

National Registry of Rare Kidney Diseases (RaDaR)

Patient information sheet.

Thank you for taking a moment to read this information sheet.

What is this research about?

It is often difficult to find out about a rare disease. Doctors may not have diagnosed or treated such a condition before. Clinical research is made more difficult because of this, and sometimes progress in understanding the disease is slow. Patients too may have difficulty finding out about their illness.

The **National Registry of Rare Kidney Diseases**, also known as **RaDaR**, is an initiative by the kidney specialists in the UK to pull together information from patients who have certain rare kidney diseases. This will allow a much better understanding of how the illness affects people. It will speed up research. If the research leads to benefits, such as better diagnosis, treatments or general advice, the registry is set up to feedback results to patients themselves.

How does it work?

You have a kidney condition that is rare. You are therefore invited to participate in the registry. This requires your consent. If you agree, clinical information about you and your illness pathway will be uploaded from your hospital and compiled on the RaDaR database. RaDaR will also seek additional information from the NHS hospital episodes statistics database, the NHS prescribing database, the UK Renal Registry, the UK Cancer Registry (if applicable) and the Office for National Statistics (births/marriages/deaths register). This is in order to obtain a complete clinical picture. From time to time the information will be updated by your kidney specialist so that the way in which your illness affects you is recorded. You will be able to see all the information that is being collected about you.

Doctors and scientists already actively researching into your specific disease are working together as a group. This is known as the **disease-specific research group**. Once your information is uploaded on the RaDaR database it will be anonymised and they will be able to access the clinical information about you, and others with the same disease, who are also on RaDaR. The disease-specific research group may get in touch with you via the Registry either to provide you with updated general information, or to invite you to participate in research projects.

What would I be agreeing to?

Participating in the registry means that you agree for your clinical information to be held on a secure computer system operated by RaDaR. You will be given a secure password that will let you see your information via the internet. You would also agree to receive information from RaDaR and the disease-specific research group from time to time. Your kidney specialist will

also know that you are participating in the registry, and he or she will be notified automatically if the research group wishes to make contact with you.

RaDaR will not share personal information with any other organization. The registry will let you and your kidney specialist know if the disease-specific research group has any information for you. The group will have signed a stringent confidentiality agreement with RaDaR in order to send any information to you. Agreeing to participate in the Registry does not commit you to engaging in any of the research projects that might be proposed in future by the research group. Any proposal from the disease-specific research group will have separate approval from a NHS research ethics committee.

Will my doctor know about this?

Yes. Your kidney specialist knows about the Registry and will discuss it with you. If you agree to join RaDaR your kidney specialist will be responsible for entering the clinical information about you. He or she will also be provided with feedback from the Registry, and will be notified if the disease specific research group working on your condition proposes to make contact with you. Your GP will be told that you have agreed to participate in RaDaR.

How secure is my clinical information?

Your data will be secure. When the information is submitted it will be encrypted so that your personal details cannot be identified. Your data will be given a unique identifier, so that when an analysis is undertaken the employees of RaDaR will only know your data by that identifier. They will not know your person details. All RaDaR employees are carefully vetted and given security clearance according to their tasks.

A disease specific research group must have signed a strict confidentiality contract with the Registry in order to use it. If they have a research proposal that they wish to bring to your attention, RaDaR will send you the information about it. You would then be able to contact the research group directly if you wish

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 the Registry at any time. You could either write to RaDaR directly or your hospital consultant to make this change. The information concerning you would then be frozen and you would receive no further contact from RaDaR or the disease-specific research group.

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. The National Registry is governed by the (UK Renal Registry). RaDaR has been approved by the North Somerset and South Bristol Research Ethics Committee, reference 09/H0106/72.

What happens if something goes wrong?

If you have any concerns about the conduct of the Registry you should raise it immediately with your kidney specialist. If this does not quickly resolve your concern you should contact the UK Renal Registry team at the address below.

The UK Renal Registry

Southmead Hospital

Bristol

BS10 5NB

0117 959 5666