

## Chapter 1: Summary of the year 2001 report on data from 2000

After consultation with the participating renal units, a phased programme towards removal of anonymity has been agreed. This year the incidence and prevalence data in chapters 4 and 5 are identified by named renal unit.

All the renal units in the UK are now negotiating participation in the Renal Registry.

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The data presented in this report relate to England and Wales. Due to technical difficulties, data held in the Scottish Renal Registry could not be transferred.

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For the first time, data are presented on acceptance rates for treatment by Health Authority.

The estimated annual rate of adult patients starting renal replacement therapy (RRT) in England and Wales is 89 per million population (pmp) indicating that approximately 5350 patients started RRT in 2000. This is identical to the 1999 report. Incidence rates calculated from health authorities with complete Registry coverage varied from 157 down to 52.

Haemodialysis was the modality of RRT at a day 90 for 60% of dialysis patients in England & Wales (58.8% in 1999). By the end of the first year, 16% of patients starting on PD had changed to HD, similar to last year's data.

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In England & Wales there was a 4.8% increase in the total number of patients on RRT between the 1<sup>st</sup> January and 31<sup>st</sup> December 2000. This comprised a 5.1% increase in the number of patients on dialysis and a 4.6% increase in those with a transplant. For individual Health Authorities, the estimated dialysis prevalence varied from 329 to 693 pmp.

The median age for all patients on treatment on 31/12/2000 was 54 years.

Reporting of ethnic origin has improved. The proportion of white patients in individual units varied from 39% to 100%, Asian from 0% to 56%, and Black from 0% to 15%.

Diabetes accounted for 16% of current incident patients, but 10% of all prevalent patients. Of prevalent dialysis patients 66% were on haemodialysis; HD is the predominant form of dialysis at all ages, but especially in the elderly. Connect PD has almost ceased. Cycling PD made little impact overall, but in a few units is the predominant form of PD

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The 90-day survival is 95% (95%CI 94-96%) for those aged less than 65 and 83% (95%CI 81-85%) for patients aged 65 and over. The one-year survival is 86% (95%CI 84-88%) for those aged less than 65 and 66% (95%CI 63-69%) for patients aged 65 and over.

The first year survival from day 0 of renal replacement therapy was 96%, 94%, 90%, 84%, 72%, 65% for patients aged 18-34, 35- 44, 45-54, 55-64, 65- 74, and 85+ respectively.

The one-year survival of all prevalent patients established on renal replacement therapy for at least 90 days was 83.7%, and the two-year survival 68.4%.

There are marked differences between centres in survival rates, but these are not consistent. Serial studies on one year survival rates for individual centres from 1997 – 1999, after adjustment to a standard age, showed wide variation. There was no relationship between a centre's 90-day or 1- year-after-90 day survival, and the mortality rate of the local population for all cause mortality, or cardiac mortality.

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There were 82 satellite units in England & Wales on 31<sup>st</sup> March 1999 (73 in 1998), with 67% of main renal units possessing a satellite. There was a diverse range of models of service provision. 43% were not on an acute hospital site; there was a median of 8 HD stations, (range 3-31), and 19 units (26%) were commercially run. Only 9 units (12%) had regular daytime onsite medical supervision. Of the 2599 patients being treated in the renal satellite units, 42% were aged 65 or over, similar to the UK as a whole.

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In England & Wales, 74 % of patients achieved a URR > 65% compared with 65% in 1999 and 57% in 1998.

There was a continuing rise in URRs over the 2 years from starting dialysis from 57% achieving a URR > 65% in the first 6 months (48% in 1999) to 83% at 2 years (73% in 1999).

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There is continuing improvement in the management of renal anaemia. In haemodialysis, 79% of patients had a haemoglobin > 10g/dl compared to 72% in 1999 and 69% in 1998. In PD 86% of patients had a haemoglobin >10g/dl in 2000, 80% in 1999, 78% in 1998

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A joint analysis of data held by UK Transplant and the Renal Registry showed that the factors significantly affecting whether a patient is listed for transplant are: age ( $p<0.0001$ ), primary renal disease ( $p<0.0001$ ), and the size of the renal unit ( $p<0.0001$ ), with large units listing patients more quickly. Gender and ethnicity of the patient and whether the dialysis hospital also has a transplant unit were not found to have a significant effect.

Pre-emptive listing (listing before dialysis) occurred in 21% of adults under 35 years old, only 4% of adults aged 55-64, and vary rarely in those over 65.

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The Renal Registry has a unique data collection system with huge potential for the future. This offers an opportunity for automated data collection for multi-centre studies and trials. There is also considerable interest in collection of data on cohorts of pre-end stage renal failure. Once the work of connecting the rest of the UK sites has been completed, the members of the Renal Association will be consulted on these future projects.

With almost complete coverage of the UK, the UK Renal Registry is ideally situated to aid the implementation and monitoring of the National Service Framework.

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