National Registry of Rare Kidney Diseases (RaDaR)

GP/Consultant Information Sheet

Thank you for taking the time to read this information sheet.

Purpose

The purpose of the National Registry of Rare Kidney Diseases (RaDaR) is to facilitate translational and epidemiological research into rare kidney diseases by setting up and maintaining a comprehensive clinical database in partnership with Rare Disease Groups (RDGs)

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 means that an increasing number of these patients 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 RaDaR allows for the aggregation of a cohort of patients with numbers sufficient to facilitate clinical research.

What is the patient consenting to?

With patient consent the local renal physician (or a member of their team) will upload patient specific data onto RaDaR. Patients will be able to view this data via a website called Patient View, if their hospital is signed up to this.

The RDG will be able to access this information in an anonymised format via RaDaR. They may also contact the patients via their nephrologist to inform them about potential research projects, for which separate consent would be required.

Information about the patient's renal condition is available on RareRenal.org where it is updated by the RDG as appropriate.

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

Patient information

RaDaR captures 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 and educational opportunities as they arise. Patient information will only be released to a RDG under the terms of the agreement between RaDaR and a RDG, and with appropriate ethical agreement in place concerning the specific proposal that a RDG will make towards the patient.

How secure is the clinical information?

The data will be secure. Each record will be given a unique identifier, so that when an analysis is undertaken approved researchers will only know the data by that identifier and must ask permission of the Operational Management Board for RaDaR if they wish to see personal details. They must give the reasons why this is necessary. All authorised RaDaR users are carefully vetted and given security clearance according to their tasks.

Patient withdrawal

The patient may withdraw from RaDaR at any time. They may either write to RaDaR directly or inform their local renal physician to make this change. The information regarding the patient would no longer be updated and they would receive no further contact from RaDaR or the RDG.

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. RaDaR is governed by the Renal Information Governance Board of the Renal Association. RaDaR has been approved by the South West - Central Bristol Research Ethics Committee, reference 14/SW/1088.

Contact details

RaDaR Operational Manager
UK Renal Registry
Learning & Research Building
Southmead Hospital
Bristol
BS10 5NB