

UK Renal Registry Patient Information Leaflet

Produced with the National Kidney Federation (patients' association)

What is the UK Renal Registry?

We, the UK Renal Registry, collect and analyse information about the treatment of kidney failure, including:

- how often treatment is provided;
- how the treatment is managed; and
- how effective the treatment is.

We monitor the quality and quantity of services provided, to support improvements in the quality of care for dialysis and transplant patients. We are a charity set up by the Renal Association (the national association for kidney doctors and researchers into kidney diseases) as a resource for developing care for patients with chronic kidney disease.

We collect information every three months from renal unit databases (computers). We publish the results each year comparing renal units in the UK concerning the available dialysis facilities, the quality of care and other measures of outcomes in kidney dialysis and transplant patients. We analyse the national information we receive and the yearly report is important to renal units, NHS trusts, NHS commissioning authorities (who contract with your renal unit to provide your care), primary care trusts (your GP), the Department of Health, public health doctors, and consumer and patient organisations. The Renal National Service Framework (the kidney service standards set by the Department of Health) say that all renal units should join the Renal Registry. In 2004, 90% of renal units in the UK sent information to us.

It is vital that kidney patients take part in our work, and you have an important contribution to make to the development of renal services. The major patient organisations support our work.

How does this affect me?

Examples of the type of information we collect include statistics about:

- types of kidney disease;
- the number of people starting dialysis or receiving transplants; and
- clinical measurements, such as blood pressure and anaemia.

We keep all of the information sent to us by renal units, confidential.

We need your name, date of birth and postcode to make sure that we don't include your information twice and over-count patient numbers (we sometimes receive

information for the same person from several places), and to allow us to analyse local services by area of the country.

Only a very small number of experienced staff have access to particular information linked to you. And we will **never** publish any results or information that could lead to your identity being revealed. We also do not carry out work for the pharmaceutical industry or any other commercial company.

We hope that, in the near future, the NHS will provide us with a patient number, similar to your NHS number, as a unique patient marker for all the information about your treatment. When this happens, we will no longer need your name.

What happens now?

This leaflet lets you know the current position. With the support of the National Kidney Federation (a UK federation of 68 kidney patients' associations), we are producing posters and information leaflets such as this one, for renal units.

If you are satisfied with these arrangements, you need do nothing further.

Or, you have the opportunity to contact your local renal unit, to ask them **not** to send your identifiable records to us. This is known as 'opting out'. If you want to opt out, please ask the doctor or nurse at your next clinic or dialysis visit. They will tell the person responsible for sending your information to us, and your wish will be recorded on the local computer database.

We would like to include all patients to get a complete picture of care in each renal unit and across the country. We hope that better information will lead to better patient care. A large amount of missing information could lead to mistakes in the national planning and assessment of care for kidney patients. To understand how we use and present the information we collect, you can see a copy of our latest report at www.renalreg.com. If you decide to opt out, your local care will not be affected in any way. However, we will no longer monitor that care. You may, of course, change your mind about taking part in the UK Renal Registry at any time.

If you have any questions, please contact Hilary Doxford, General Manager, at the Renal Registry.

Phone: 0117 959 5665 E-mail: info@renalreg.com

Relevant information

We work within the data-protection laws in both the UK and Europe. In England and Wales, we have been granted specific exemption by the Secretary of State under section 60 of the Health and Social Services Act 2001. This allows us to receive information that identifies patients from renal units without first asking for permission from each individual patient.