

Issue Six, Summer 2016

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 renal centres, adult and paediatric.

RaDaR opens to Postal Consent

Patients can now be consented to RaDaR by post, following a successful amendment submission to the South West - Central Bristol Research Ethics Committee. The amendment has resulted in changes to the RaDaR Protocol and all consent documents. Although existing patients do not need to be re-consented, renal units are asked to use the new documentation going forward.

The new versions of all documents can be downloaded from: <http://bit.ly/radarconsent>

Kidney Animation

Although the conditions covered by RaDaR are rare, kidney health is important to everyone.

Our partner website **Think Kidneys** have produced a brilliant animation on **Almost Everything you Need to Know About Your Kidneys**, as part of their Public Campaign this Summer.

You can view the video via their Campaign page: www.thinkkidneys.nhs.uk/campaign

RaDaR on Social Media

Keep in touch with the latest updates and recruitment figures via our social media channels. Our Facebook page is [@RenalRadar](https://www.facebook.com/RenalRadar) and our Twitter feed is [#RenalRadar](https://twitter.com/RenalRadar).

Young Nephrologist's Pregnancy and Kidney Disease Course

The ERA-EDTA's Young Nephrologists' Platform (YNP), are hosting a course on **Pregnancy and Kidney Disease** in Lisbon, Portugal on 22-23 September.

Online registrations are now open, and you can find further information on the course website <http://bit.ly/Pregnancy-Course>

RaDaR's Portfolio Status

As a result of the expansion of the **Pregnancy and CKD** cohort's inclusion criteria (see page 2), RaDaR has been added to the **Reproductive Health and Childbirth** speciality on the NIHR Portfolio.

RaDaR is therefore now officially under the Renal speciality and co-adopted by both Paediatrics and Reproductive Health. We hope that this will serve to boost recruitment for the Pregnancy cohort.

Accruals will still go to the recruiting Trust.

If the change in speciality is likely to cause a problem for your renal unit in terms of funding allocation, please contact your R&D department or LCRN.

Top Recruiters

69 UK Renal Units are currently recruiting to RaDaR. The table below shows the top five recruiting sites as of 1st August 2016.

Centre	Recruits
Nottingham City Hospital	373
Lister Hospital, Stevenage	361
Royal Stoke University Hospital	311
Glasgow Queen Elizabeth	298
Birmingham Children's Hospital	286

RaDaR is generously supported by:



Extension of Pregnancy and CKD Inclusion Criteria

The RaDaR inclusion criteria for Pregnancy and Chronic Kidney Disease patients has been extended to include **women with CKD stages 1 and 2**, in addition to existing criteria of CKD stages 3-5, renal transplant recipients and patients with a history of lupus nephritis.

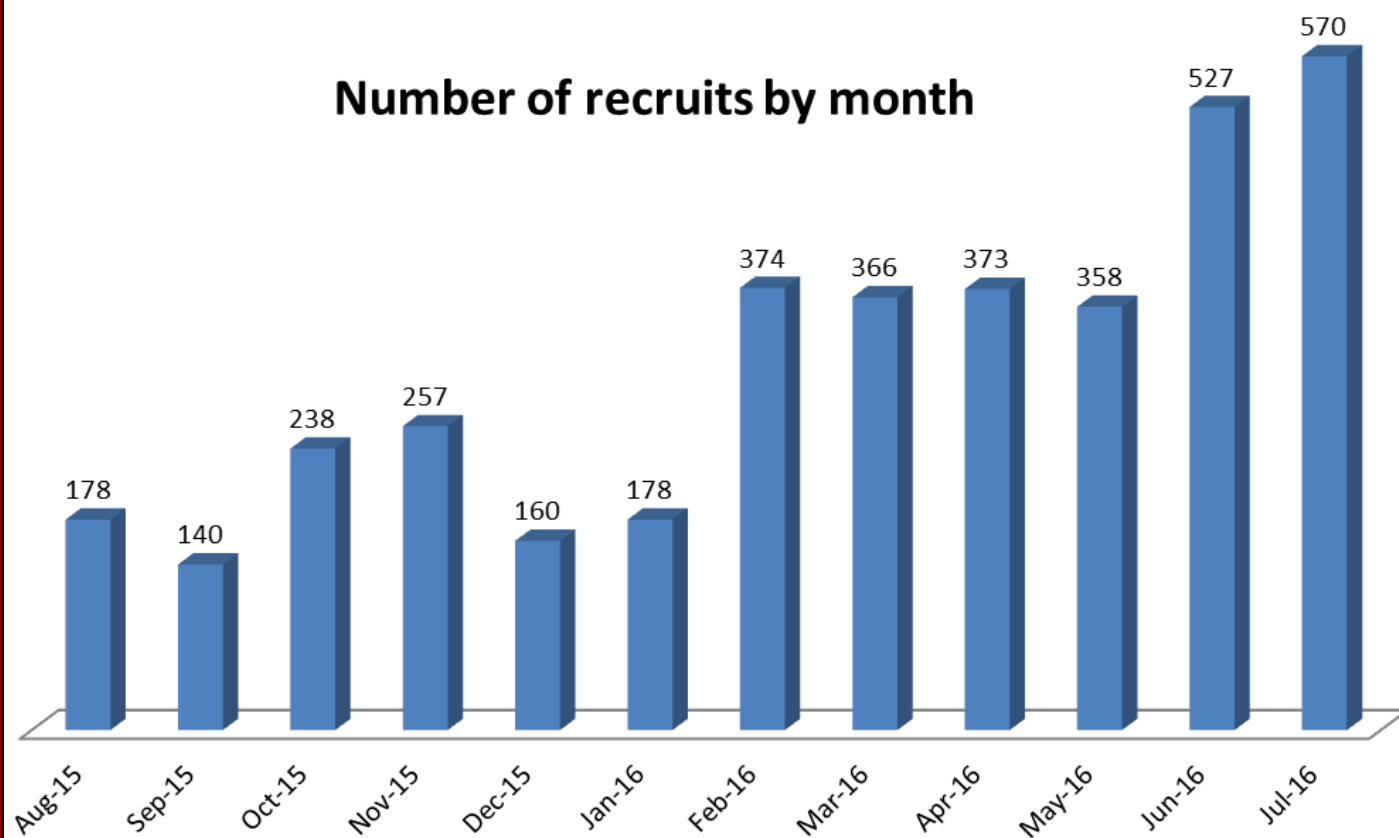
This follows the publication of observational data series from Europe that have identified increased risks of some pregnancy outcomes for women with CKD stages 1 and 2, compared to controls.

The full inclusion criteria can be found at <http://bit.ly/PregnancyConsent>

Recruitment Boost

Recruitment to RaDaR has seen a real boost since the launch of the new website in February and the introduction of postal consent in June.

Number of recruits by month



Automatic Data Transfer for RaDaR

Automatic data transfer has now been enabled for selected RaDaR data fields. **Medications** and the majority of the **Results** tabs will now be auto-populated from **Patient View (PV)**, via the **UK Renal Data Collaboration's (UKRDC)** Data Warehouse.


This data will be updated on a daily basis, providing that the patient is registered on PV and their record is flagged on your renal IT system to send data to PV. Condition-specific data entry instructions are now available for all conditions under the green **Cohort** tab, once a patient has been registered.

If your renal unit is not currently using Patient View but would like to, please contact Fiona.Braddon@nhs.net for help getting set up.

If you have patients on RaDaR whose results are not coming through from PV, please check with your local PV administrator or Renal IT system manager that the patient has been flagged for PV on your Renal IT system. If results are still not appearing then please contact nbn-tr.radar@nhs.net for assistance.

Please pass this information on to any interested patients in your renal unit.

Rare Diseases
Translational Research
Collaboration

 NHS
National Institute for
Health Research

Pregnancy and Kidney Disease Patient Day

30th Sep 2016

For all women with kidney disease who are planning a pregnancy, have been pregnant or are currently pregnant

Families and partners are welcome

Interactive Sessions including:

- Preparing for pregnancy
- Antenatal and postpartum support
- Medications in pregnancy

**Arlington Conference Centre,
220 Arlington Road Camden,
London. NW1 7HE
9.30-13.30**

To register please email

kch-tr.kidneypregnancy@nhs.net
RareRenal.org

Information on rare kidney diseases

 THE RENAL
ASSOCIATION
founded 1958

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of 1st August 2016, when there were 6,480 UK patients in RaDaR from 69 Renal Units.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	705
ADTKD/FUAN	√	√	76
aHUS	√		89
Alport Syndrome	√	√	285
APRT-D	√		2
ARPKD	√	√	83
Calciphylaxis	√		16
Cystinosis	√		61
Cystinuria	√		177
Dent Disease & Lowe Syndrome	√		33
HNF1-B	√	√	35
Stec HUS	√		56
Hyperoxaluria	√		57
Hypokalaemic Alkaloses	√	√	164
IgA Nephropathy	√		627
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	457
Membranous Nephropathy	√		858
Nephrotic Syndrome	√	√	1217
Pregnancy & Chronic Kidney Disease	√	√	143
Pure Red Cell Aplasia	√		2
Retroperitoneal Fibrosis	√		12
Vasculitis	√		1342

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

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