

National Registry of Rare Kidney Diseases (RaDaR)

Re-Consenting Letter

Items in red should be edited by the renal unit as applicable

<address>

<Date>

Dear

Please find enclosed information sheets about a research registry which **HOSPITAL NAME** renal unit are currently supporting.

It is called the **National Registry of Rare Kidney Diseases (RaDaR)** and it collects information about people with rare kidney diseases.

I would be grateful if you would take the time to read these information sheets.

You have previously consented to join RaDaR. However we have recently made some changes to the study. These include allowing us to link your data to other studies that you have taken part in and the ability for researchers to contact you directly about patient information events. We would therefore like you to re-consent to your ongoing participation in RaDaR.

OR

Your parents have already agreed for you to take part in RaDaR as a child. Now that you are over 16, we would like you to decide on your own behalf if you would like to continue.

If you would like to re-consent and continue to take part, please complete the enclosed Consent Form by putting your **initials** in each box and signing and dating at the bottom. Please return the form in the stamped addressed envelope provided.

OR

You can discuss any questions you may have with me at your next outpatient appointment and if you are in agreement you can sign the consent form in clinic.

Please note that participation in RaDaR is entirely voluntary and if you choose not to take part it will not affect your treatment or medical care in any way.

If you would like to discuss RaDaR further – please call **XXXXXXXXXX**.

Thank you for your time.

Yours sincerely,