



The UK Renal Registry and Data

The UK Renal Registry (part of the Renal Association, both of which are charities) is the national organisation for renal doctors and researchers working with patients with kidney disease.

The Data Protection Act 1998 regulates the use of digitally held patient information and the UKRR is registered as required by this legislation. However the UK Renal Registry (UKRR) has been granted specific exemption for the use of patient information by the Secretary of State on the basis that there is “overriding public interest to do so”.

The Common Law Duty of Confidentiality states that

“Information given in confidence must not be disclosed without consent unless there is a justifiable reason e.g. a requirement of law or there is an overriding public interest to do so.”

It is recognised that the work of hospital teams and researchers is enhanced and made more reliable, credible and has more validity with the addition of information about patients’ treatment, how care is managed and the effectiveness of treatment. To that end patient identifiable data is gathered within each hospital and sent digitally to the UK Renal Registry. The data are then collated and published in reports. The report does not contain patient identifiable data and provides comparison of the performance of each unit for the purposes of service improvement and greater understanding of the prevalence and severity of kidney disease. This information is useful for patients, clinicians, researchers, commissioners of health care services, GPs and the Department of Health.

Approval to collect the data is granted annually to the UK Renal Registry by the Health & Social Care Information Centre who require UK Renal Registry staff to be trained and the appropriate policies to be in place and rigorously adhered to. It is on this basis that NHS organisations’ are permitted to send patient data to the UK Renal Registry, as the Common Law Duty of Confidentiality is overridden by [Section 251](#).

This means that individual patient consent is not required for the UKRR to receive patient data. This is however conditional on the UK Renal Registry providing hospitals with a process to allow patients to opt out of sharing their patient identifiable data with them. To understand how patient data is used and how to opt out, please click here for the [UKRR leaflet](#). Visit the [Think Kidneys](#) website for information for patients and carers on acute kidney injury.

Patients are able to opt out from having their data sent by their hospital to the UK Renal Registry, and information on how to do this is available in every unit. It is the duty of each hospital not to send data relating to a patient if he or she has opted out of the scheme.

While patient identifiable information is held by the UK Renal Registry it is very tightly controlled and can only be accessed by a very strictly limited number of people.

If you would like to know more about the UK Renal Registry and its work please visit the website at www.renalreg.org