Chapter 12: Comparison of UK Registry Data with other National Renal Registries

Fergus Caskey, Anna Casula and David Ansell

Summary

- In 2006, the incidence of RRT in the United Kingdom was 113 per million of the population (pmp) using the day 0, 'first ever RRT' definition and including paediatric patients.
- This RRT incidence rate placed the UK 26th out of the 38 countries reporting to the USRDS in 2006. The overall incidence for the UK masked a higher incidence rate in Wales of 137 pmp, 20th of the 38 countries.
- The proportion of patients with diabetes as the cause of established renal failure was relatively low in the UK at 19%, compared to 45–60% in the United States, Malaysia and Jalisco (Mexico). Within the UK, Wales had the highest proportion of incident RRT patients with diabetes recorded as the cause of their renal disease at 26%.
- In 2006, the prevalence of RRT in the United Kingdom including paediatric patients was 733 pmp.
- Relative to the 39 other countries reporting prevalence data to the USRDS, the UK RRT prevalence rate was 23rd. Rates in Scotland and Northern Ireland were higher at 783 and 791 pmp respectively, but still considerably lower than in the United States, Taiwan and Japan where rates were 1,585–1,857 pmp.
- PD utilisation amongst prevalent dialysis patients varied around the world from 0% in Luxembourg to 83% in Hong Kong. Within the UK, rates of PD use varied from 14% in Northern Ireland to 25% in Wales. Home haemodialysis accounted for 2% of dialysis patients in the UK, but Australia and New Zealand achieved rates of 9% and 15%.
- The number of transplants performed each year was highest in the United States, France and Spain at 59–67 pmp. This compared with rates of 20 pmp in Northern Ireland, 22 pmp in Scotland, 28 pmp in Wales and 29 pmp in England. Conversely, the number of patients alive with a functioning renal transplant per million of the population was highest in Scotland and Northern Ireland.

Introduction

International renal registry comparisons form an important part of the quality control process of a registry by enabling benchmarking of activity and performance between countries. This year, for the first time, UK Renal Registry (UKRR) data for England, Wales and Northern Ireland appeared in the international comparison chapter of the United States Renal Data System (USRDS) annual data report (USRDS 2007). This followed an exercise, presented in the Ninth Annual Report of the UK Renal Registry, exploring various approaches that might be adopted to prepare and present the UK data[1].

This year's analysis presents the data on RRT epidemiology: RRT incidence, RRT prevalence, the proportion of incident patients with diabetes mellitus, the dialysis modality mix and the transplant rate – for the four countries constituting the United Kingdom alongside data submitted to and published by the USRDS.

Methods

Data on numbers of incident and prevalent RRT patients in England, Northern Ireland, Scotland and Wales for the year 2006 were extracted from the UKRR database and collated to meet the specifications on the USRDS international data collection form. In order to overcome the issue of cross boundary referral, the five dialysis centres not reporting to the UKRR in 2006 were contacted and the number

of incident and prevalent patients by RRT modality established. The resulting numerators for incidence and prevalence rates were therefore based on all incident and prevalent patients in England and Wales and the general population data for the denominator were based on the entire populations of the four countries (from the Office for National Statistics). The international data for comparison came from the USRDS annual data report 2007[2] and with one or two exceptions, related to the year 2005.

As discussed in last year's International Comparison chapter, a day 0 definition of RRT has been adopted for RRT incidence rates. It is important to note however, that in order to be consistent with the definitions used in the USRDS report, the definitions used for the RRT incidence and prevalence rates in this chapter differ slightly from those used elsewhere in the report:

1. The rates quoted include an adjustment for paediatric patients – 2 pmp has been added to the RRT incidence rate and 14 pmp has been added to the RRT prevalence rate.
2. The definition used in this chapter is the first take-on ever for a given patient, so that a patient is only counted once. In the Incident chapter the definition is slightly different and some patients were counted more then once. For example, a patient can be taken-onto dialysis at some point in 2005, recover sufficient renal function to become dialysis-independent but then be taken back onto dialysis again the next year (by the International chapter definition he is counted only once in 2005, while in the Incident chapter he is counted both in 2005 and 2006).

Results

Incidence of RRT

In 2006, the incidence of RRT in the UK was 113 per million of the population (pmp) (Figure 12.1). This rate placed the UK 26th out of the 38 countries reporting incident data to the USRDS for 2005. However, the overall RRT incidence for the UK masked higher rates in Scotland, Northern Ireland and Wales (115, 116 and 137 pmp respectively, compared with 111 pmp in England).

The percentage of incident RRT patients with diabetes recorded as the cause of the established renal failure was relatively low in the UK at 19%, compared with rates of over 40% in 7 of the 33 countries that were able to report this statistic (Figure 12.2). Within the UK, the percentage of incident patients with diabetes as the

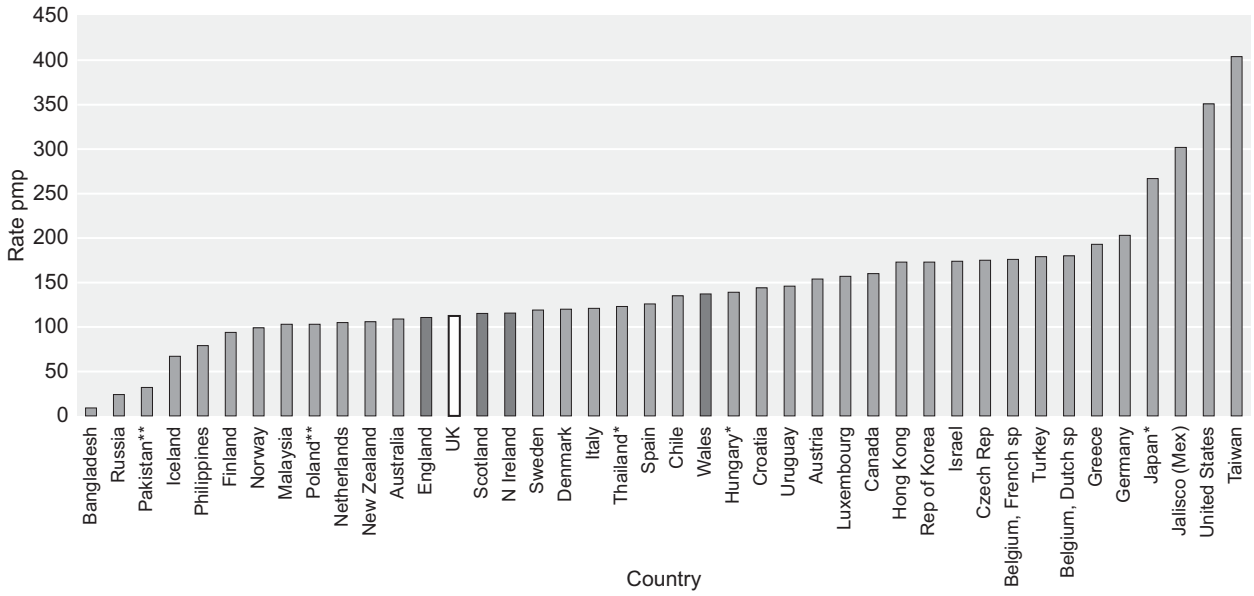

Figure 12.1: Incidence of RRT in different countries (pmp)

* 2004 data
** 2003 data

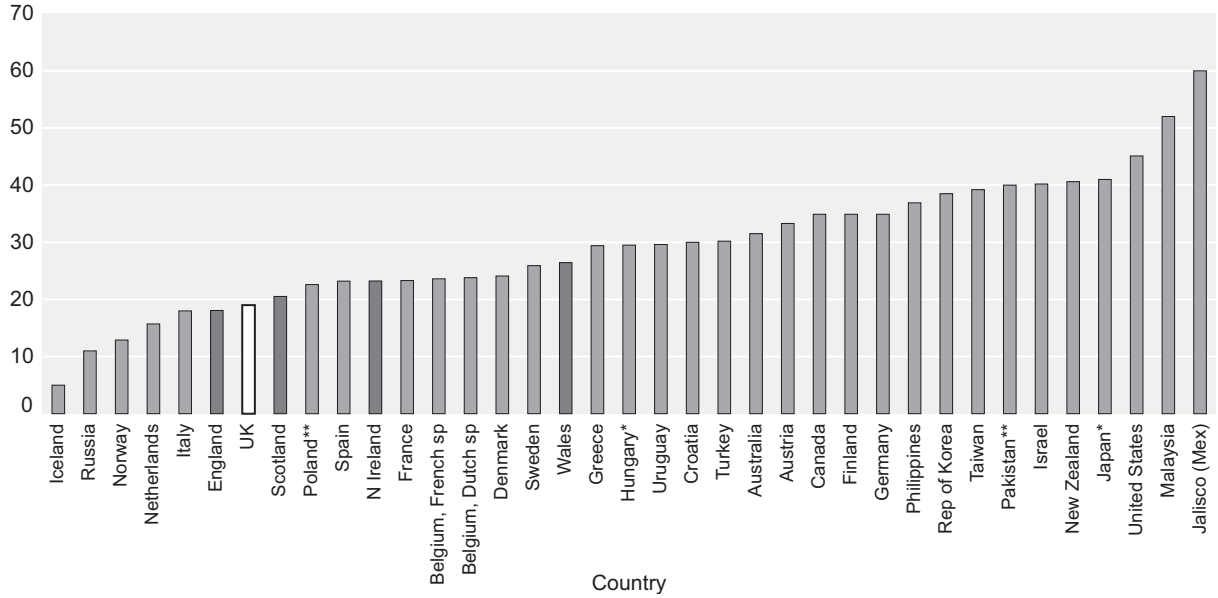

Figure 12.2: Percentage of incident RRT population with diabetes mellitus as cause of established renal failure

* 2004 data

** 2003 data

cause of established renal failure varied from 18% in England to 26% in Wales.

Prevalence of RRT

The RRT prevalence rate of 738 pmp in the UK was 23rd of the 39 other countries reporting prevalence data to the USRDS (Figure 12.3). Within the UK, rates were lowest in England at 731 pmp and highest in Northern Ireland at 791 pmp. The percentage of prevalent patients on peritoneal dialysis varied from 14% in Northern Ireland to 25% in Wales. Home haemodialysis use varied little within the UK at between 1.8–2.0% of the prevalent dialysis

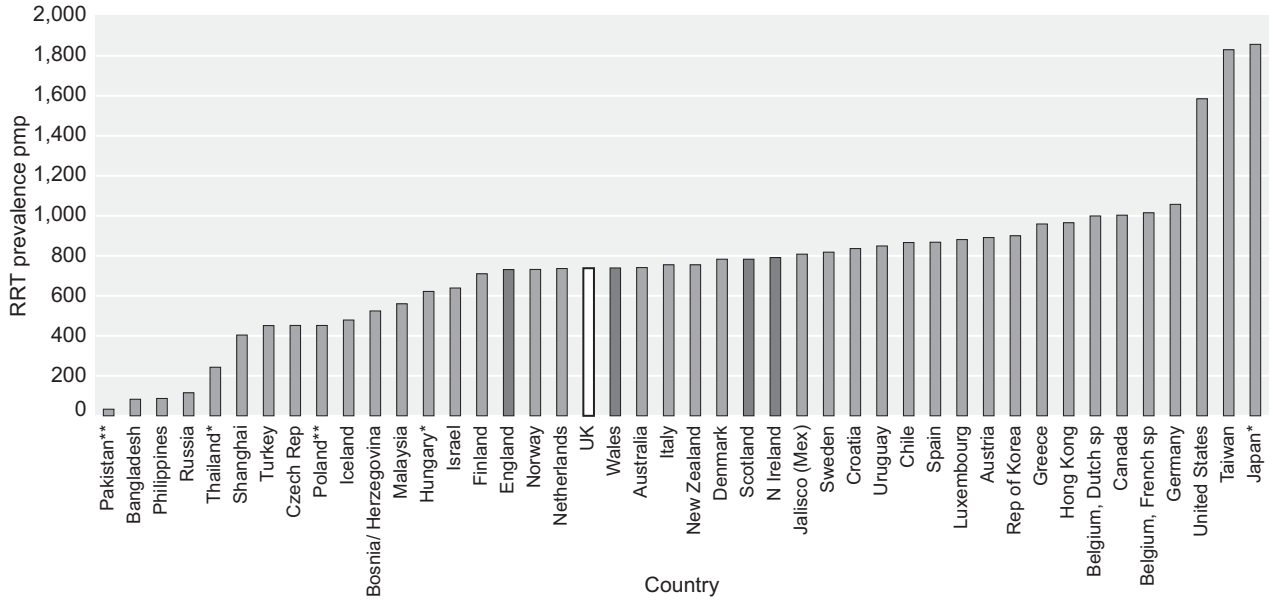

Figure 12.3: Prevalence of RRT by country (pmp)

* 2004 data

** 2003 data

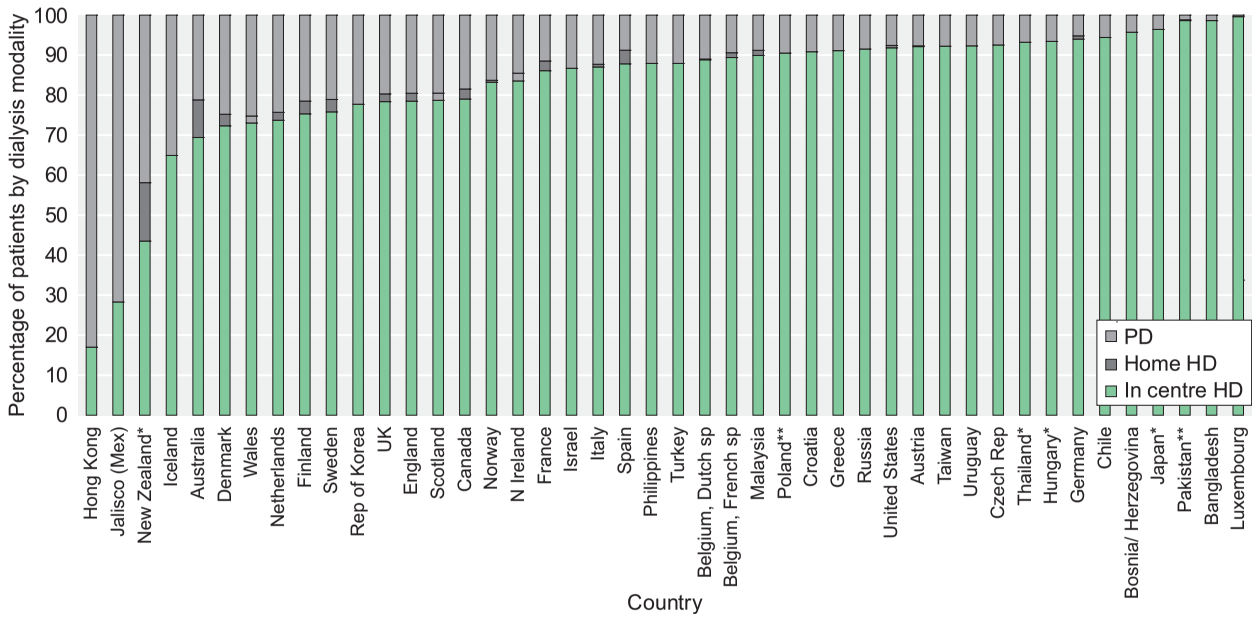

Figure 12.4: Percentage of prevalent dialysis population by dialysis modality

* 2004 data
** 2003 data

population; Australia and New Zealand however, achieved rates as high as 9–15% (Figure 12.4).

When considering the number of renal transplants pmp (deceased and live donor) performed in each country each year, the UK's rate of 28 pmp placed it 20th of 35 countries, considerably lower than Spain, Norway and the United States where rates varied between 59–67 pmp (Figure 12.5). In 2006, England had the highest transplantation rate of the four countries at 29 pmp compared with 28 pmp in Wales, 22 pmp in Scotland and 20 pmp in Northern

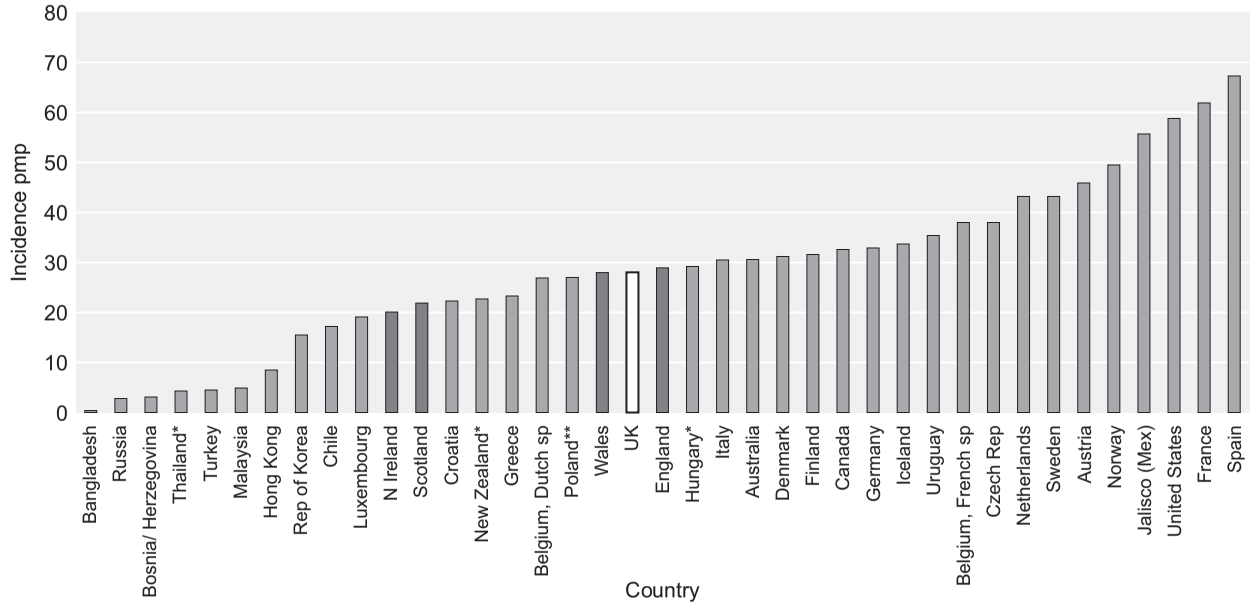

Figure 12.5: Renal transplant incidence rate by country (pmp)

* 2004 data
** 2003 data

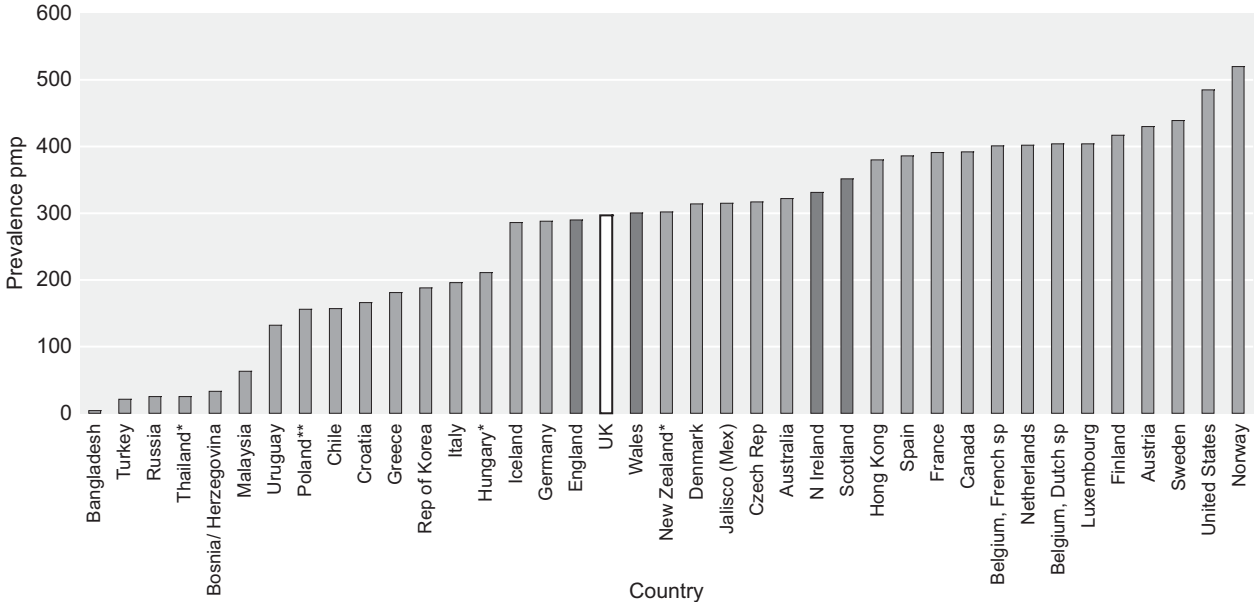

Figure 12.6: Renal transplant prevalence rate by country (pmp)

* 2004 data
** 2003 data

Ireland. The number of RRT patients with a functioning renal transplant per million of the population was lower in England than Wales, Northern Ireland or Scotland (Figure 12.6).

Discussion

The incidence of RRT in the UK continued to rise slowly, remaining on a par with rates in a number of demographically similar countries around the world, such as Australia, Norway, the Netherlands and New Zealand.

Home haemodialysis has been promoted by the National Institute for Health and Clinical Excellence[3], yet only 2% of the UK prevalent dialysis population were receiving this modality of treatment. While this rate was comparable to or higher than those observed in a number of other countries, rates of 9–15% have been achieved in Australia and New Zealand. Examination of the non-medical factors behind these markedly higher rates of home haemodialysis may inform future policy in the UK.

Renal transplantation rates in the UK remained relatively low by international standards. The transplantation rate should largely be determined by the organ donation rate in the country rather than the RRT prevalence rate (although as living kidney donation is increasingly adopted this statement becomes less true). France and Spain achieved renal transplantation rates more than twice as high as those achieved in the UK and while some of these differences had been identified previously, there remains potential for further study to better understand the differences in organisation and policy behind these variations in organ donation rate.

References

1. Caskey F, Steenkamp R, Ansell D. International comparison of UK registry data (chapter 17). *Nephrol Dial Transplant* 2007;22 (suppl 7):vii185–193.
2. U.S. Renal Data System, USRDS 2007 Annual Data Report: Atlas of End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2006. (Available from www.usrds.org accessed 17th November 2007.)
3. National Institute for Clinical Excellence. Guidance for home versus hospital haemodialysis for patients with end-stage renal failure. Technology Appraisal Guidance – No. 48. September 2002, London.