

# National Registry of Rare Kidney Diseases (RaDaR)

## Parent/Guardian Consent Form

For parents of children under the age of 18 and legal guardians of adults with limited capacity.

Patient Identification: (Please affix Hospital Label if available)      First Name:  
 Last Name:  
 NHS No/CHI No:  
 D of B:

Please **initial** the box if you agree with the statement

I have read the information sheet and have had an opportunity to ask questions about RaDaR.	
I understand that my child/ward's participation in RaDaR is voluntary and that we can withdraw at any time without giving a reason. I also understand that this agreement will lapse when my child reaches 18 years of age when they can choose to consent on their own behalf, subject to capacity.	
I understand that relevant sections of my child/ward's medical record may be looked at by individuals from RaDaR and regulatory authorities and NHS Trusts where it is relevant to taking part in research. I give permission for these individuals to have access to such records.	
I agree that my child/ward's past, present and future clinical data can be used for ongoing and future research into kidney disease and related conditions. I understand that this includes linking their RaDaR record to data obtained from their GP and hospital records and from any ethically approved research studies or registries that they have previously consented to and participated in, or will do so in the future, if this is permitted by their own Ethics approval. I give permission for the use of my child/ward's personal identifiers (including NHS number and Date of Birth) to search such records. These include NHS Digital for the Hospital Episode Statistics and Office of National Statistics databases, Health Education England, the UK Renal Registry and any UK-based bio-banking scheme.	
I agree that the central RaDaR team and the Rare Disease Group Lead for my child/ward's condition can contact me and my child/ward's doctor with information about patient events and research projects relevant to their condition.	
I agree to sign-up to Patient View, subject to availability at my child/ward's hospital. I understand that I will be sent log-in details by e-mail to view my child/ward's information online	
I agree that my child/ward's GP will be informed of their participation in RaDaR.	
I agree for my child/ward to participate in RaDaR.	

Your name..... Date.....

Your signature.....

Your e-mail address (for Patient View. Please print) .....

Researcher's name ..... Date.....

Researcher's signature .....

Consent obtained in person/by post (delete as applicable)

Thank you for your help.

*Copies: 1 for patient, 1 for the site file, original in hospital notes*