

National Registry of Rare Kidney Diseases (RaDaR)

Adolescent Information Sheet

Thank you for taking the time to read this information sheet.

What is this research about?

The **National Registry of Rare Kidney Diseases (RaDaR)** is a research initiative by UK kidney specialists (the Renal Association and the UK Renal Registry). It is designed to gather information from patients with rare kidney diseases. This will give a much better understanding of how these illnesses affect people. It will also speed up research.

How does it work?

If you agree (consent) to take part, information about your treatment and any medications you are on will be entered into the RaDaR database by a member of your hospital's research team. You will be given login details to see your information online via a website called **Patient View** (www.PatientView.org), if your hospital is signed up to this.

Doctors and other researchers who are interested in your specific condition are working together as part of a Rare Disease Group. They have access to RaDaR to view your anonymised data and that of others with the same condition.

Up to the age of 16 we need your parent/guardian's permission for you to take part in RaDaR. However we would like you to give your permission as well. When you are 16 we will ask you to consent for yourself. If you haven't consented by the time you turn 18 we will stop collecting information on you.

What would I be agreeing to?

Taking part in RaDaR means that you agree that relevant information about your medical history can be held on a secure computer system operated by the UK Renal Registry. You will be given a secure password that will let you see your information via Patient View if this is available at your hospital. 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 clinical data for ongoing and future ethically approved research into kidney disease and related conditions.

Data will be collected from a number of places including:

- Your GP and hospital records
- **The UK Renal Registry** – which collects data on patients with chronic kidney disease stage 3 and above and those who are on renal replacement treatments such as dialysis or transplant waiting lists. This helps monitor standards of care across the country. By taking part in RaDaR you agree for your UK Renal Registry data to be linked with that in your RaDaR record. This will include medications, dialysis sessions and transplant outcomes where applicable.

- **NHS Digital** – which collects, stores and analyses information from a variety of sources across the NHS. By taking part in RaDaR you agree for your identifiable data (NHS number, Date of Birth and initials) to be sent to NHS Digital to link this information to two main databases:
 - **Hospital Episode Statistics (HES)** - this includes information about all hospital admissions, including when, why and for how long they happen. This will allow researchers to track the long term health of patients recruited to RaDaR. Equivalent systems to HES exist in Wales (**Patient Episode Database for Wales, PEDW**), Scotland (**Information Services Division Scotland, ISD**) and Northern Ireland (**Health and Social care services Northern Ireland, HSNI**). If you live in these areas, the study team will obtain information on hospital admissions from these sources.
 - **Office for National Statistics (ONS)** – this includes information on patients who have died, including the date and cause of death. This will allow researchers to find out what happens to patients in RaDaR and importantly to prevent any attempts at contacting those who are no longer alive.
- **Public Health England** – which records details of anyone in the UK who is diagnosed with cancer.
- Any other **UK-based ethically approved national research studies, registries or bio-banking schemes** that you have taken part in, or will do so in the future. By consenting to RaDaR you agree that your identifiable data (including NHS number and Date of Birth) can be used to confirm your participation in such studies, if this is permitted by their own Ethics approval.

Agreeing to take part in RaDaR doesn't mean you have to take part in any related research projects in the future if you don't want to.

Taking part in RaDaR is entirely voluntary. If you choose not to take part, it will not affect your treatment or medical care in any way.

Why is this data needed?

As your condition is rare, it is important that as much data as possible is gathered for analysis. Researchers may want to investigate if certain aspects of your condition (e.g. blood results or medications) are linked with specific benefits or complications. By allowing the research team to link your data with that gathered from other clinical studies, researchers will be able to study the long-term outcome of your condition and any treatments that you receive.

How will I be contacted?

You may occasionally be contacted by a member of the central RaDaR team or the Rare Disease Group lead for your condition. This may include invitations to patient information days, details of further research studies that you may want to join or requests to re-consent to RaDaR if any changes are made in the future. All contact will be pre-approved by the RaDaR Operational Management Board (OMB) before it is sent to you. Your contact details will not be provided to any other organisations or individuals.

Your anonymised data may be shared with other researchers, including those from Universities and commercial companies, who are investigating your condition. Any such requests will be approved by OMB and the Lead Clinician of the relevant Rare Disease Group. You will not be able to be identified or contacted by any of these researchers.

Will my doctor know about this?

Yes. Your 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 Rare Disease Group wants to contact you. Your GP will also be told that you have agreed to take part in RaDaR.

How safe is my information?

Your data will be secure. Your record will be given a number, so that when an analysis is undertaken the researchers will only know your data by that number. They will not know your personal details. All RaDaR staff are carefully checked and given security clearance according to their tasks. The Rare Disease Groups have signed a strict confidentiality contract with RaDaR in order to use it.

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 however we would advise you to speak to a parent or guardian before you do so. If you still wish to withdraw, you could either contact RaDaR directly as below or talk to your doctor. Your information will no longer be updated and no one will contact you.

Who is responsible for RaDaR?

RaDaR was set up as a joint initiative of the Renal Association of Great Britain, the British Association for Paediatric Nephrology and the UK Renal Registry. RaDaR is governed by the Renal Information Governance Board of the Renal Association. RaDaR has been approved by the South West – Central Bristol Research Ethics Committee, reference 14/SW/1088.

What happens if something goes wrong?

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

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