

# National Registry of Rare Kidney Diseases (RaDaR)

## Parent/Guardian 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 child's doctor will tell you.

### How does it work?

If you agree (consent) for your child to take part, information about their treatment and any medications they are on will be entered into RaDaR by a member of your hospital's research team. You will be given login details to see this 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 child's specific condition are working together as part of a Rare Disease Group. They will have access to RaDaR to view your child's anonymised data and that of others with the same condition.

The Rare Disease Group may get in touch with you through your child's doctor to tell you about patient information events or to invite your child to take part in further research projects. You can find out more about your child's kidney condition on [RareRenal.org](http://RareRenal.org), which is supported by the Renal Association and the Rare Disease Groups.

### What would I be agreeing to?

Taking part in RaDaR means that you agree that relevant information about your child's 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 child's 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 child's doctor know about this?

Yes. Your child's 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 child's GP will also be told that they are taking part in RaDaR.

### How secure is my child's information?

Your child's data will be secure. Your child's record will be given a unique number so that when analysis is undertaken the researchers will only know your child's data by that identifier. They will not know any personal details. All RaDaR employees are carefully vetted 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 ask the permission of the board that manages RaDaR to see personal details but they must explain why this is necessary. If they want to contact you about a new research project they will send your doctor the information, who will pass it on to you. You can then contact the research group 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 your child from RaDaR at any time. You could either contact RaDaR directly as below or talk to your child's doctor. Your child's information would no longer be updated and your family would not be contacted in the future.

### What happens when my child grows up?

When your child turns 16 they will be sent an information sheet about RaDaR and asked if they would like to continue to take part. If they do not consent for themselves before they turn 18 it will be assumed that they do not wish to remain in RaDaR. Their data will be no longer be updated and no further contact made. They could reactivate their participation later if they wish.

### 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. The Registry 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 to your child's doctor. If you are still worried you can contact the RaDaR team at the address below.

RaDaR Operational Manager  
UK Renal Registry  
Learning & Research Building  
Southmead Hospital  
Bristol  
BS10 NB