

National Registry of Rare Kidney Diseases (RaDaR)

Parent/Guardian Consent Form (children up to 18 years of age)

For parents of children up to the age of 18 and legal guardians of adults with limited capacity

RaDaR No: First name, Last name: Address: NHS No/CHI No:

In signing up to RaDaR, I agree to the following:

- 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 my child/ward's data will be linked to other data sources as described in the patient information sheet. These include any other UK-based approved national research studies, registries or bio-banking schemes
- I give permission for the use of my child/ward's personal identifiers (including NHS number and Date of Birth) to search such records.
- 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 kidney doctor with information about patient events and research projects relevant to their condition.
- I agree that any of my data that is held on any patient digital record (e.g. PatientView, Patient Knows Best etc.) may be shared with and included in RaDaR.
- I agree for my child/ward to participate in RaDaR.

Your name.....

Date.....

Your e-mail address (Please print)

Your signature.....

Thank you for your help.

For office use only

Researcher's name

Date.....

Researcher's signature

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