**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

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

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

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| * I have read the information sheet and have had an opportunity to ask questions about RaDaR.
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| * 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.
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| * 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.
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| * 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.
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| * 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.
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| * I agree for my child/ward to participate in RaDaR.
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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)