

National Registry of Rare Kidney Diseases (RaDaR)

We would like to invite you to take part in our research database.

This leaflet contains information to help you decide whether to take part.

What is this research about?

The **National Registry of Rare Kidney Diseases (RaDaR)** is a database which aims to gather information from patients with rare kidney conditions.

This will give a much better understanding of how these conditions affect people. It will also help improve research.



Who is responsible for RaDaR?

RaDaR is part of the Renal Association (RA), a charity which supports UK kidney doctors and nurses to improve the care given to kidney patients.

RaDaR was set up to help understand rare kidney conditions and support kidney research. To do this, RaDaR has been approved by the South West – Central Bristol Research Ethics Committee, (reference 14/SW/1088).

How does it work?

If you agree (consent) to take part, information about your kidney treatment, medical information and any medicines you are on will be entered into the RaDaR database. This will be done from the hospital that manages your kidney conditions.

Doctors and researchers who are interested in understanding your condition work together as part of a Rare Disease Group (RDG). They will be able to see your information in RaDaR but will not be able to see personal information such as your name or date of birth. This means they will not be able to identify you. Your information will be linked to a unique number, which will be used instead of your personal information.

If you are 16 or under, you will need your parent or guardian's permission to take part.

However, we would like to have your permission as well. When you are 16, we will ask you to consent for yourself. If you have not consented by the time you turn 18, we will stop collecting information on you.



Why does this research matter?

As your condition is rare, it is important that we try and collect as much data as possible from young people who have your condition. This will allow researchers to learn more about how the condition affects young people, now and in the future.

What would I be agreeing to?

Taking part in RaDaR means that you agree that medical information can be held on a secure computer managed by the UK Renal Registry. You can find out more about your kidney condition at the website **RareRenal.org**, which is supported by the Renal Association and the Rare Disease Groups.

By joining this study, you agree that researchers can use your past, present and future medical information for current and future research into kidney conditions.

Data will be collected from a number of places including:

- **NHS Digital** – which collects and stores information from NHS databases. If you take part in RaDaR, you agree for your personal information (NHS number, date of birth) to be sent to NHS Digital to collect information who in return will provide information about any visits you may have had to hospital and other information about your general health.
- **NHS Digital equivalents in Wales, Northern Ireland and Scotland** – Wales (Patient Episode Database for Wales), Scotland (Information Services Division Scotland) and Northern Ireland (Health and Social care services Northern Ireland).
- **Public Health England** – which records details of anyone in the UK who is diagnosed with cancer or certain infections.
- **Digital Patient Records** – these are online websites that allow patients to view their medical information. They also allow patients to enter information about themselves, such as how they are feeling and what medicines they are on. If you take part in RaDaR, you will allow this information to be shared with RaDaR.

If you take part in RaDaR, you don't have to take part in any research projects if you don't want to. RaDaR is voluntary. If you choose not to take part, it will not affect your treatment or medical care in any way.

How will I be contacted?

From time to time, you may be contacted by a member of the RaDaR team or the RDG. They may invite you to patient information days or to take part in research projects. They may also need to ask for your permission to hold additional information. Occasionally, RaDaR may use an outside organisation to help prepare and send these messages.

We will hold a contract with any outside organisation which will set out the limits of what they are allowed to do and how they store information. This is required by law. Organisations contracted by RaDaR will be considered data processors, meaning that they will use your personal information on behalf of RaDaR (the data controller) for specific purposes set by RaDaR.

Your contact details will not be provided to other organisations or individuals unless an outside organisation is working for the UKRR, as described above.

Your medical information held by RaDaR, may be shared with other researchers. This may include Universities and companies who are investigating your condition. This will not include personal information that could identify you. Any requests for information will have to be approved by the Renal Association.

The Renal Association will make sure any information that is shared is for the benefit of your kidney condition and is done in accordance with the law.

Will my kidney doctor know about this?

Yes. Your kidney doctor knows about RaDaR and can discuss it with you if you wish. They will also be provided with news from RaDaR and will be told if the RDG wants to contact you.



How safe is my information?

Your data will be secure. Your record will be given a unique number, so that researchers using the database will only know your information by that number. They will not know your personal details.

RaDaR staff have training to make sure information is stored and used safely. Only staff members who have been approved to use your information will be able to use it. The RDG have signed a contract to keep your information confidential.

Can I have time to think about this?

Yes, you can take as much time as you need.



What happens if I change my mind?

You can withdraw from RaDaR at any time. We do advise you to speak to a parent or guardian before you do so. If you still wish to withdraw, you can either contact RaDaR directly or talk to your doctor. Your information will no longer be updated and no one will contact you.

Thank you for taking the time to read this leaflet.

If you have questions about RaDaR you should talk about it with your family or your doctor. But if you are still worried, you or your family should contact the RaDaR team at the address below.

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