



UK Renal Registry:

What Happens To Your Information?

UK Renal Registry – WHO ARE WE?

The UK Renal Registry is part of the Renal Association, a charity set up as the national association for kidney doctors and researchers into kidney diseases. We, with the National Kidney Federation and Kidney Care UK, have produced this leaflet to tell you what we are doing to improve your care and treatment by gathering information about patients with kidney disease.

WHAT DO WE DO?

We collect and analyse information about the treatment of kidney failure from the information kept by each hospital renal unit including how often treatment is provided, how the treatment is managed and the effectiveness of each type of treatment. We monitor the kidney services provided to improve the quality of care of dialysis and transplant patients.

We publish the results each year, providing a comparison of the performance of each hospital in terms of kidney patient care – such as quality of care against national guidelines.

We produce an annual report which provides important information for all those who plan, deliver and use services for kidney patients. This includes the NHS, who commissions those services, GPs, hospitals and the Department of Health.

Our aim is to provide information which will:

- reveal areas of the country where treatment may not be equally available to all
- identify best practice and improve patient care and outcomes
- inform patient and health care professional decision making
- support research for patient benefit

HOW DOES THIS AFFECT YOU?

We keep information about you – your name, date of birth, postcode and medical information such as blood pressure and blood tests. Some hospital patient records are incomplete or may contain inaccurate information. By linking your renal patient record with records such as NHS Blood and Transplant, the Hospital Episode Statistics system, the Office for National Statistics and Public Health England we can obtain missing data and improve the accuracy of your record and therefore any audit or research that we do. For the purposes of approved audit and research, we will send the following identifiers to NHS Digital: your date of birth, NHS number, UKRR study ID, postcode and gender. We will receive back your Hospital Episode Statistics data and in the event of your death, the cause and date of death from the Office of National Statistics.

We analyse that information by area of the country, or by age group, gender, etc. This way we build up national and regional information about types of kidney disease, the number of people starting dialysis or receiving a transplant.

We never publish information that could lead to your identity being revealed.

The Data Protection Act 1998 regulates the use of computerised information. The UK Renal Registry is registered as required by this legislation. We have been granted specific exemption on the use of patient information by the Secretary of State under the relevant section of the NHS Act 2006. This means that, unless patients have chosen to opt out, we can use information that identifies them without first asking for permission from each individual patient.

CAN I CHOOSE NOT TO PARTICIPATE?

If you are happy for us to use your information you need do nothing further. You have the right to opt out of the UK Renal Registry being sent information which identifies you. This will not affect the standard of care or treatment you receive in any way. If you wish to 'opt-out' please contact your GP or renal unit to arrange this. Alternatively, please contact the UK Renal Registry by telephone or email (contact details below) and we can contact them.

If you have any additional questions about how we use your information please email: renalregistry@renalregistry.nhs.uk or call 0117 414 8150. You can also go to <http://www.renalreg.org> for more information about our work and our reports.

