



National Registry of Rare Kidney Diseases (RaDaR) Adult (18 and over) Consent Form

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 patient information sheet and have had a chance to ask questions about RaDaR.
- I understand that my participation in RaDaR is voluntary and that I can withdraw at any time without giving a reason.
- I understand that relevant sections of my medical record may be looked at by individuals from RaDaR, regulatory authorities and NHS Trusts where it is relevant to taking part in research. I give permission for these individuals to have access to my records
- I agree that my past, present and future clinical data can be used for ongoing and future research into kidney disease and related conditions.
- I understand that my 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 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 condition can contact me and my kidney doctor with information about and research into my 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 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)