

# Chapter 17: International Comparison of UK Registry Data

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## Summary

- In 2005, the incidence of RRT in the United Kingdom was 110 per million of the population (pmp) using the day 0 definition and 103 pmp using the day 90 definition.
- Relative to the 42 countries reporting data to the USRDS, the day 0 and day 90 rates for RRT incidence in the UK are the 32nd and 35th lowest respectively. However, the overall incidence for the UK masks higher rates in Scotland, Wales and Northern Ireland (123, 129 and 140 pmp, respectively).
- Of the six countries with RRT incidence rates comparable to those in the UK (Australia, Finland, Malaysia, New Zealand, Norway and the Netherlands) three had relatively high rates for the age band 20–44 and two had relatively high rates for the age band 45–60.
- The proportion of incident patients with diabetes as the cause of established renal failure also varied considerably between these six comparator countries from 16–40% but rates of peritoneal dialysis utilisation were comparable to that in the UK and generally higher than in countries with higher rates of RRT incidence.
- When transplantation rates were considered alongside prevalence rates for RRT, the UK position appeared relatively high at 46% (11th out of 37 countries), although still considerably lower than in Norway and the Netherlands (72% and 54%, respectively).
- Although variation in RRT incidence rate exists within the four countries of the UK, the overall RRT incidence, reported for the first time this year, appears similar to that observed in a number of demographically similar countries around the world.

- Examining the UK alongside the six comparator countries, different patterns of RRT incidence were observed across the age bands and variation in the RRT incidence secondary to diabetes mellitus raised interesting questions.
- The higher rates of renal transplantation achieved in several of the comparator countries also justifies further analysis.

## Introduction

There has been a revival of interest in international comparisons of renal replacement therapy (RRT) in recent years. This has in part been due to the work being done in re-establishing the European Renal Registry in Amsterdam<sup>1,2,3,4</sup>, collaborative work with other registries that has become possible as a result (The ESRD Incidence Group 2006<sup>5</sup>, Stewart 2006<sup>6</sup>), as well as the prospective international study comparing outcomes and practice patterns in a sample of haemodialysis patients, DOPPS<sup>7,8</sup>.

International renal registry comparisons provide an opportunity for benchmarking between countries, providing reassurance when data are consistent and driving further research when differences are seen. The analysis in this chapter aims to define the methodology the UK Renal Registry (UKRR) would need to adopt if it is to report data to the United States Renal Data System's (USRDS) international comparison chapter in future years. It also examines the current position of renal replacement therapy in England, Wales, Scotland and Northern Ireland in relation to the 42 other countries and regions of the world reporting to the USRDS.

The number of national and regional renal registries is increasing. In 2006, age-specific (although not age-standardised) data on RRT

incidence, prevalence, dialysis modality and transplantation rates from 42 registries were included in the USRDS annual data report, with striking results: Taiwan and Jalisco (Mexico) were shown to have higher RRT incidence rates even than the United States with rates of RRT in these countries three times those in a number of predominantly European populations, such as Norway, the Netherlands, Australia and New Zealand<sup>9</sup>.

Such comparisons are important in generating hypotheses – defining the research questions for future epidemiological research. To date however, although the UKRR has been publishing such data in its own reports it has not contributed to the USRDS international comparison chapter. There has been the issue of population coverage to address. The USRDS international data collection form asks for the reporting country's population by age band but as the UKRR doesn't cover the whole of the UK, the covered population would have to be very carefully established and its composition by age band estimated. The cross boundary referral of patients (between areas covered and not covered by the UKRR) has complicated these calculations. Secondly, there is the question of whether numbers of all new RRT patients should be used or numbers of patients surviving to 90 days. The USRDS international data collection form does not specify whether numbers should be provided based on day 0 or day 90. Reporting within the United States is based on patients surviving the first 90 days of RRT due to the constraints of financial reimbursement from the government starting from this period with prior data being incomplete. In contrast, many countries collect data on incident RRT patients from day 0 and are also likely to report to the USRDS based on this definition. Although variation in when patients are included in national RRT registries will distort international survival comparisons its effect on RRT incidence rates is likely to be small<sup>10</sup>.

In previous years<sup>11</sup>, this chapter has concentrated on using the many different data available from other national registry reports and analysing the UK data in a comparable fashion (eg co-morbidity, death rates, haemoglobin achievement etc). This year the analyses will be restricted to defining the methodology

for reporting data from the UKRR to the USRDS for inclusion in their international comparison chapter. This will enable timely reporting to the USRDS in future years. The chapter also examines our current position in relation to the 42 other countries and regions of the world reporting to the USRDS.

## Methodology

Data on numbers of incident and prevalent RRT patients in England, Northern Ireland, Scotland and Wales for the year 2005 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 renal units in England not reporting data electronically to the UKRR in 2005 were contacted and the number of incident and prevalent patients by RRT modality established. Age band data were not available for these five centres so an assumption was made that their age distribution was similar to that of the reporting centres. A possible small variation from this distribution will not result in any change in these calculations as these five centres contribute to a very small proportion of the total data.

As the numerator for incidence and prevalence rates generated by this approach was based on all incident and prevalent patients in the UK, the general population age band data for the denominator could be based on the entire populations for the four countries (from the Office for National Statistics). As data on the number of incident and prevalent patients were only available for the year 2005 in the five non-reporting centres, UKRR data from 2005 had to be compared with the published USRDS data for the year 2004.

Two definitions of incident RRT patients were used:

1. The UKRR definition which includes patients from the date of their first RRT (excluding those who recovered within 90 days and including patients presenting with acute renal failure who do not recover renal function within 3 months).
2. Patients were included once they have survived the first 90 days of RRT (a definition

more in line with practice in the United States).

In order to review the UKRR's relative position in comparisons of RRT incidence, prevalence, modality use and rates of transplantation, data from tables in the USRDS annual data report 2006 were used. Variation in the UKRR's relative position for RRT incidence, prevalence and transplantation in different age bands was then examined by comparing it with a sub-group of the six countries with overall RRT incidence rates closest to the UKRR incidence rate (excluding countries that did not provide age specific data).

## Results

### Incidence of RRT

In 2005, the incidence of RRT in the UK was 110 pmp using the UKRR day 0 definition and 103 pmp using the USRDS day 90 definition (Figure 17.1). Depending on which of these rates is taken for the comparison, the UK RRT incidence is either 32nd or 35th out of the 42 countries reporting to the USRDS. However, the overall RRT incidence for the UK masks higher rates in Scotland, Wales and Northern Ireland (123, 129 and 140 pmp, respectively compared with 105 pmp in England).

The six countries with data available by age band that flank the UK at the lower end of the RRT incidence range are Australia, Finland, Malaysia, New Zealand, Norway and the Netherlands. The relative ranking of these countries differs considerably however within the various age bands, with several ranking quite highly in the 20–44 age band (Malaysia, New Zealand and Finland) and the 45–64 band (Malaysia and New Zealand) (Figures 17.2a–e). The UK also ranked relatively highly in the 20–44 age band. Several of the comparator countries also have quite different percentages of their incident RRT patients with diabetes as the cause of treated established renal failure; 17% for the Netherlands and Norway, 30% for Australia, 40% in New Zealand and 55% in Malaysia, compared with 19% in the UK (Figure 17.3). Table 17.1 shows the incidence rates of RRT pmp for diabetes and also compares the percentage of all incident RRT patients. The low diabetes rates in Russia are likely to reflect limited availability for treatment rather than a true low incidence of diabetes.

### Prevalence of RRT

The RRT prevalence rate of 694 pmp in the UK is comparable to those of five of the six countries with similar RRT incidence rates (Malaysia being the exception) (Figure 17.4).

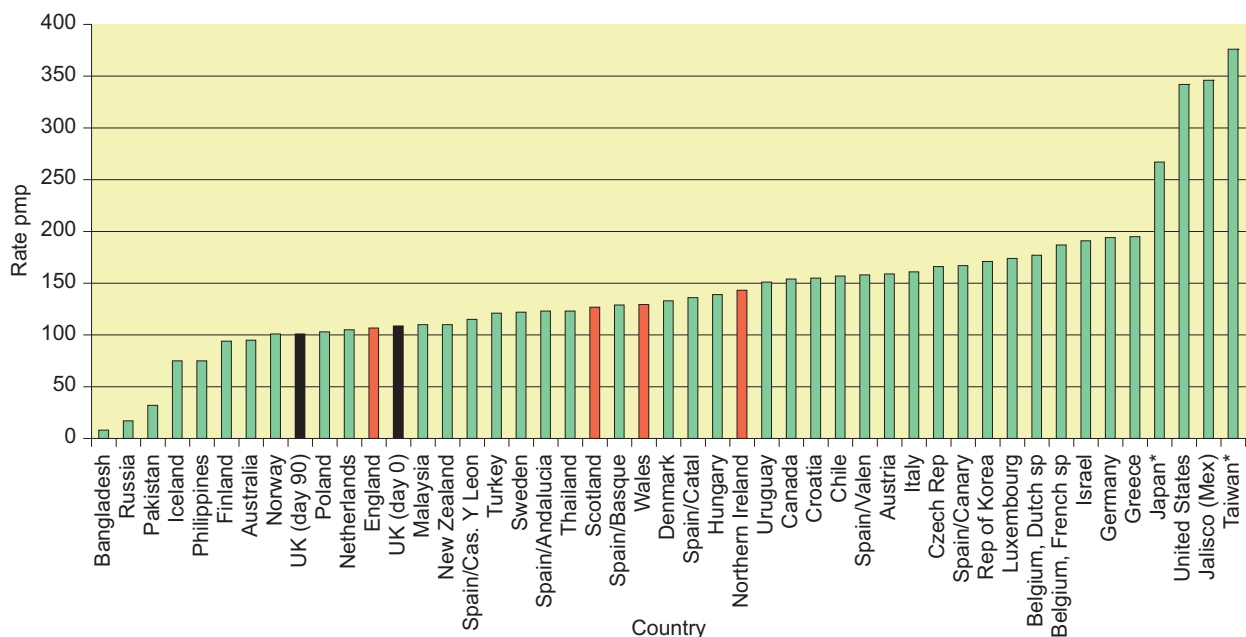


Figure 17.1: Incidence of RRT in different countries (pmp)

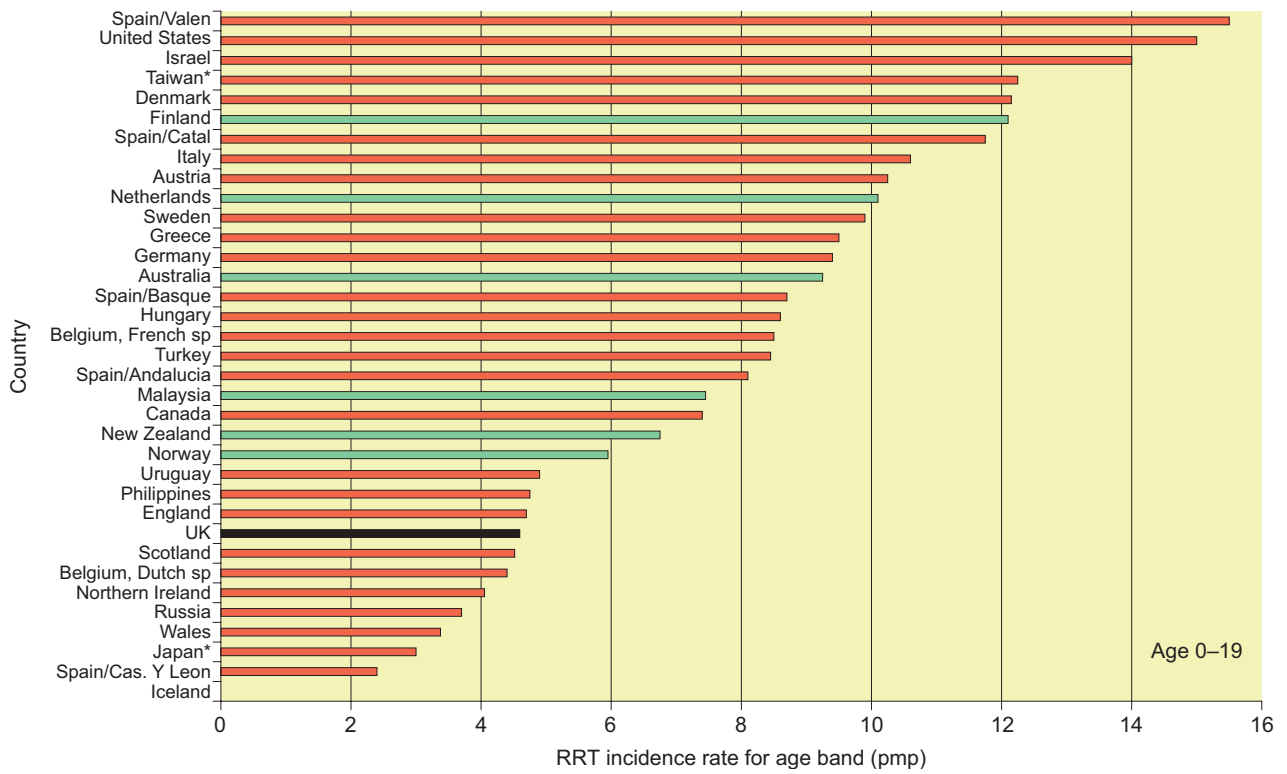


Figure 17.2a: Incidence of RRT pmp, 0–19 years in different countries

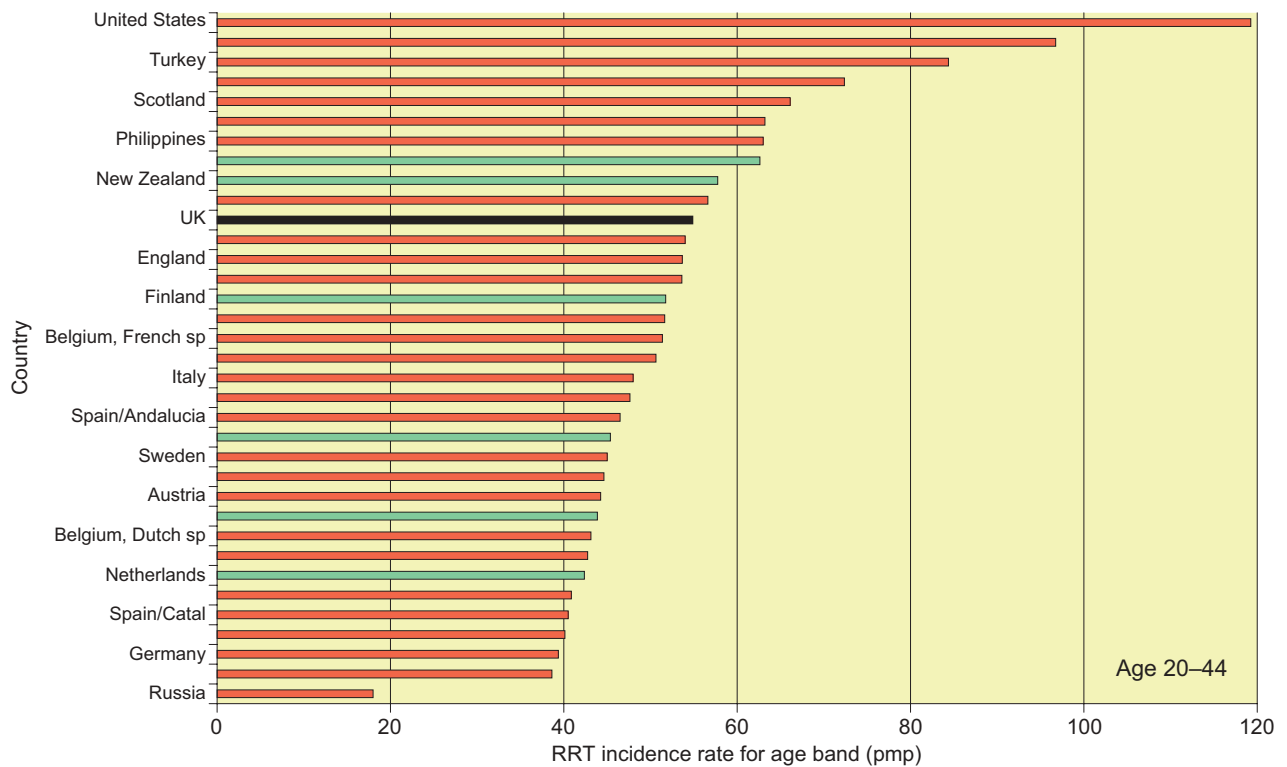


Figure 17.2b: Incidence of RRT pmp, 20–44 years in different countries

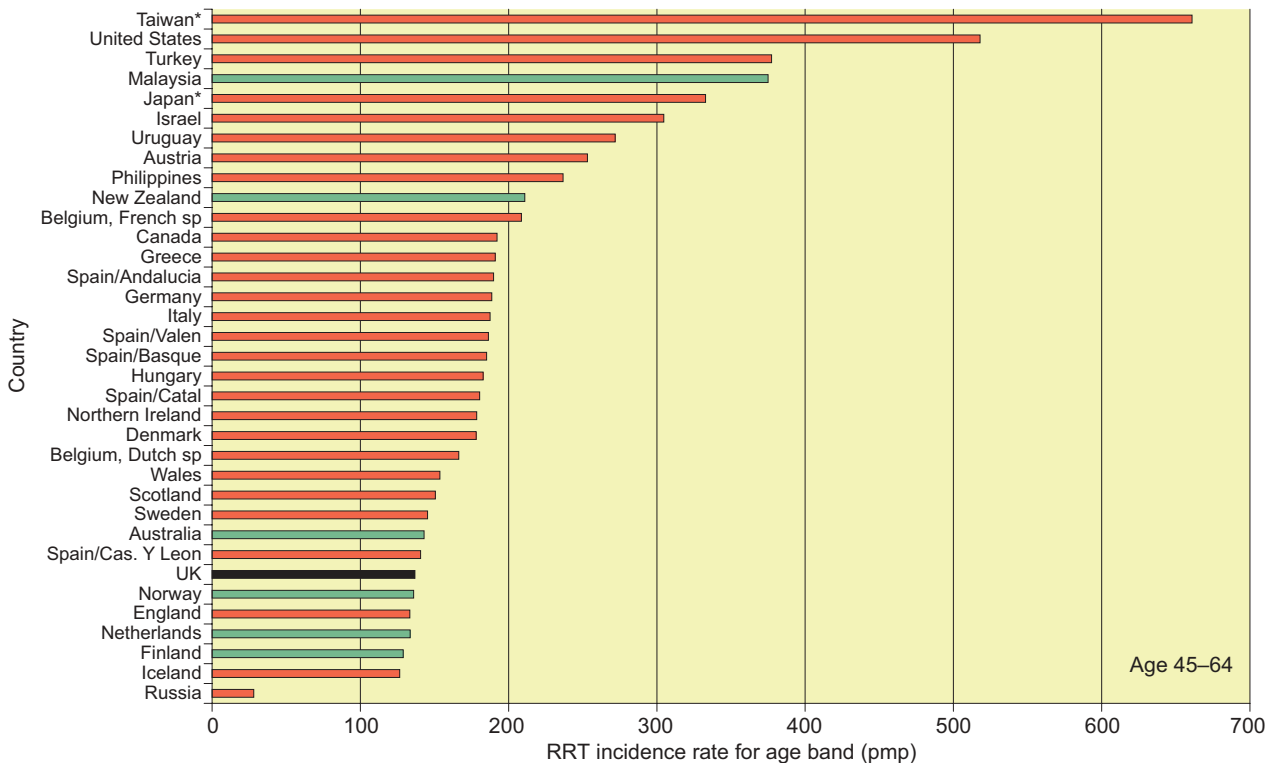


Figure 17.2c: Incidence of RRT pmp, 45–64 years in different countries

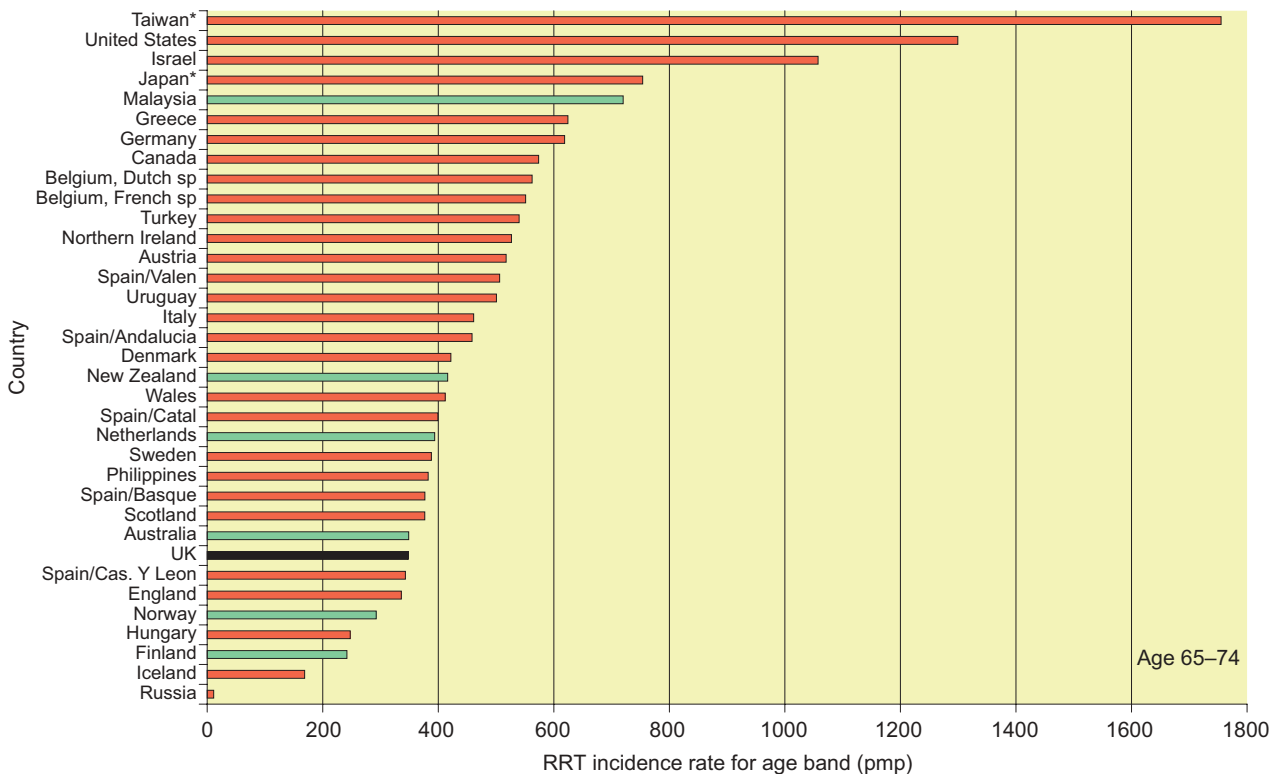


Figure 17.2d: Incidence of RRT pmp, 65–74 years in different countries

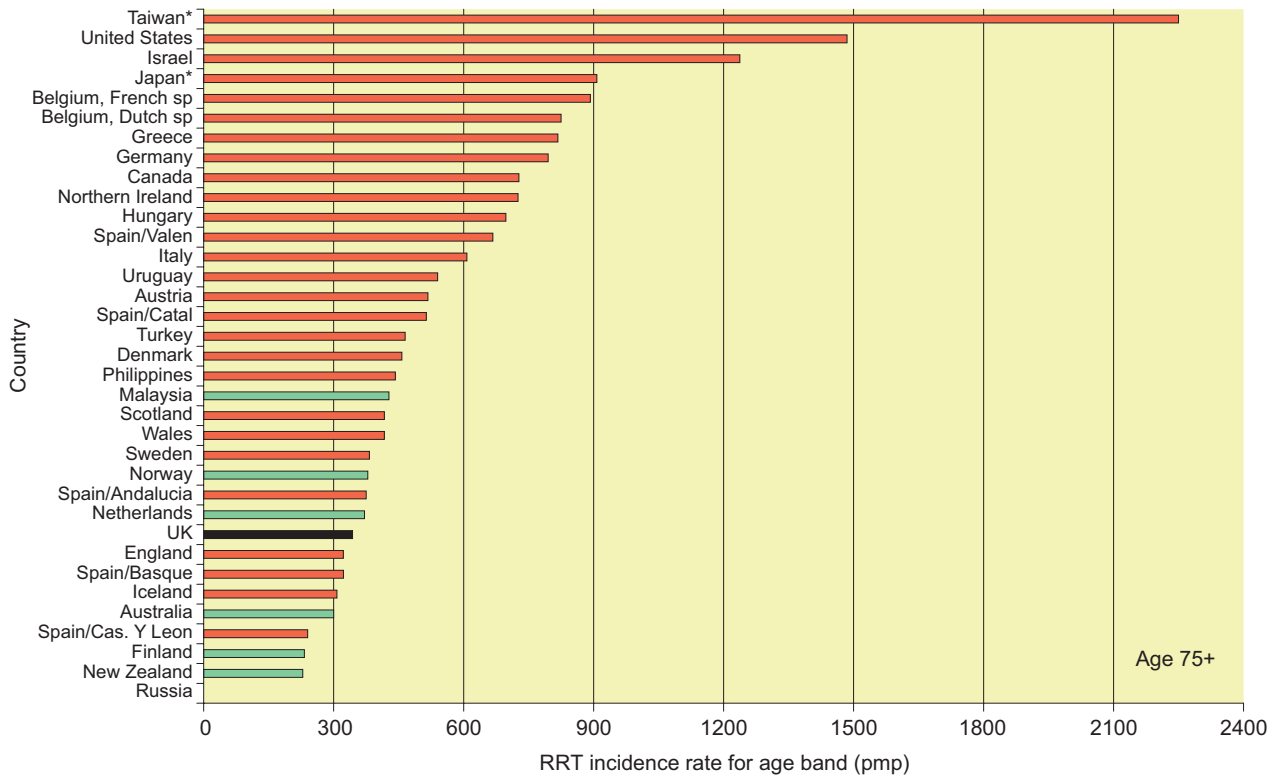


Figure 17.2e: Incidence of RRT pmp, 75+ years in different countries

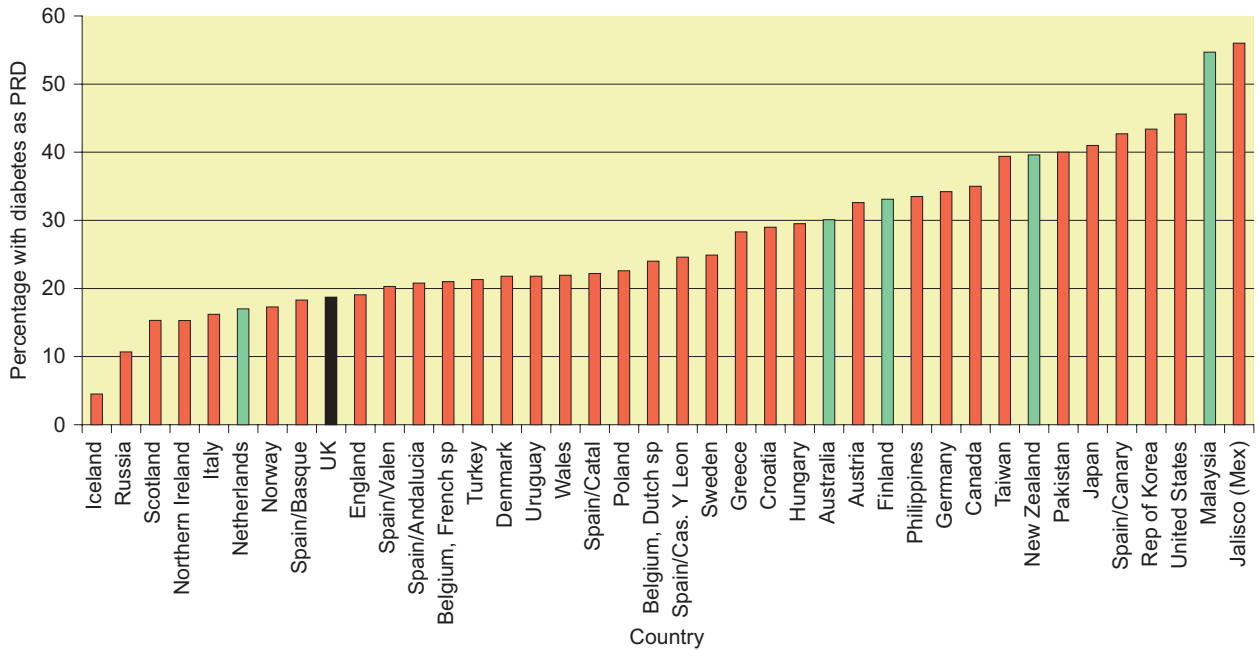


Figure 17.3: Percentage of incident RRT population with diabetes mellitus as cause of established renal failure

These countries (again with the exception of Malaysia) also have relatively high rates of peritoneal dialysis use (between 17 and 42%) compared with countries with higher RRT incidence rates (Figure 17.5).

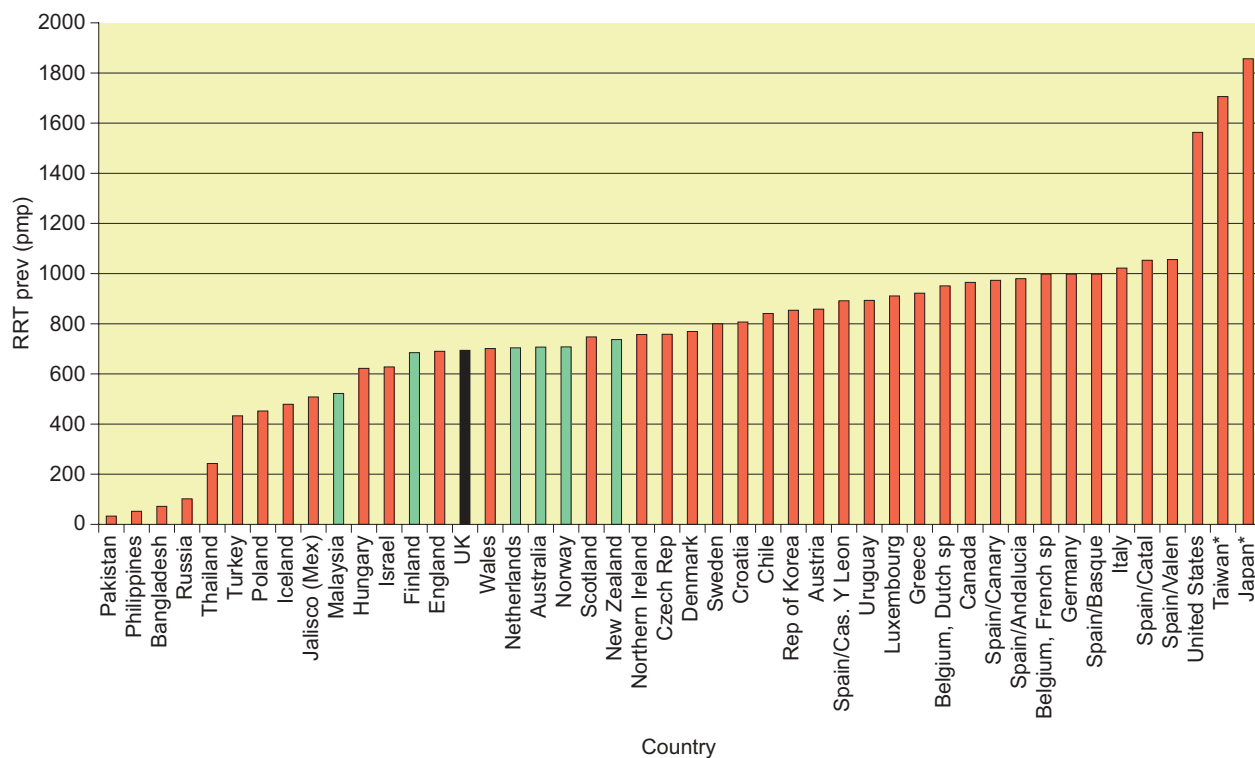
When considering the number of renal transplants per million of the population (deceased and live donor) performed in each country each year, the UK's rate of 25 pmp places it 28th of 42, considerably lower than Spain, Norway and

**Table 17.1: Rates of diabetic nephropathy in the incident RRT population**

	Incidence of diabetic nephropathy pmp	% of incident RRT pts with DN		Incidence of diabetic nephropathy pmp	% of incident RRT pts with DN
Russia	2	11	Sweden	30	25
Iceland	3	5	Finland	31	33
Pakistan	13	40	Spain/Valen	32	20
Norway	17	17	Uruguay	33	22
Netherlands	18	17	Belgium, French sp	39	21
<b>Scotland</b>	19	15	Hungary	41	30
<b>UK</b>	20	19	Belgium, Dutch sp	42	24
<b>England</b>	22	19	New Zealand	44	40
<b>Northern Ireland</b>	22	15	Croatia	45	29
Poland	23	23	Austria	52	33
Spain/Basque	24	18	Canada	54	35
Philippines	25	34	Greece	55	28
Spain/Andalucia	26	21	Malaysia	60	55
Turkey	26	21	Germany	66	34
Italy	27	16	Spain/Canary	71	43
Spain/Cas. Y Leon	28	25	Rep of Korea	74	43
Australia	29	30	Japan	109	41
Denmark	29	22	Taiwan	148	39
<b>Wales</b>	29	22	United States	156	46
Spain/Catal	30	22			

the United States where rates vary between 58 and 64 pmp (Figure 17.6). When transplantation rates are considered alongside the prevalence rates for RRT, the UK position appears

relatively high at 46% (13 out of 37 countries), although still considerably lower than in Norway and the Netherlands (72% and 54%, respectively) (Figure 17.7).



**Figure 17.4: Prevalence of RRT by country (pmp)**

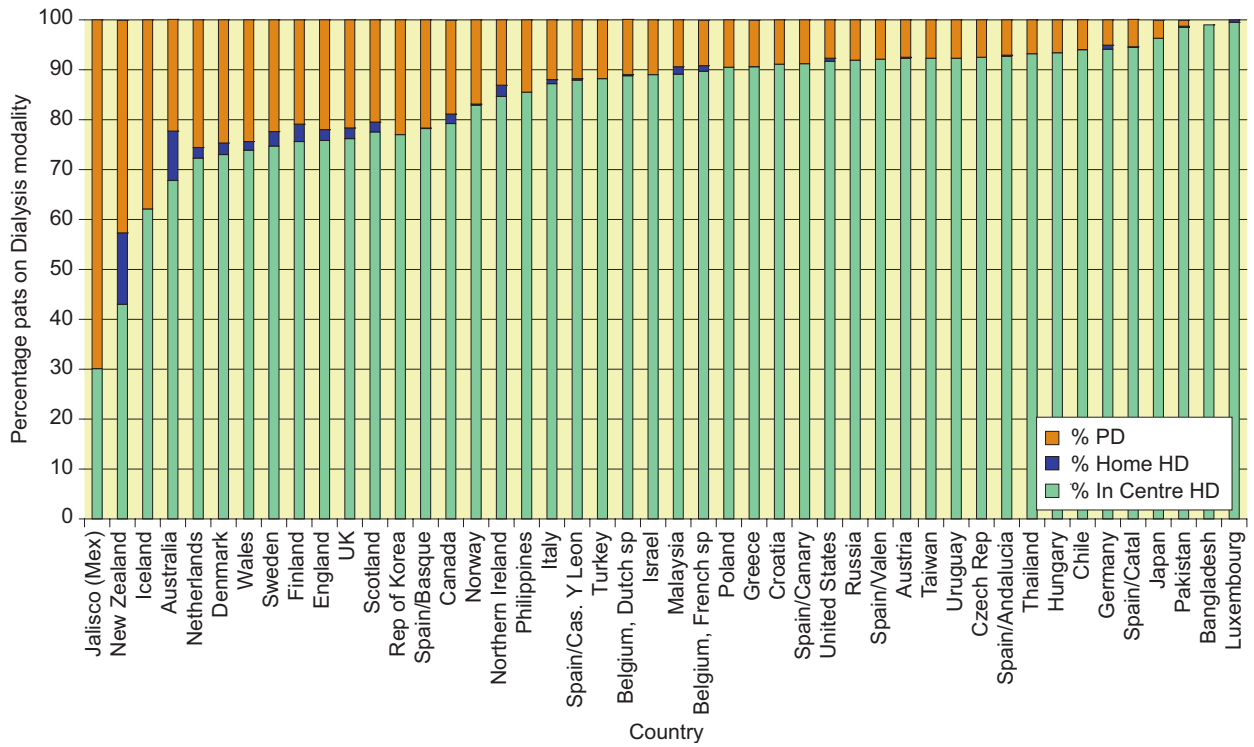


Figure 17.5: Percentage of prevalent dialysis population by dialysis modality

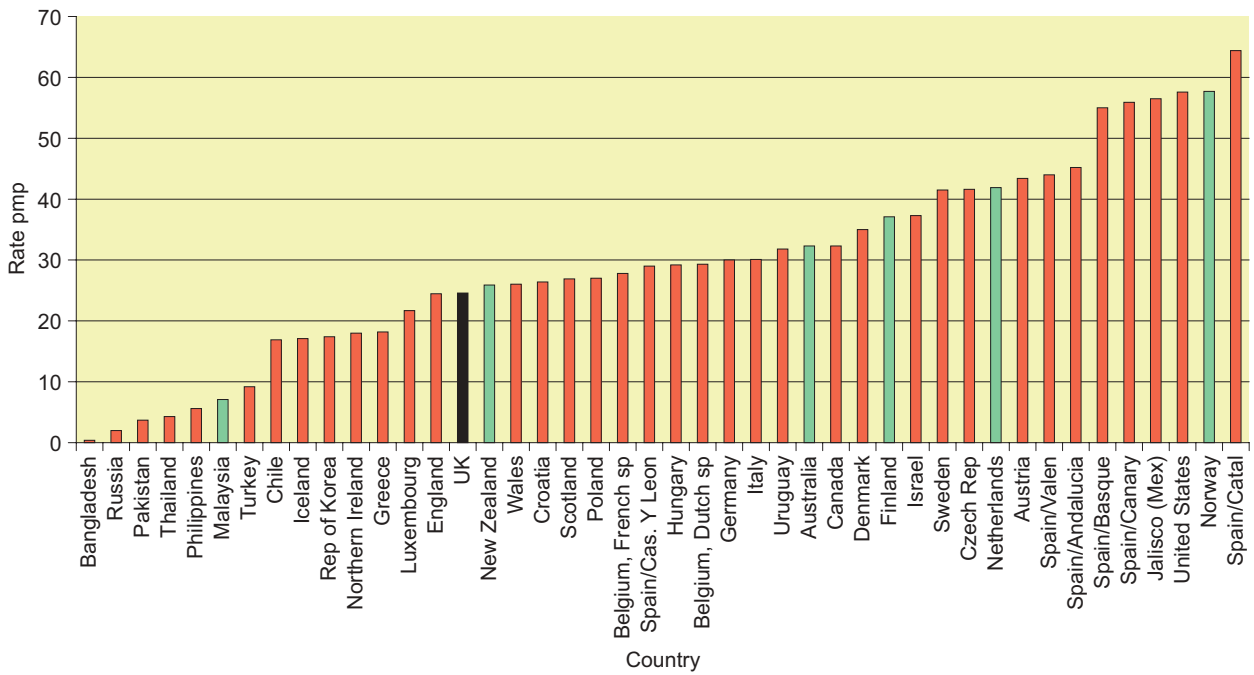


Figure 17.6: Renal transplant rate by country (pmp)



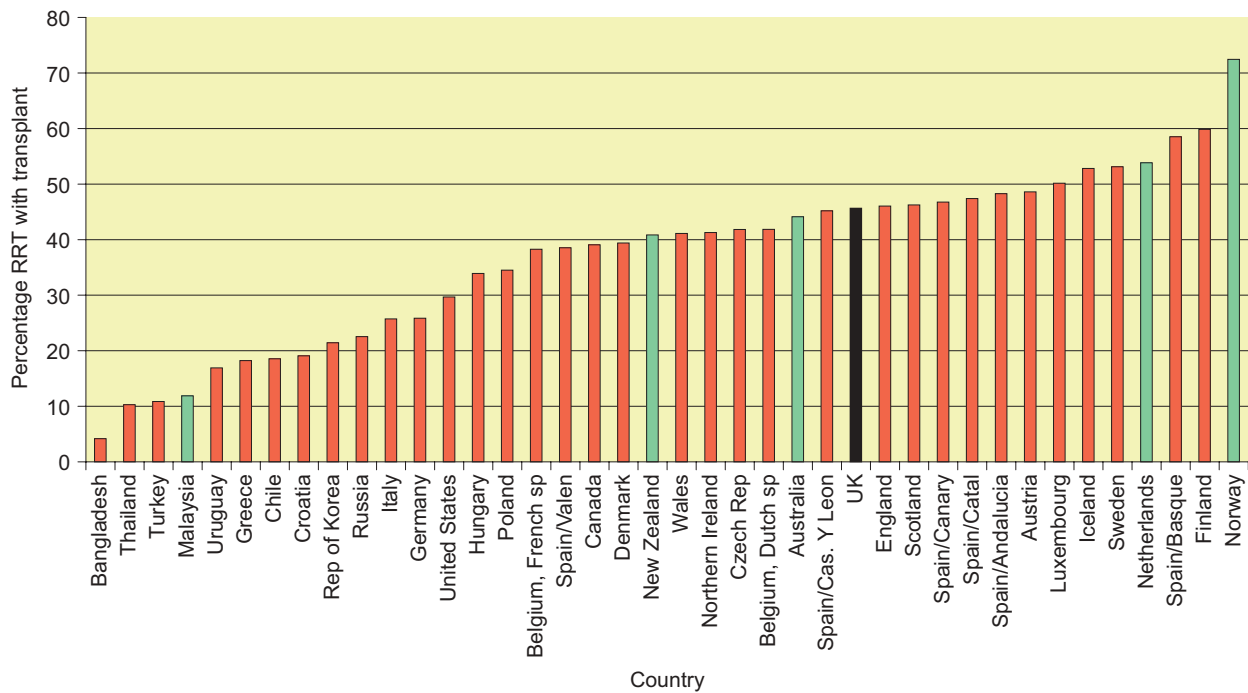


Figure 17.7: Percentage of prevalent RRT population with functioning renal transplant by country

## Discussion

It has been recognised for many years that the UK has an RRT incidence rate considerably lower than some other developed countries, especially the United States. International comparisons such as presented in this chapter, show that the RRT incidence rate in the UK is very similar to that observed in a number of similar countries with predominantly European populations, such as Australia, the Netherlands, New Zealand and Norway.

Considering the wide distribution of RRT incidence rates between all the countries reporting to the USRRS, the 7 pmp reduction in RRT incidence (from 110 to 103 pmp) that results from adopting the 90-day rule is relatively small. For the purposes of ensuring consistency and transparency with other data reported by the UKRRR, the RRT incidence rates quoted in future in the USRRS annual data reports will be based on patients alive on RRT at day 0.

In the sub group of six countries (with age-specific data) flanking the UK in the RRT incidence chart – Australia, Finland, Malaysia, the Netherlands, New Zealand and Norway – there are interesting differences in relative RRT incidence when considered by age band. Malaysia appears to have relatively high incidence

rates for all individual age bands (Figures 17.2a–e), yet is at the low end of the distribution for overall RRT incidence along with the UK. The explanation for this lies in the age distribution of the Malaysian general population. In 2006, Malaysia had a median age of 24 years compared with 38 years in the UK and 34 to 39 years for the other five comparator countries ([www.cia.gov](http://www.cia.gov) accessed 7th January 2007). As the elderly make up a smaller proportion of the general population in Malaysia, the overall crude RRT incidence rate in Malaysia is less influenced by the incidence rate in elderly individuals. As a result of this, their overall crude RRT incidence rate appears low. Age-standardising the RRT incidence rates would overcome such differences in underlying demography and facilitate inter-country comparisons.

Although RRT incidence rates are consistently high in some countries, such as Taiwan and the United States and consistently low in others, such as the Netherlands, some countries have rates which are high in some age bands and low in others. On the basis that in developed countries young patients with established renal failure would not be denied access to RRT, a pattern of low RRT incidence rates across all age bands suggests a truly low rate of established renal failure, not just a low rate of acceptance onto replacement therapy. The UK,

Finland and New Zealand however have relatively high RRT incidence rates for the age band 20 to 44 years (and 45 to 64 years for New Zealand) and then relatively low rates for all older age bands. Access to RRT has been shown not to be a significant factor determining differences in RRT incidence in individuals aged less than 65 years and in most developed countries in those aged less than 75 years<sup>6</sup>. Therefore other explanations, such as differences in age-related risk factors for chronic kidney disease<sup>10</sup> or variation in rates of progression of chronic kidney disease in different countries<sup>12</sup> should be considered and studied.

Comparing dialysis modality use in the six countries with similar RRT incidence rates (excluding Malaysia for the reasons outlined above), it is interesting that rates of peritoneal dialysis use are relatively high in these countries compared to those with higher incidence rates. The similar patterns of dialysis modality use in these countries suggest that there may be similarities between them in terms of organisation of renal services that have influenced RRT incidence rates. Peritoneal dialysis is likely to be favoured where haemodialysis facilities are, or have historically been limited, or where there are geographical barriers to providing local haemodialysis facilities. Improving our understanding of how such organisational factors have shaped RRT provision around the world may prove useful to countries in earlier stages of developing renal services.

## Conclusion

This chapter has described the methodology that the UKRR has adopted to provide data for the four countries of the UK individually or collectively on RRT incidence, prevalence, modality use and transplantation rates to the USRDS for the international comparison chapter in their annual data report. It has demonstrated that the RRT incidence rate in the UK is comparable with a number of demographically similar countries around the world. There is some variation in the RRT incidence in different age bands and also variation in RRT incidence secondary to diabetes mellitus which raises interesting questions. There is enormous potential for further collaborative

epidemiological work, both at the chronic kidney disease and the RRT level, to improve our understanding of the driving forces behind these observed differences.

## References

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