National Registry of Rare Kidney Diseases (RaDaR)

GP/Consultant information sheet.

Thank you for taking a moment to read this information sheet.

Purpose

The purpose of the **National Registry of Rare Kidney Diseases** (**RaDaR**; *rare disease registry*) is to facilitate translational and epidemiological research into rare kidney diseases by setting up and maintaining comprehensive clinical databases in partnership with disease-specific research groups.

Background

Rare diseases are arbitrarily defined as having an incidence such that they cannot be studied effectively on patient groups drawn from one or a few medical centres.

A high proportion of such disorders have a genetic background and often these diseases are first expressed in childhood. The success of chronic and end-stage renal failure programmes in childhood permit some of these patients to survive into adulthood. Small numbers of patients are then diluted between adult centres such that an adult renal physician may only see such cases sporadically. Similarly with rare complications of disease or therapy.

The development of this database allows for the aggregation of a cohort of patients with numbers significant enough to facilitate clinical research.

To what is the patient consenting?

Once a specific disease or complication is identified a disease specific research group (DSRG) will be established. With patient consent the local renal physician (or team) will up load patient specific data onto the RaDaR website and continue to update it as appropriate. Both patients and the local physician will be able to view this data with password encrypted access.

The DSRG will be able to access this information in a link anonymised form and with the UK Renal Registry will perform data analysis. They will also contact the patients via the RaDaR group to inform about potential research projects (separate consent would be required). Contact from the DSRG will be in the form of a letter to the home or via the local renal physician during a routine consultation. Consent will be obtained, again, during a routine consultation by the local renal physician.

Consent will also allow RaDaR to seek additional information from the NHS hospital episodes statistics database, the NHS prescribing database, the UK Renal Registry, the UK Cancer Registry (if applicable) and the Office for National Statistics (births/marriages/deaths register).

General information about the condition will be available on the website and updated by the DSRG as appropriate.

Agreeing to participate in the Registry does not commit the patient to participate in any of the research projects that might be proposed in future by the DSRG. Any proposal from the disease-specific research group will have separate approval from a NHS research ethics committee.

Governance

Governance will be undertaken under the authority of the Renal Association of Great Britain, via its Clinical Affairs Board.

The RaDaR Committee will be a subcommittee of UK Renal Registry (UKRR) Committee, and will be responsible for all operational aspects of the rare disease registry. The RaDaR Committee will report to both the UKRR Committee and to the Research Committee of the Renal Association.

Patient information

The registry will capture both generic and disease specific information. The former will include patient identifiers. This is justified by the intention of the registry which is to put patients in touch with research opportunities as they arise. Patient information will only be released to a DSRG under the terms of the agreement between the NRRKD and a DSRG, and with appropriate ethical agreement in place concerning the specific proposal that a DSRG will make towards the patient. Generic information will include estimated kidney function obtained longitudinally, the date of end-stage renal failure, the modality of renal failure management and death.

How secure is the clinical information?

The data will be secure. When the information is submitted it will be encrypted so that personal details cannot be identified. Each patient will be given a unique identifier, so that when an analysis is undertaken the employees of RaDaR will only know the data by that identifier and not personal details. All RaDaR employees are carefully vetted and given security clearance according to their tasks.

A disease specific research group must have signed a strict confidentiality contract with the Registry in order to use it. If they have a research proposal, RaDaR will send on the information about it.

Patient withdrawal

The patient may withdraw from the Registry at any time. They may either write to RaDaR directly or inform the local renal physician to make this change. The information regarding the patient would then be frozen and they would receive no further contact from RaDaR or the disease-specific research group.

Who is responsible for RaDaR?

RaDaR was set up as a joint initiative of the Renal Association of Great Britain, the British Association for Paediatric Nephrology, and the UK Renal Registry. The National Registry is governed by the (UK Renal Registry). RaDaR has been approved by the North Somerset and South Bristol Research Ethics Committee, reference 09/H0106/72.

Contact point

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