

National Registry of Rare Kidney Diseases (RaDaR)

Patient information sheet for adolescents.

Thank you for taking a moment to read this information sheet. You are being invited to participate in a research study and it is important that you understand why the research is being done and what it will involve. Please ask if you have any questions.

What is this research about?

The disease the doctors are treating you for is quite rare. Unfortunately it is often difficult to find out about a rare disease. Research helps the doctors (and patients!) learn more about the disease but is difficult to do when only a small number of people are affected.

The **National Registry of Rare Kidney Diseases**, also known as **RaDaR**, is an initiative by the kidney specialists to pull together information from patients from all around the UK who have certain rare kidney diseases. This will give us 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, RaDaR will give these results to the patients.

How does it work?

If you agree (consent) to participate, clinical information about you and what has happened to you since having the disease, will be uploaded by your kidney doctor and stored on the RaDaR database. Your doctor will update this when things change. You will be able to see all the information that is being collected about you.

Doctors and scientists who are already researching your specific disease are working together as a group. This is known as the **disease-specific research group**. They will look at the RaDaR database. They won't be able to see your name or address but they will be able to use the information about you and other patients with the same condition.

The disease-specific research group may get in touch with you or your family via the Registry either to give you news about your disease, or to invite you to participate in research projects.

Up to the age of 16 we need your parent/guardian's permission although we would like you to give yours as well (on the assent form). After you reach 16 we will ask for you to consent by yourself. If you haven't consented by the time you turn 18 years we will stop collecting information on you.

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.

RaDaR will not share personal information with any other organization. The registry will let you and your kidney doctor know if the disease-specific research group has any information for you. The group will have signed a confidentiality agreement with RaDaR in order to send any information to you.

Agreeing to participate in the Registry doesn't mean you have to be in any research projects in the future if you don't want to.

Will my doctor know about this?

Yes. Your kidney doctor knows about the Registry and will discuss it with you. If you agree to join RaDaR your doctor will be responsible for entering the clinical information about you. He or she will also be provided with news from the Registry, and will be told if the disease specific research group wants to write to 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 number, so that when an analysis is undertaken the employees of RaDaR will only know your data by that number. They will not know your personal 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 want to speak to you about a new

project RaDaR will send you the information. You can then contact the research group if you want.

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 withdrawal. You can even contact the RaDaR group directly to discuss with them any concerns using the number below. If you still wish to withdraw, you could either write to RaDaR directly or your hospital consultant to make this change. Your information would then be frozen and nobody would try to 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. 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 are worried about the Registry you should talk about it with your family or your kidney doctor. If you are still worried you or your family should contact the UK Renal Registry team at the address below.

The UK Renal Registry

Southmead Hospital

Bristol

BS10 5NB

0117 959 5666