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 (or parent/guardian in the case of minors) 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 to inform them about potential research projects, for which separate consent would be required.

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. Taking part in RaDaR is entirely voluntary. If the patient chooses not to take part, it will not affect their treatment or medical care in any way.

By joining RaDaR, patients give permission for researchers to use their past, present and future clinical data for ongoing and future research into kidney disease and related conditions. Such data may be obtained from GP and hospital records and from any UK-based ethically approved national research studies or registries that the patient has previously consented to and participated in, or will do so in the future. These include the Hospital Episode Statistics and Office of National Statistics databases, Health Education England, the UK Renal Registry and any UK-based bio-banking scheme. Patients consent for the use of their personal identifiers (including NHS number and date of birth) to confirm their participation in such studies, if this is permitted by their own Ethics approval.

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

How will the patient be contacted?

Patients may occasionally be contacted by a member of the central RaDaR team or the Rare Disease Group lead for their condition. Such contact may include invitations to patient information days, details of further research studies that they may be eligible to join or requests to re-consent to RaDaR following subsequent amendments. Any such contact will be pre-approved by the RaDaR Operational Management Board (OMB) before it is sent to the patient. Patient contact details will not be provided to any other organisations or individuals.

Patients' anonymised data may be shared with other researchers, including those from Universities and commercial companies, who are investigating specific conditions. Any such requests will be approved by OMB and the Lead Clinician of the relevant Rare Disease Group. Patients will not be able to be identified or contacted by any of these researchers.

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 number. They will not know the patient's personal details. All RaDaR employees are carefully checked and given security clearance according to their tasks. The Rare Disease Groups have signed a strict confidentiality contract with RaDaR in order to use it.

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

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