

RaDaR Update following NHS Cyber Attack

In regards to the cyber attack on the NHS back in May, we want to reassure you that RaDaR was **not** affected and that the patients' data remains secure.

Neither the RaDaR servers nor North Bristol Trust (where our admin team are based) were affected by this attack. Although data transfer to Patient View was temporarily suspended, this was just as a precaution in case there were further developments over the weekend of the 12th-15th May.

RaDaR is held on a secure N3 server that has been fully security tested and is kept up-to-date with the latest security patches. The UK Renal Registry, who manage the daily operation of RaDaR, has Section 251 approval as an indication of their robust security and information governance policies and practices.

This particular breach was concerned with encrypting information to deny organisations access their files and to cause wide-spread disruption. It was not concerned with stealing patient data.

If you have any concerns about the security of RaDaR you can contact our technical team at:
nbn-tr.radar@nhs.net

RaDaR Case Study

RaDaR features as a Case Study on the new **Understanding Patient Information** website, with the focus on supporting research into rare kidney disease. The Case Study can be accessed at:
<http://bit.ly/RaDaR-Case-Study>



Kidney Care UK

The British Kidney Patient Association - a key supporter of RaDaR - have changed their name to **Kidney Care UK**. Their new website can be accessed at:
www.kidneycareuk.org



Top Recruiting Adult Sites	Recruits
London Royal Free	742
Glasgow Queen Elizabeth	565
Lister Hospital, Stevenage	552
Nottingham City Hospital	523
London Evelina & Guys	517

Top Recruiting Paediatric Sites	Recruits
Birmingham	358
Nottingham	164
Leeds	149
London Great Ormond Street	123
Manchester/Southampton	108

RaDaR is generously supported by:



IgA Nephropathy Grant and Research Article

The IgA Nephropathy research group in Leicester has been given £2.7 million to establish the world's first international registry of IgA Nephropathy patients. The registry will follow the same format as RaDaR and will collect clinically characterised data from IgA Nephropathy patients across Europe, Asia and South America.

Further details about the award can be found at: <http://bit.ly/IgAN-grant>

The IgAN Rare Disease Group have also had an article published in the latest issue of the **Journal of Kidney Care**. The article discusses how having access to an international rare disease registry with data on this disease can help improve kidney care around the world.



The article can be accessed at: <http://bit.ly/IgAN-article>

Re-Consenting Adult Patients

The central RaDaR team have had several queries lately about re-consenting paediatric patients when they move to adult care and what happens to the records of those who are not re-consented as adults.

The RaDaR Protocol and consent documents state that a patient should be approached to consent on their own behalf from the age of **16 onwards**. If they have not done so by the time they turn **18** then it is assumed that they no longer wish to be part of RaDaR and their record is **frozen** and removed from view.

In such cases we **remove the patient from the paediatric site** as it is assumed that they have now transitioned to adult care. The data remains intact and will be re-activated as soon as we are told that they have consented as an adult. It does not affect the accrual from the paediatric site and the statistics on RaDaR under **Recruiting Hospital** remain correct.

Paediatric sites are asked to tell the adult hospital that the patient is moving to that they have been recruited to RaDaR so that they can be re-consented.

UK Kidney Week



RaDaR was credited in several posters at the Renal Association's conference in Liverpool in June, including those for **APRT-Deficiency**, **ARPKD** and **Retroperitoneal Fibrosis**, which covered the results of their recent patient survey.



There was also considerable interest in RaDaR via the Renal Association and UK Renal Registry's stand in the exhibition hall. With the permission of the authors, the posters have now been uploaded to the **Presentations** page of RareRenal: www.rarerenal.org/radar-registry/radar-presentations.

New aHUS website



The **National Renal Complement Therapeutics Centre** in Newcastle has launched a new website – www.atypicalHUS.co.uk – containing information for both patients and clinicians on atypical haemolytic uraemic syndrome and C3 glomerulopathy.



The site contains information about the diagnosis and management of aHUS, including patients who have end-stage renal failure and may benefit from the prophylactic use of eculizumab at time of renal transplantation.

Reminder: Please enter your patients onto Patient View - if it is available at your hospital - in order to ensure data transfer to RaDaR

New Sites

RaDaR is now open in **87 hospitals** across the UK.

The latest sites to start recruiting are:

- Basildon
- Bury St Edmunds
- Dartford
- Dumfries & Galloway
- Peterborough



A full list of currently recruiting sites is available at:
www.rarerenal.org/radar-registry/renal-units

Coming Soon

A further five sites are currently in set-up. They will be open to recruitment shortly.

- Antrim
- Huddersfield
- Kirkcaldy (Fyfe)
- Sandwell
- Torbay



We are still open to new sites. If you would like to take part please contact:
Melanie.Dillon@renalregistry.nhs.uk

Proposed Ethics Amendment for RaDaR

The RaDaR Operational Management Board and Rare Disease Group Leads have agreed to apply for an Ethics amendment to clarify the fact that **RaDaR consent covers Patient View sign-up**, subject to availability at individual renal units.

The proposed amendment will also allow for data linkage to other registries, including the **Hospital Episode Statistics (HES)** and **Office for National Statistics (ONS)** databases. This will allow for 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.

In addition, it is proposed to ask patients to 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. Such communication would always be approved by the RaDaR Operational Management Board before being sent out and will largely be circulated via Patient View.

Approval will be sought from **NHS Digital's Data Access Request Service (DARS)**.

It is aimed to submit the Ethics amendment in the Autumn. **Please continue to recruit patients to RaDaR in the meantime, using the current consent documents.**

Further details will follow in the coming weeks but we would welcome suggestions over the proposed amendment to Melanie.Dillon@RenalRegistry.nhs.uk.

Patients Consented at Other Sites

With the number of patients recruited to RaDaR rapidly increasing, several sites have found that they have consented a patient who has already been recruited by another site. Although patients cannot be entered into RaDaR twice, it is not an efficient use of staff time and resources to consent a patient who has already agreed to take part.

To check if a patient has already been recruited by another site you can either:

1. Contact Melanie.Dillon@renalregistry.nhs.uk
2. Go to the **Recruit Patient** screen, enter their NHS number and fake the details for the remaining fields. If they have already been recruited by another site it will tell you so when you click on the **Search Patients** button.

Cystinosis Patient Education Day

Tuesday 19th September 2017

09.30am – 4.30pm

Being held at the Post Graduate Centre,
Queen Elizabeth Hospital, Birmingham

Inviting Patients and Health Professionals with an
Interest in Cystinosis

To register for a place, please contact Michelle Lowe:

Michelle.lowe@uhb.nhs.uk or 07810654864



Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st August 2017** when there were **13,702** UK patients in RaDaR from **87 hospitals**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	3167
ADTKD/FUAN	√	√	112
aHUS	√		145
Alport Syndrome	√	√	471
APRT-D	√		6
ARPKD	√	√	150
Calciphylaxis	√	√	23
Cystinosis	√		108
Cystinuria	√		323
Dent Disease & Lowe Syndrome	√	√	47
Fabry Disease	√		20
Fibromuscular Dysplasia	√		11
HNF1-B	√	√	52
Stec HUS	√		89
Hyperoxaluria	√		87
Hypokalaemic Alkaloses	√	√	221
IgA Nephropathy	√	√	1786
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	695
Membranous Nephropathy	√		1329
Nephrotic Syndrome	√	√	2101
Pregnancy & Chronic Kidney Disease	√	√	312
Pure Red Cell Aplasia	√		3
Retroperitoneal Fibrosis	√		68
Tuberous Sclerosis	√		61
Vasculitis	√		2369

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

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