

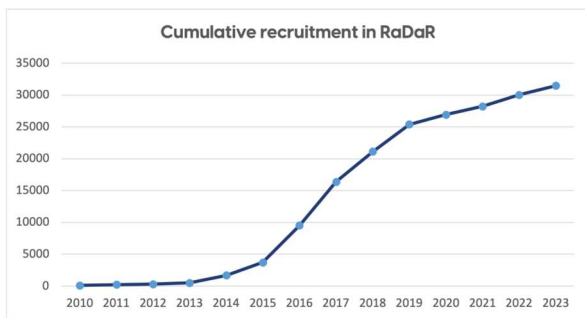
RaDaR Newsletter

Welcome to the Autumn 2023 National Registry of Rare Kidney Diseases (RaDaR) newsletter!

We would like to thank you for taking part in RaDaR. The information that you have allowed us to use from your records is continuing to improve national understanding of rare kidney diseases.

Current recruitment

Current overall recruitment is **31,473 patients** (September 2023) from 110 sites.



Top recruiting centres overall are London - Royal Free Hospital with **1,425 patients** (for adults) and Birmingham Children's Hospital with **630 patients** (for paediatric).

The top recruiting centre in the last three months has been Oxford- Churchill with 69 patients recruited. The newest centre is Rhyl - Ysbyty Glan Clwyd in Wales.

Data improvement plans

To make sure our data is as accurate and up-to-date as possible, we are working closely with kidney centres and laboratories around the UK.

This map shows the hospitals and laboratories we are working with:

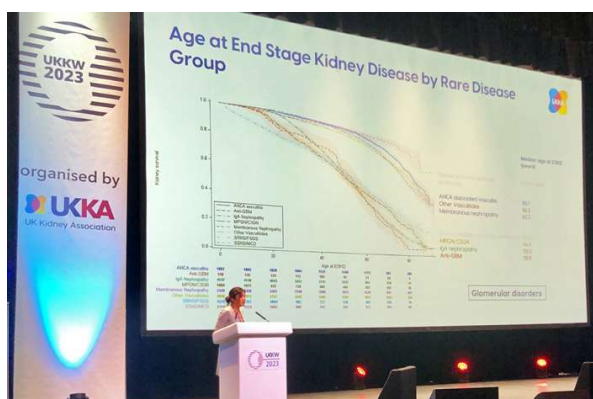


We have added older blood and urine test results to the RaDaR database from hospitals who have given us a data file of historical back data.

We are also working with centres to get **important genetic test results** and specific blood marker results. These include Cambridge, London Guy's St Thomas, and Sheffield. Others in the future include Newcastle and Bristol.

RaDaR in action

- Work looking at how severe kidney disease is in all the people living with IgA nephropathy **who have agreed to join RaDaR** has now been published in a medical journal. [Read more about it here.](#)
- We have looked at what age people living with rare kidney diseases are diagnosed, how quickly rare kidney diseases can lead to kidney failure and how this compares with other causes of kidney disease – highlighting the huge need for better treatments for rare kidney diseases. We have also looked at how diverse people recruited to RaDaR are and how well we are recruiting people of all ethnicities and from all social backgrounds.
 - This research was presented at the [UK Kidney Week \(UKKW\)](#) Conference in Newport in June 2023, the European Renal Association (ERA) Conference in Milan in July 2023, and at the American Society of Nephrology (ASN) conference in Philadelphia in November 2023.



New projects

We are excited to announce the first **RaDaR patient questionnaire**, looking at understanding loin pain in rare kidney disease. Loin pain is a discomfort in the mid-lower back and/or sides which can also sometimes be felt in the front.

Loin pain is a recognised symptom of some kidney diseases, particularly **IgA Nephropathy**, **Autosomal Dominant Polycystic Kidney Disease** and **Alport Syndrome**. We currently do not understand what causes this pain, how it impacts every day life, nor how it can be managed. With researchers from the University of Leicester, this patient survey aims to answer these questions, which will help improve the care of those with this pain.

All patients who have joined RaDaR will have the opportunity ask to take part in this questionnaire. We will send an email to everyone signed up to RaDaR with details about how to get more information or to enrol.

If you would like to take part, please make sure we have an up-to-date email for you by either letting your kidney centre know, or contacting us directly on radar@ukkidney.org

Patient portal

There are exciting plans for a RaDaR Patient Portal, so that you can enter your patient experiences and symptoms. This will be hosted on the Patients Know Best Platform.

[Please sign up to PKB here if you would like to take part.](#)

Patient information

Information for patients with rare kidney conditions is available here

Consenting to RaDaR

Most people taking part in RaDaR have signed an up-to-date consent form with us. Some patients may still need to sign a new, up-to-date consent form to be able to take part in RaDaR.

- If you have turned 18 years old in the last year and have not signed an adult (>18 years) consent form
- Or if you are an adult (>18 years) and have not signed a consent form since 2017

Please contact your kidney centre or RaDaR directly via radar@ukkidney.org with the name of your centre if you would like to continue to take part in RaDaR and we can arrange for an up-to-date consent form to be sent to you by post or email.