

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 an initiative by UK kidney specialists (the Renal Association and the UK Renal Registry). It is designed to pull together information from patients who have certain rare kidney diseases. This will give a much better understanding of how these illnesses affect people. It will also speed up research. If the research discovers something helpful or leads to benefits, such as better diagnosis, treatments or general advice, your doctor will tell you.

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 RaDaR 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, 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.

The Rare Disease Group may get in touch with you through your doctor to tell you about patient information events or to invite you to participate in further research projects. You can find out more about your kidney condition on RareRenal.org, which is supported by the Renal Association and the Rare Disease Groups.

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 for 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. You would also agree to receive information from RaDaR and the Rare Disease Group from time to time.

The UK Renal Registry will not share your personal information with any other organisation other than to allow patient educational material to be sent to you via your doctor. 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.

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. They may seek the permission from the board that manages RaDaR to see personal information but they must explain why they need that information. If they want to contact you about a new research project they will send your doctor the information who will then pass it on to you. You can then contact the research group yourself if you want to.

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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