



UK Renal Registry: What Happens To Your Information?

WHAT DOES THE UK RENAL REGISTRY DO WITH YOUR INFORMATION?

We collect and analyse information about the treatment of kidney failure. We receive patient information from renal units, hospital systems, NHS Blood and Transplant, Public Health England and the Office for National Statistics. Linking to the Office for National Statistics means that in the event of your death your date and cause of death will be collected. Using this information we produce an annual report which provides important information for all those who plan, deliver and use services for kidney patients.

Our aim is to provide information which will:

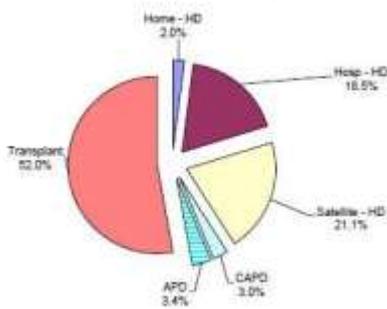
- reveal areas of the country where treatment may not be equally available to all
- identify best practice and improve patient care and outcomes
- inform patient and health care professional decision making
- support research for patient benefit

HOW DOES THIS AFFECT YOU?

We keep information about you and your treatment which we use to analyse that information by area, 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.**

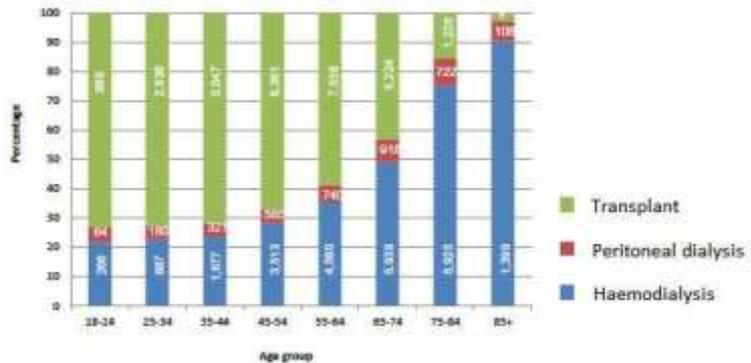
Did you know.....

Treatment modality in prevalent RRT patients on 31/12/2014



Taken from the Eighteenth UK Renal Registry Report: (fig. 2.6, page 21)

Treatment modality distribution by age in prevalent RRT patients on 31/12/2014



Taken from the Eighteenth UK Renal Registry Report: (fig. 2.7, page 22)

The Data Protection Act 1998 regulates the use of computerised information. The UK Renal Registry is registered as required by this legislation. We fulfil all the national requirements on information security and governance. 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 you have chosen to opt out, a very small number of authorised and appropriately trained individuals, approximately ten, have controlled access to information that identifies you without first asking for permission from each individual patient.

If you are happy for us to use your information in this way you need do nothing further. Data is only shared with organisations which fulfill all the national requirements on information security and governance, such as NHS Digital in England. 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 (HES) data and in the event of your death, the cause and date of death from the Office of National Statistics. All published data will be pseudonymised. You have the right to opt out of sending 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 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 would like to know more please pick up one of our leaflets or alternatively you can email the UK Renal Registry at RenalRegistry@renalregistry.nhs.uk or phone 0117 414 8150. You can also go to <http://www.renalreg.org> for more information about our work and our reports.

