

National Registry of Rare Kidney Diseases (RaDaR)

Consent Form

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 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 this includes linking my RaDaR record to data obtained from my GP and hospital records and from any ethically approved research studies or registries that I 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 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 condition can contact me and my doctor with information about and research into my condition.	
I agree to sign-up to Patient View, subject to availability at my hospital. I understand that I will be sent log-in details by e-mail to view my information online	
I agree that my GP will be informed of the study.	
I agree to participate in RaDaR.	

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

Your e-mail address (for Patient View – please print)

Your signature.....

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