

## Child Patient Information Sheet (Age 12-15)

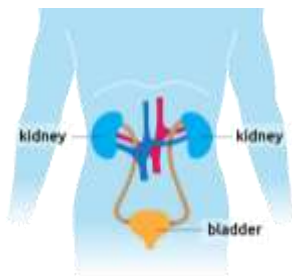
### To be shown and read by parent/guardian if required

We would like to invite you to take part in our research. This leaflet contains information to help you decide whether to take part.

#### 1. What is research?

Research is something we do to find out the answers to important questions. We want to do research to help us answer questions about rare kidney diseases.

#### 2. What does 'rare kidney disease' mean?



The kidneys are two bean-shaped organs. They clean waste and remove extra water from your blood, making urine. Kidney disease means the kidneys are damaged and can't work the way they should. This can make someone feel very poorly. A rare disease is one that not many people have.

#### 3. What is RaDaR?

The National Registry of Rare Kidney Diseases (RaDaR) is a database that gathers information from people with rare kidney diseases. Sometimes we also collect information from healthy people and people with more common diseases if it will help us with our research.

Having a large collection of information gives us a much better understanding of how kidney diseases affect people. It also helps us improve our understanding of what causes disease and how treatments can be improved.



RaDaR now has information on more than 34,000 people and is the biggest collection of its kind in the world!

#### 4. Who is responsible for RaDaR?

RaDaR is part of the UK Kidney Association, a charity that supports UK kidney doctors and nurses to improve the care given to kidney patients.

As RaDaR information is used for research and not for general care of patients, it has been approved by a special research ethics committee.

#### 4. What will happen if I agree to take part?

If you agree to take part, you won't need to do anything extra. Information about your kidney treatment, medical information and any medicines you are on will be entered into the RaDaR database. This will be done by someone at the hospital that manages your kidney disease.

Doctors and researchers who are interested in understanding your disease work together as part of a Rare Disease Group (RDG). They will be able to see your information in RaDaR but will not be able to see personal information such as your name or date of birth. We use a special RaDaR number for you instead.

When you turn 16, we will check you are happy to continue to take part and will ask you to sign your own form.

#### 5. Where will my information come from?

By joining RaDaR, you are giving permission for us to use your past, present and future medical information for current and future research into kidney diseases.

Information is collected from several places other than your hospital including:

- Your GP
- Wider NHS data collections
- Public Health Data collections
- Digital Patient Records (if you have one)



#### 6. Will anyone contact me?

From time to time, you may be contacted by a member of the RaDaR team or the RDG. They may invite you to patient information days or to take part in specific research projects. For example, if there is a new treatment that might help you.

#### 7. Will my doctor know about this research?

Yes, your kidney doctor knows about RaDaR.

#### 6. Will my information be kept safe?

Information about you and your kidney disease is very important and we promise to look after it very carefully. You and your family can ask us questions about what we do with your information at any time.

### 7. What if I don't want to take part?

That is OK! You don't have to take part if you don't want to.

### 8. What if I say yes and then change my mind?

That's Ok too! You can withdraw at any time and don't have to give a reason. You can contact RaDaR directly or talk to your doctor. Your information will no longer be updated, and no one will contact you.



### 9. What if I have questions?

If you have questions about RaDaR you can talk about it with your family or your doctor. You or your family can also contact the RaDaR team using the details below:

RaDaR Operations Manager  
UK Kidney Association  
1<sup>st</sup> floor Brandon House, Building 20A1,  
Southmead Road, Bristol, BS34 7RR  
Email address: radar@ukkidney.org

Thank you for taking the time to read this leaflet 😊