

National Registry of Rare Kidney Diseases (RaDaR)

We would like to invite you to take part in our research database.

This leaflet contains information to help you decide whether to take part.

What is this research about?

- This study is for children with a rare kidney condition
- We will collect information about you and your kidneys
- This will help doctors be even better at looking after you and other children like you



Why does this research matter?

- Your kidney condition is rare
- Only a small number of children have a kidney condition like yours
- We want to find out as much as we can about your kidney condition
- This helps doctors find new ways to look after your kidneys

Who is running this research?

- A group of doctors, nurses and scientists who are interested in rare kidney conditions
- Some of these doctors and nurses are in your hospital
- Others will be in other hospitals looking after other children



What will happen to me during the research?

- If you take part, a researcher that works in the hospital will enter information about you and your kidney condition into a computer
- This information will be studied along with information about other children with kidney conditions
- Sometimes, your kidney doctor might ask if you want to take part in other studies
- Your kidney treatment will happen as normal

Will my doctor know about this research?

- Yes
- Your kidney doctor knows about RaDaR
- We will tell your doctor if there is any information about your kidney condition which may help you



How safe is my information?

- Information about you and your kidney condition is very special
- We promise to look after the information about you very carefully
- You and your family can ask us questions about what we do with your information at any time

What if I don't want to take part

- That's ok!
- It **won't** affect your kidney treatment

What if I agree to take part but change my mind?

- That's ok too.
- It's ok to change your mind at any point.

Thank you for taking the time to read this leaflet.

If you have questions about RaDaR you should talk about it with your family or your doctor.

You or your family can also contact the RaDaR team at the address below:

RaDaR Operational Officer
UK Renal Registry
1st floor Brandon House,
Building 20A1,
Southmead Road,
Bristol,
BS34 7RR

Email address: nbn-tr.radar@nhs.net

Telephone number: 0117 4148150

REC 19/SW/0173