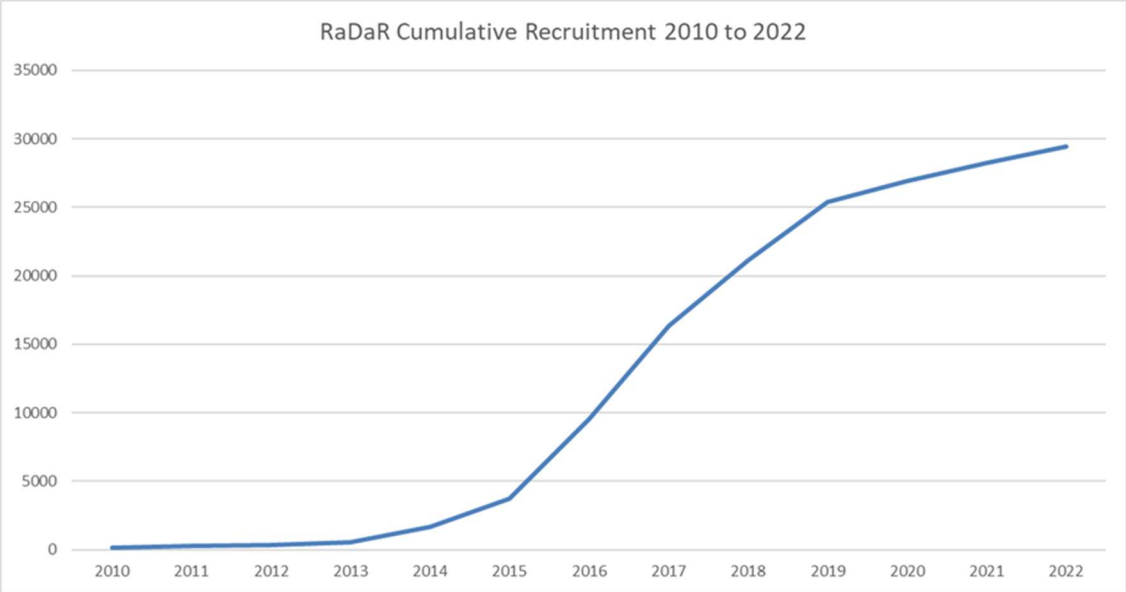
Welcome to the National Registry of Rare Kidney Diseases (RaDaR) newsletter!

Thank you for taking part in RaDaR, the information that you have allowed us to use is already improving our understanding of rare kidney diseases. RaDaR is now in its 13th year and has grown enormously since it started.

We have several exciting projects happening that we want to share with you.

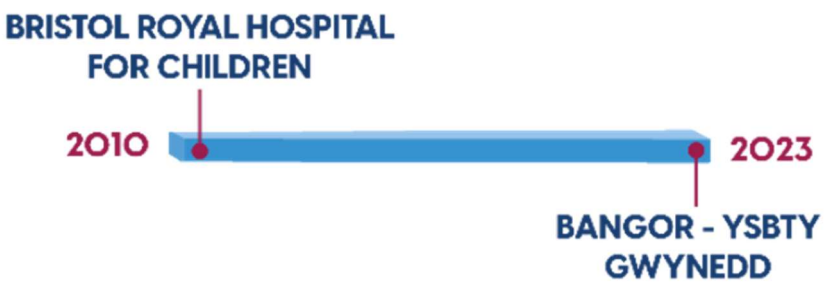
Current Recruitment

RaDaR collects information about people living with **30 different rare kidney conditions**. People are recruited from 108 different sites, across all 4 nations of the United Kingdom.



On 19th December 2022, we recruited our 30,000th patient!

Our oldest recruiting centre is Bristol Royal Hospital for Children, which started recruiting in 2010. The most recent centre to join is Bangor- Ysbty Gwynedd in Wales which has already recruited 16 patients.



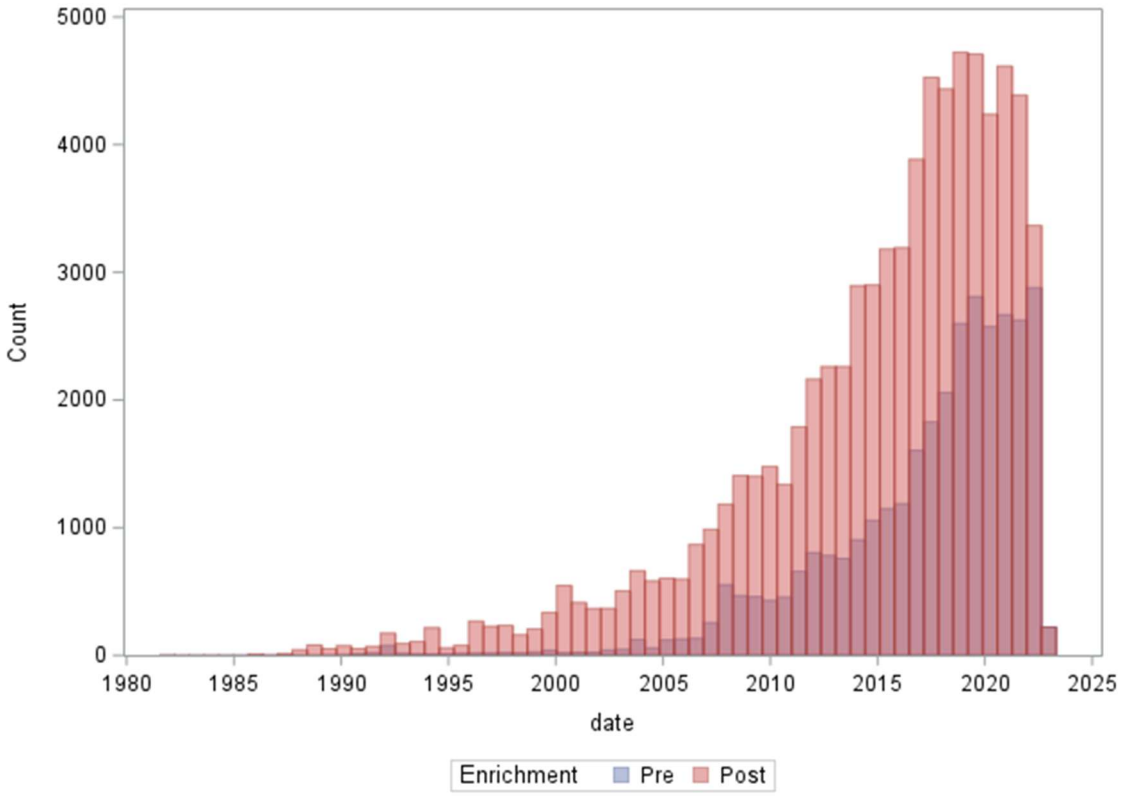
Top recruiting centre overall: London, Royal Free Hospital
Top recruiting centre in last 6 months: Manchester Royal Infirmary

Data improvement plans

We are constantly working to make sure that the data we collect is as in-depth and up-to-date as possible.

Kidney Function Results:

- We have added **362,503 kidney function results to the RaDaR database** in the last 6 months using older data supplied by kidney centres. We now have a total of over **2.1 million kidney function readings** stretching back over 40 years for some participants.
- The graph below shows the total number of kidney function readings per year that we collected for all the participants registered at one hospital. Dark red bars show the numbers before we added the older data and light red bars show how many readings we have after the older data has been added.



Genetic reports

- We have received nearly **350 genetic reports** for RaDaR patients with Alport Syndrome from Guy's and St Thomas' Genetic Laboratory.
- The analysis team at RaDaR have been able to use these to identify **the exact genetic change** for each of these patients. These genetic results help us understand how different types of genetic changes might affect how severe each person's kidneys disease may become.
- We are in the process of obtaining more reports from genetics laboratories at Great Ormond Street Hospital and Bristol.

RaDaR in action

RaDaR was approached by researchers looking to identify people with Alport Syndrome with a particular type of genetic change who might be able to take part in a study for a new drug. RaDaR was able to find participants who might be suitable and tell them about the research. Some of these people have now been enrolled in this trial. Without RaDaR gathering and **analysing genetic report data**, finding people suitable for this clinical trial would be almost impossible. Similar studies are being planned for other RaDar conditions.

We have also looked at how severe kidney disease is in all the people living with IgA nephropathy who have agreed to join RaDaR. This report describes, for the first time, how severe IgA nephropathy is in the UK. We hope the results will help efforts to **find new treatments**. They have been accepted to a journal for publication. Analysis of other RaDaR diseases and groups is well on the way and further reports are currently being written up for publication.

Contact information

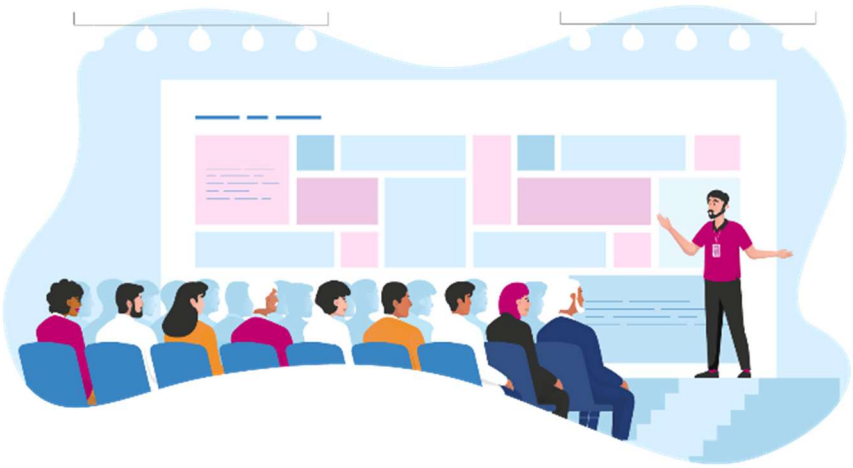
- If you change your email or home address, please remember to update your renal unit so that we have the correct details for you. Alternatively, you can let us know by directly emailing nbn-tr.RADAR@nhs.net.

- If your child is more than 16 years old and now has their own email address, they can add this to their RaDaR details so we can contact them directly if they wish. This is particularly important around their 18th birthday, when we will be contacting them to consider consenting to RaDaR as an adult. Again, please let your renal unit know or email us on nbn-tr.RADAR@nhs.net

Upcoming Events

The next RaDaR patient representative meeting is on the 28th April 2023.

Patient representatives from each Rare Disease Group (RDG) have been invited with the aim to improve the running and effectiveness of patient groups. Please get in touch with your RDG lead if you would like to be involved.



New projects

There are exciting plans to set-up a RaDaR Patient Portal this year, so that you can enter your patient experiences and symptoms.