**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 foryour help.

*For office use only*

Researcher’s name ………………………….……………......................................... Date…………………..…

Researcher’s signature ………………………………………………………………..……..…

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