

# Chapter 5: Joint Analyses with UK Transplant in England and Wales; Access to the Renal Transplant Waiting List, Time to Listing, Diabetic Access to Transplantation and the Influence of Social Deprivation

## Summary

- This chapter reports on new collaborative analyses carried out with UK Transplant (UKT).
- There is significant variation between renal units in the proportion of dialysis patients listed for renal transplantation.
- Patient specific factors that influence the probability of a patient being listed for renal transplantation include primary renal disease, age, regrafting, ethnicity and social deprivation but not gender. After correcting for co-morbidity, ethnicity is no longer significant.
- Centre specific factors that influence the probability of a patient being listed include size of the renal unit, size of the living donor programme and the listing practice for living donor recipients. Whether the renal unit is also a transplant centre is not important.
- There is no agreed “standard” proportion of dialysis patients that renal units should list for transplantation. However, renal units with a higher proportion of listed patients do not have a higher “refusal rate” or lower one year transplant or patient survival than units listing a lower proportion of patients.
- There are unexplained differences in listing practice between centres that may reflect a selection bias by healthcare professionals.
- 17% of 18–44 year old patients are pre-emptively listed.
- Within one year of starting dialysis, 45% of patients under the age of 65 years are listed for transplantation. Within two years this proportion has increased to 57% and by five years is 66%.
- Time to transplant listing is dependent on age and primary renal disease. Older patients and those with diabetes mellitus and reno-vascular disease are least likely to be listed and are listed more slowly than other patient groups.
- In 2003, 9.1% of all prevalent transplant patients had diabetes mellitus listed as their primary renal disease. This proportion has increased progressively from 2.1% in 1988.
- Patients with diabetes mellitus are less likely to be listed pre-emptively for renal transplantation.
- The differences between centres in the proportion of diabetic patients less than 65 years with established renal failure that have a renal transplant varies from 5–62% of patients and this may indicate differences in the policy of listing diabetic patients.
- One and five year death censored allograft survival is no different for patients with diabetes mellitus than for patients with glomerulonephritis, however, there is an increased risk of death one year after transplantation. By five years, the increased risk of death is more than double that of patients with glomerulonephritis.
- The Townsend index, a measure of social deprivation, is lower (less social deprivation) in transplanted patients across all age groups under 65 years compared with patients receiving either peritoneal or haemodialysis.
- Transplanted patients have a lower social deprivation score than both new registrants to the waiting list and prevalent patients on the waiting list.
- The social deprivation score is also lower in recipients of living donor transplants than deceased donor transplants.

The analyses in this chapter are part of the extensive collaborative work being undertaken between the UK Renal Registry and UK Transplant.

## Access to the renal transplant waiting list

### Introduction

Patients with established renal failure should have equitable access to renal transplantation. UK Transplant coordinates deceased-donor kidney allocation according to a nationally agreed algorithm based largely on blood group identity and HLA matching. However, for patients to have an opportunity of receiving a kidney transplant there needs to be equity of access to the transplant waiting list between and within renal units.

Data from the UK Renal Registry on date of starting of renal replacement therapy and the number of patients at each centre on RRT were combined with date of listing for transplantation from UK Transplant. Differences between individual renal units in the proportion of dialysis patients listed for renal transplantation were investigated and possible reasons for any differences analysed.

These analyses were undertaken before individual patient data from the Scottish Registry became available and therefore only include England and Wales.

### Methodology

All adult patients receiving dialysis treatment on 31 December 2003 were included as the dialysis denominator.

Since the proportion of patients listed for a kidney transplant will depend on the renal unit's case-mix, logistic regression was used to investigate which patient variables influenced the probability of a patient being placed on the waiting list. These variables included;

1. Primary renal disease (9 categories).
2. Age.
3. Gender.
4. Ethnicity (White, non-White, not reported).

5. Whether a previous renal transplant had been performed (first transplant vs second or subsequent transplant).
6. Social deprivation was assessed with the Townsend score, a combination of four variables (unemployment, car ownership, home ownership, and overcrowding) derived from the census and calculated for each postcode. A high Townsend score indicates greater social deprivation.

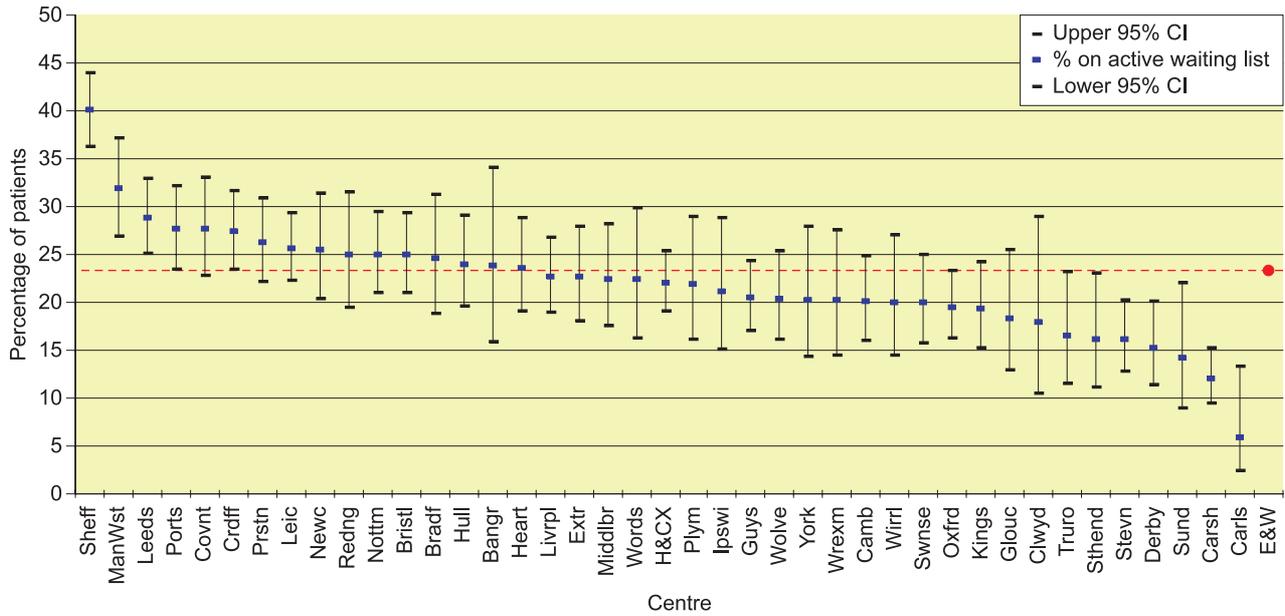
Renal unit specific variables were also investigated and these included;

1. The size of the renal unit (less than 200, 200–350, 350–500, and more than 500 patients receiving dialysis on 31 December 2003).
2. Whether the renal unit also performed renal transplantation.
3. The size of the adult living kidney donor transplant programme at the transplant centre (up to 7 per million population (pmp) per year and more than 7 pmp per year).
4. The centre's practice with respect to listing living kidney transplant recipients on the deceased donor waiting list prior to transplant.

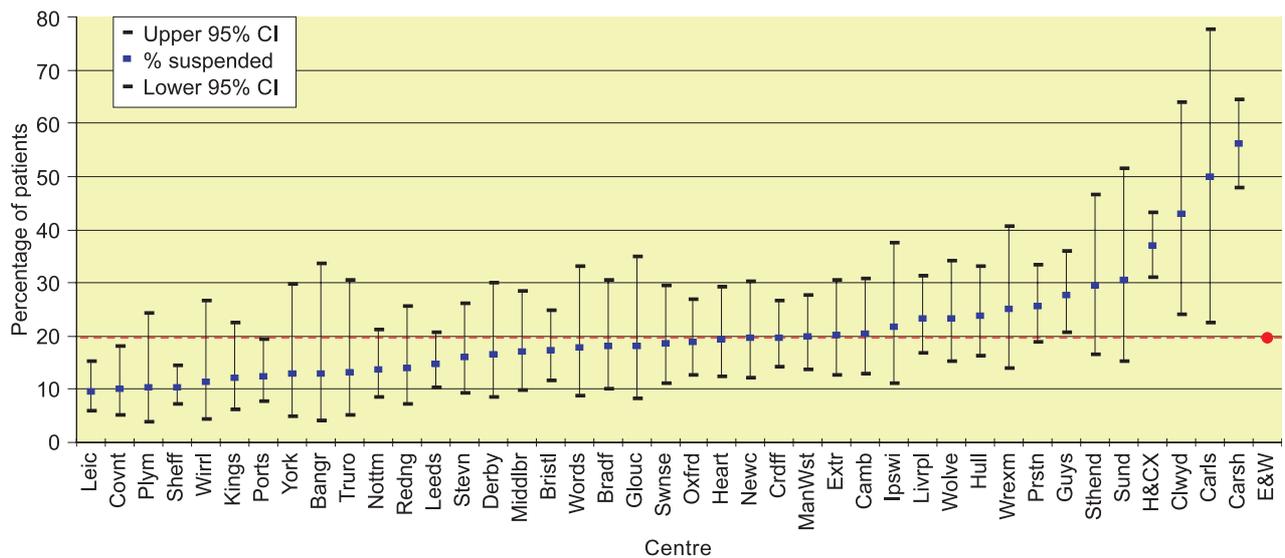
Centres that perform a large number of living donor transplants and do not list these patients on the deceased donor waiting list may appear to have proportionally fewer of their dialysis patients on the list. It was important to adjust for this in the analysis. Renal units, which do not perform renal transplantation, were considered to have the living kidney transplant programme characteristics of the transplantation centre to which their patients would usually be referred.

### Results

On 31 December 2003 the UK Renal Registry held records on 12,175 adult patients who were on dialysis in 41 renal units across England and Wales, of whom 23.3% were on the active transplant waiting list. Between individual renal units there was variation in the proportion of patients on the active transplant list from 5.9% to 40.1% (Figure 5.1). Part of this variation may be due to the variation in the practice of suspension of patients and that some renal units do not list patients being worked up to receive a live donation. Figure 5.2 shows that in England & Wales 20% of wait-listed patients were suspended. Carshalton has 56%



**Figure 5.1: Percentage of all dialysis patients by centre on the active transplant waiting list on 31 December 2003**



**Figure 5.2: Percentage of all dialysis patients by centre who are suspended on the transplant waiting list on 31 December 2003**

of wait-listed patients suspended which is due to the practice of listing all patients being worked up and then suspending them till they are worked up. This practice has changed since this analysis. The low rate of actively listed patients at this centre (6%) has also improved dramatically since being highlighted in this audit.

The change in listing practice over time from 1998 to January 2004 is shown in Figure 5.3. In England & Wales this has changed only slightly from 49.3% to 46.6% over this period.

An unadjusted funnel plot shows the percentage of patients on the active waiting list according to renal unit size (number of patients receiving renal replacement therapy) scattered around the national average (Figure 5.4). A number of renal units fall outside the 99.8% confidence interval both above and below the national average.

Patient variables that were found to be significant at the 5% level in explaining the variation observed included age, primary renal disease,

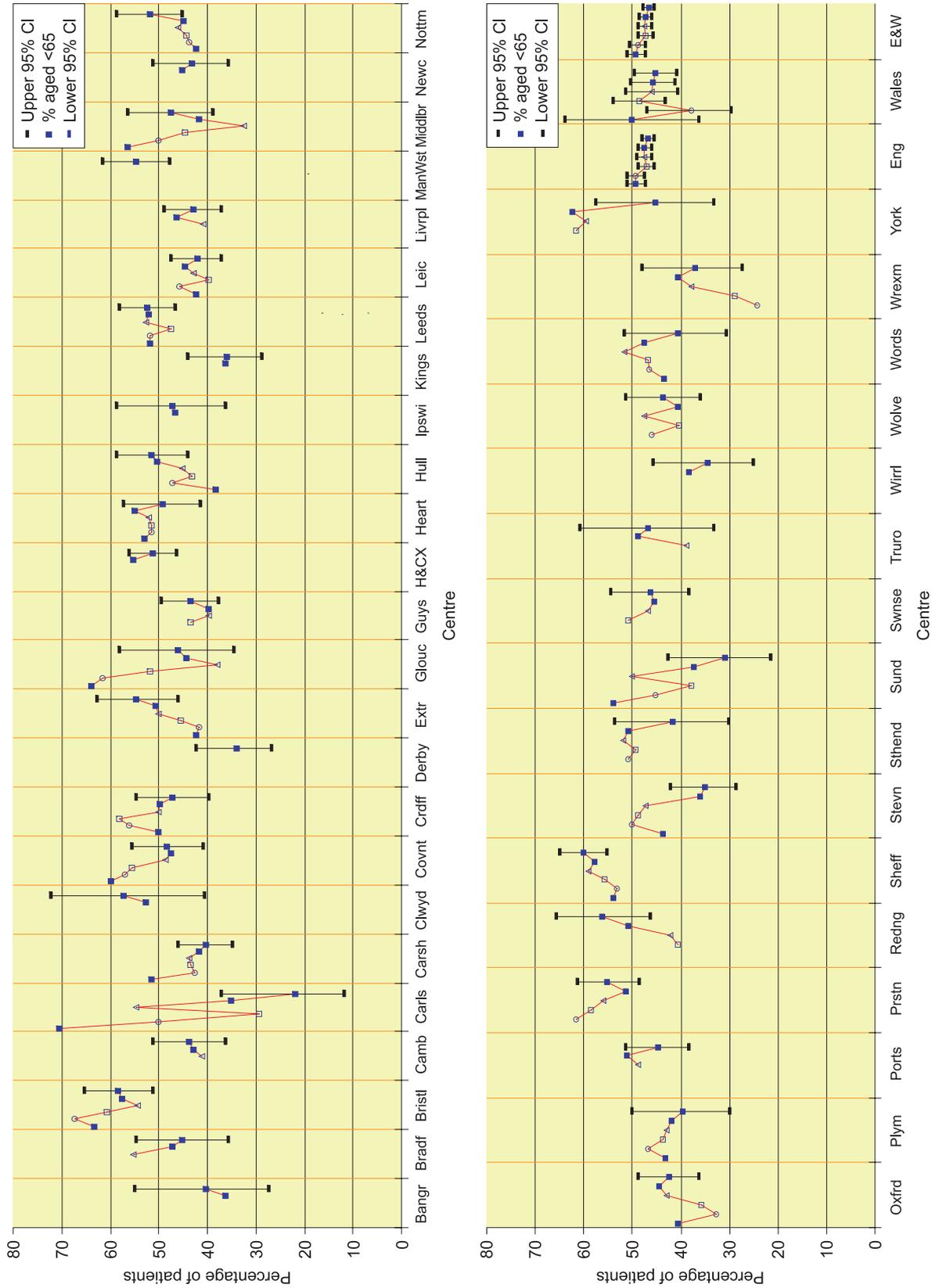
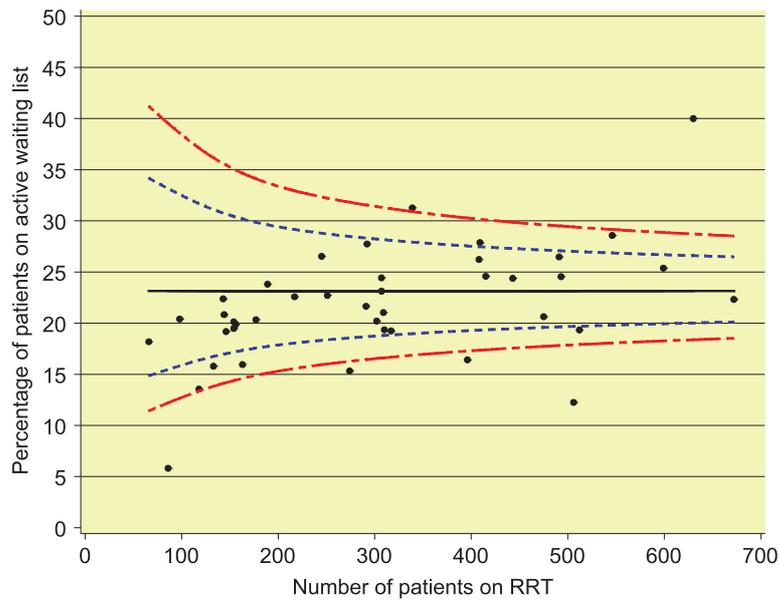


Figure 5.3: Change in percent of dialysis patients aged <65 on waiting list 1998–2003 (inc suspended)



**Figure 5.4: Unadjusted funnel plot showing the variation in listing rates according to renal unit size**

**Table 5.1: Significance of patient specific variables on the probability of a dialysis patient being listed for transplant**

Factor	p-value
Primary renal disease	$p < 0.0001$
Age	$p < 0.0001$
Gender	$p = 0.80$
Regraft	$p < 0.0001$
Ethnicity	$p < 0.001$
Townsend index	$p < 0.001$

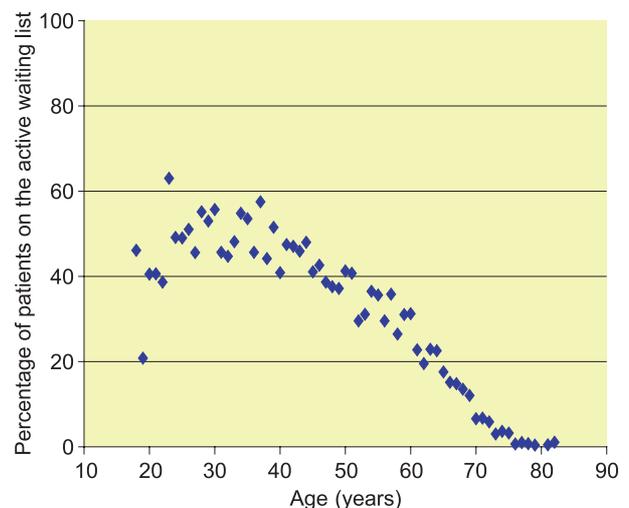
graft number, ethnicity and deprivation score but not gender (Table 5.1).

Figure 5.5 shows the percentage of adult patients on the active waiting list across England and Wales according to their age. The highest proportion of patients on the active waiting list was 63% at age 23 years. For patients aged less than 65 years, only those with autosomal dominant polycystic kidney disease were more likely to be on the waiting list than the reference group (glomerulonephritis) (Table 5.2). In contrast, patients with a primary renal diagnosis of diabetes mellitus were the least likely to be on the active waiting list. Non-White patients were more likely to be listed than White patients, although patients without ethnicity recorded were less likely to be listed. Patients in the most deprived Townsend quintile were least likely to be listed compared with the other quintiles although there was a step-wise

reduction in likelihood of listing from the first to fifth quintile.

A funnel plot adjusted for these patient variables is shown in Figure 5.6 and the inclusion of a random effects term in the model for unexplained centre effects was highly significant ( $p < 0.0001$ ), demonstrating that there is still significant variation between centres in the proportion of patients listed for transplant after adjusting for patient case-mix.

Centre-specific variables that were significant at the 5% level were size of the renal unit, size

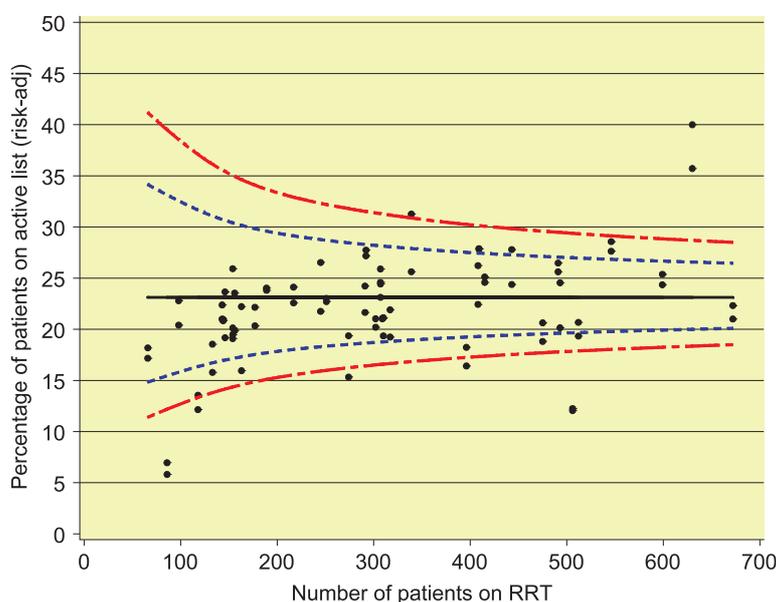


**Figure 5.5: Proportion of dialysis patients on the active waiting list across England and Wales, by age**

**Table 5.2: The effect of primary renal disease on the odds of listing for patients aged less than 65 years**

Primary disease	N	Odds ratio of listing	95% CI
Polycystic kidney disease	597	1.4*	1.1–1.7
Glomerulonephritis	1,119	Ref	Ref
Aetiology uncertain	1,481	0.7*	0.6–0.9
Hypertension	441	0.7*	0.6–0.9
Pyelonephritis	798	0.7*	0.6–0.8
Other	1,024	0.6*	0.5–0.8
Renal vascular disease	157	0.5*	0.4–0.8
Not reported	325	0.4*	0.3–0.6
Diabetes	1,223	0.3*	0.2–0.4

\*p < 0.0001



**Figure 5.6: Funnel plot adjusted for significant patient variables (age, diagnosis and graft number)**

of the living donor programme and the listing practice for living donor transplants, but not whether the renal unit was also a transplant centre (Table 5.3).

A funnel plot adjusted for both patient and centre-specific significant variables is shown in Figure 5.7.

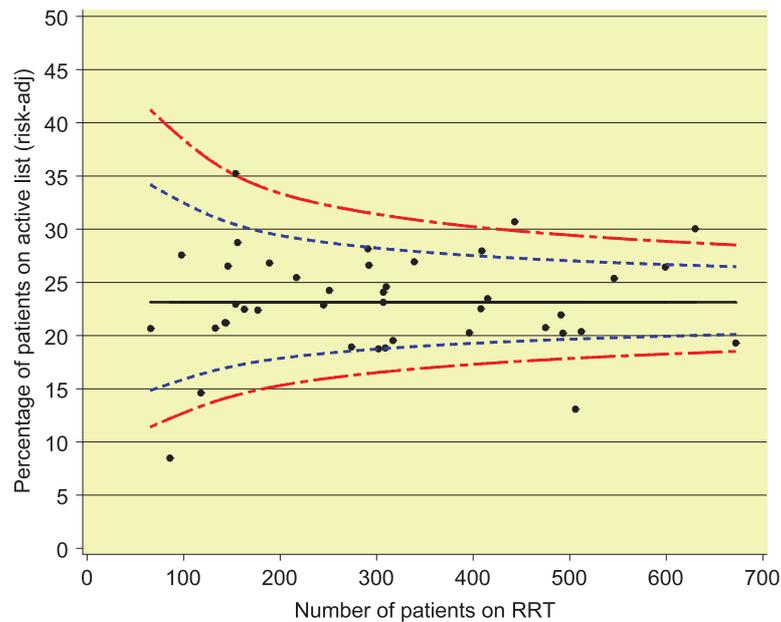
**Table 5.3: Significance of centre-specific variables on the probability of a dialysis patient being listed for transplant, after adjusting for patient-specific factors**

Factor	p-value
Size of the renal unit	p = 0.023
Renal unit also a transplant centre	p = 0.671
Size of living donor programme	p = 0.002
Listing practice for living donor transplants	p < 0.0001

Even after taking these patient and centre-specific factors into account, there is still significant unexplained variation between renal units in the proportion of dialysis patients on the transplant waiting list (p < 0.0001).

### Discussion

Both patient and centre-specific factors influence the probability of a patient being listed for renal transplantation. Not surprisingly, age was an important factor with few dialysis patients older than 65 years old being listed. In contrast with many other studies however, gender was not a significant determinant of access to the waiting list suggesting that in England and Wales disparities have been eliminated that in other countries have led to a gender bias.



**Figure 5.7: Funnel plot adjusted for significant patient and centre-specific variables\***

\*Age, diagnosis, graft number, centre size, size of centre's living donor programme and centre's listing practice for living donor kidney recipients

Patients whose underlying renal disease was polycystic kidney disease were most likely to be listed whilst those with diabetes mellitus were least likely. The most obvious explanation for this observation is the well recognized difference in co-morbidity associated with each condition. Surprisingly, patients with a previously failed renal transplant were more likely to be listed. Again in contrast with other reports, non-Whites were more likely to be listed than White patients. However, after correcting for differences in co-morbidity (in a subset of patients for whom these data are available) this racial difference became insignificant (although patients without reported ethnicity were still less likely to be listed).

The likelihood of placement on the waiting list declined with increasing socio-economic deprivation. Although patients who are socially disadvantaged may have more co-morbidity, socio-economic deprivation remained an independent predictive factor after correction for differences in co-morbidity. Possible explanations include inadequate patient education and understanding of the benefits of transplantation and a lack of self-advocacy. A selection bias by healthcare workers cannot be excluded.

Reassuringly for both patients and providers, whether a renal unit that was also a transplant centre cared for the patient did not influence

access to the transplant waiting list. However, patients in larger renal units, linked with transplant centres with active living donor transplant programmes whose practice was not to list living kidney transplant recipients prior to transplantation were less likely to access the national deceased donor transplant waiting list.

Could the maturity of the renal unit explain these observed centre differences? That is, older renal units who have been transplanting for longer may have transplanted the majority of appropriate patients thereby leaving a smaller proportion of suitable dialysis patients on the transplant list. However, all UK transplant centres have been established for over 25 years so maturity of the renal unit cannot explain this difference. Another possible explanation is that a centre may have had a less selective policy on tissue match grade resulting in a higher proportion of highly sensitised patients on the waiting list which are unlikely to be offered a transplant. Analysis of the percentage of highly sensitised patients by centre shows no significant difference between centres. Analysis of dialysis prevalence pmp by Local Authority (LA), for those LAs close to transplant centres shows a similar prevalence of dialysis to the UK average. Some LAs have lower rates but this correlates with their lower renal replacement therapy acceptance rates. These observations suggest that a concept of 'maturity' has

no basis and cannot be the explanation for the difference demonstrated in listing practice between centres.

There is no consensus either in the UK or the rest of the developed world, on what constitutes the “standard” proportion of dialysis patients that a renal unit should list. It might be that some UK renal units with a high proportion of listed patients are selecting inappropriate patients that may be considered medically unsuitable by other units. If this was true then a higher “refusal rate” of organs might be observed in these renal units together with a higher one year transplant mortality. Analysis of the data showed no relationship between the proportion of listed patients and the proportion of offers declined, or accepted and then not used due to the recipient being unfit (data not shown). Additionally, for the period from 2002 to 2004, there was no significant difference in one year patient or transplant survival between centres (UKT data).

In conclusion, this analysis showed that there are differences in listing practice between centres that cannot be explained by either differences in patient case-mix or centre characteristics and are most likely to reflect a selection bias by healthcare professionals.

## Time to listing in renal transplantation

### *Introduction*

Waiting time spent on dialysis has been shown to be an important factor in determining mortality (Meier-Krische Transplantation 2002; 74:1377). Median waiting time after activation onto the transplant waiting list varies significantly between transplant centres. A recent analysis by UKT has identified those variables that govern how long a patient is likely to spend on the national transplant waiting list before receiving a kidney allograft. These factors include patient age, gender, ethnicity, blood group, matchability score, degree of HLA sensitisation, HLA-DR homozygosity and number of previous grafts. Centre specific factors include balance of exchange and number of deceased adult donors (greater chance of transplant if these are higher), offer

refusal rate and size of waiting list (lower chance of transplant if these are higher). Recently, changes have been made to the national organ allocation scheme to take into account these variables to try and make organ allocation more equitable. However, the time it takes for patients to be placed on the national transplant waiting list is also important in ensuring equity of access to renal transplantation but has been much less well studied.

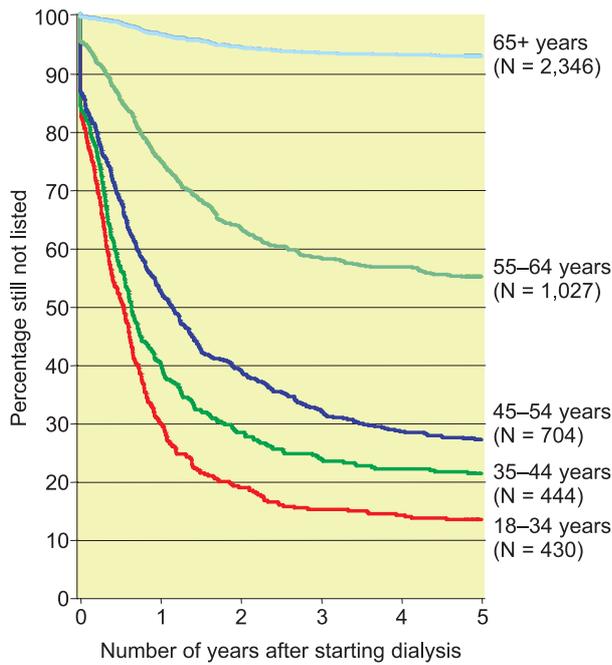
### *Methodology*

By combining data from the UK Renal Registry and UK Transplant, the time from the start of dialysis to activation on to the national transplant waiting list was determined for each patient from a cohort of 4,951 patients (53% aged less than 65 years old) who commenced RRT in 1998/1999 in the centres covered by the Registry. Patients who died or were not listed by the time of analysis (October 2004) were included with censored times. Patients listed before the need for dialysis were given a time to listing of zero days. Time to listing was analysed by age band and primary renal disease. The two year time to listing was repeated for the 2000/2001 cohort of 5,513 patients starting RRT.

### *Results*

Overall, 45% of patients under the age of 65 years were activated on the national transplant waiting list within one year of starting dialysis and 66% were activated within five years. The time to listing according to the patient’s age is shown in Figure 5.8 as Kaplan-Meier survival curves and in Table 5.4.

For patients aged between 18–34 years at the start of RRT, 70% were activated on UKT’s waiting list within one year and 87% by five years. The proportion of patients listed fell with each increasing age group such that for patients over the age of 65 years only 7% were listed within five years. The effect of age on time to listing is not surprising and reflects the increasing co-morbidity associated with increasing age. However, an additional selection bias in favour of younger patients cannot be excluded. Between one and five years of commencing RRT, an additional 21% of patients under 65 years of age were added to the list with the



**Figure 5.8: Kaplan-Meier curves showing time to listing by patient age**

greatest proportion (25%) observed in the 45–54 year old group.

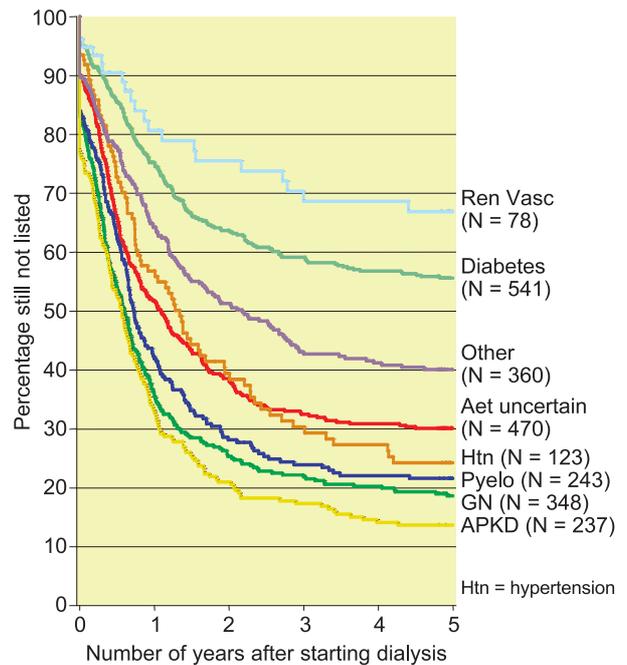
Listing rates also vary significantly according to the primary renal disease as shown by the Kaplan-Meier curves in Figure 5.9.

79% of patients with adult polycystic kidney disease were listed within 2 years of starting RRT in contrast to 25% of patients with renovascular disease and 36% with diabetes mellitus. Once again these differences in listing rates can be explained by the well-recognised increased co-morbidity (especially cardiovascular) and early death associated with renovascular disease and diabetes mellitus.

Figures 5.10 and 5.11 show the time of listing by patient age and primary renal disease.

**Table 5.4: One, two and five year listing rates according to patient age (1998/1999)**

Age (years)	Percentage of patients listed within			
	Pre-emptive	1 year	2 years	5 years
18–34	17	70	81	87
35–44	16	60	72	79
45–54	13	48	61	73
55–64	5	25	37	45
65+	<1	4	6	7
All < 65	11	45	57	66



**Figure 5.9: Kaplan-Meier curves showing time to listing by primary renal disease**

Younger patients and patients with APKD, pyelonephritis and glomerulonephritis were more likely to be listed before starting dialysis.

Late listing of patients between two and five years after starting RRT was uncommon (8%) in patients aged 55–64 years and rare (1%) in those aged over 65 years (Figure 5.10). It was also least common in patients with renovascular disease and diabetes mellitus as their primary renal disease (Figure 5.11).

Comparison was made with a cohort of 5,513 patients who started RRT in 2000/2001. Table 5.5 shows that the one and two year listing rates according to different age groups were no different from those in 1998/1999 (Table 5.4).

**Discussion**

The renal NSF part one, Standard 2 (preparation and choice) recommends that as a marker of good practice suitable patients be wait listed prior to start of RRT.

*Patients for whom transplantation is an option should be assessed before being placed on the national transplant list. Currently fewer than 40% of dialysis patients are on the national transplant list, and the proportion varies widely from unit to unit. UK Transplant has consulted with the*

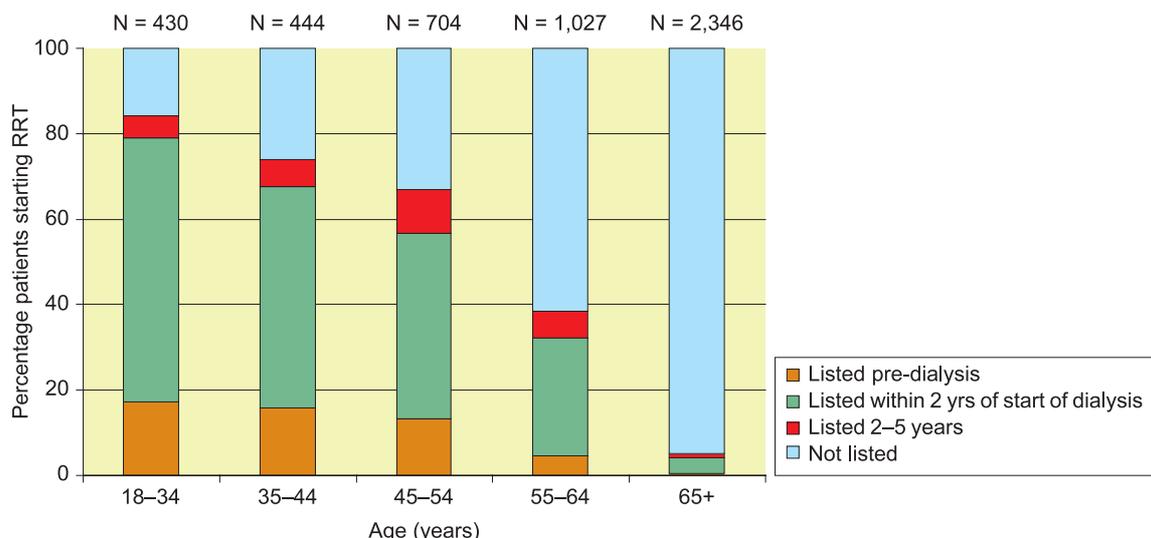


Figure 5.10: Listing time by patient age

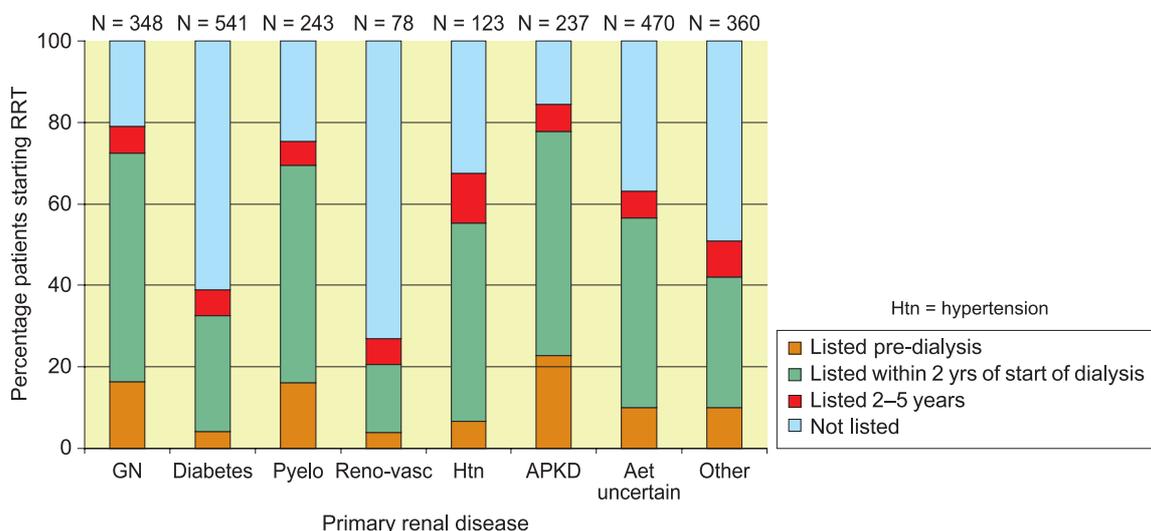


Figure 5.11: Listing time by primary renal disease

*British Transplantation Society and the Renal Association to develop protocols for the assessment of adults, and with the British Association for Paediatric Nephrology to do the same for children. These will ensure that*

*all patients are assessed to uniform standards.*

*Suitable people close to ERF may benefit most if they have a transplant before they need to start dialysis. This is known as a 'pre-emptive' transplant. The guideline published by UK Transplant is that people should be eligible for the national transplant list if dialysis is predicted to start within six months – typically with a GFR <15 mls/min.*

Table 5.5: One and two year listing rates according to patient age (2000/2001)

Age (years)	Percentage of patients listed within	
	1 year	2 years
18-34	67	81
35-44	60	73
45-54	45	57
55-64	23	38
65+	4	6
All <65	44	57

Younger patients were more likely to be pre-emptively listed, with 25% being listed in the 18-34 age group.

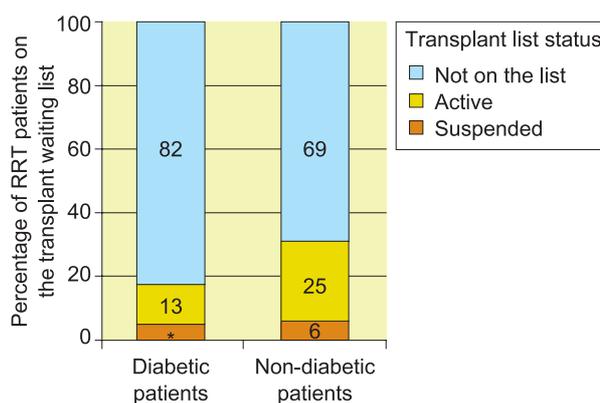
In patients aged under 65 years at the start of RRT, 57% are activated on the national transplant waiting list within two years of

starting dialysis. This was identical for both the 1998/9 and the 2000/1 cohorts indicating that the 1998/9 data is representative and that practice has not changed. The rate at which patients are listed and the proportion that are listed, are determined by the patient's age and primary renal disease. Older patients and those with reno-vascular disease and diabetes mellitus are less likely to be listed and are also listed more slowly. Concomitant co-morbidity and its investigation (eg by coronary angiography) is the likeliest explanation for this observation.

The reason why 13% of patients in younger age groups take between one and two years to be activated on the transplant waiting list is unknown, but is less likely to be due to co-morbid conditions. Some renal units do not list patients who are being worked up for live donor transplant. If the donor was found not suitable this may account for a delay in listing. A few younger dialysis patients opt to remain off the waiting list (personal communication from renal units). An additional 6% of young patients take up to five years to be activated on the waiting list.

## Transplantation in patients with diabetes mellitus

The most common identifiable cause of established renal failure in the United Kingdom is diabetic nephropathy accounting for 17.9% of all patients starting renal replacement therapy on 31 December 2003 (Table 5.6). Patients with diabetes mellitus also have more co-morbidity and an increased risk of death than patients



\*Suspended = 5% of diabetic patients

**Figure 5.12: Status of diabetic and non-diabetic RRT patients on the transplant list on 31 December 2003**

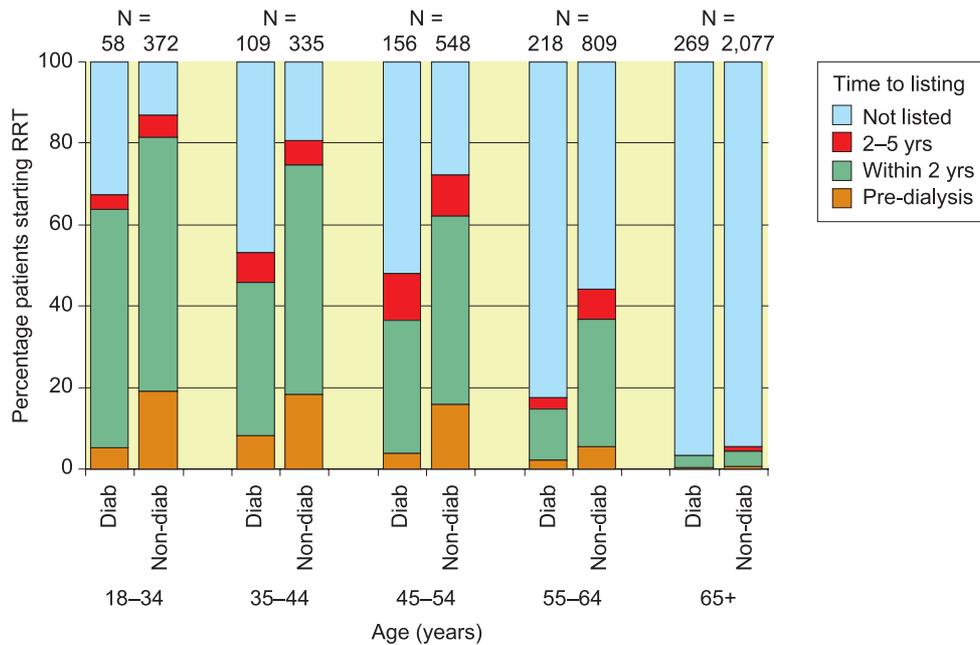
with other primary renal diagnoses. Data from the UK Renal Registry and UK Transplant were combined to evaluate access to renal transplantation in this important diagnostic group and to assess transplant outcome compared with other patient groups.

Figure 5.12 shows that diabetic patients with ERF were less likely to be listed for renal transplantation than non-diabetic patients. This was observed across all age groups (Figure 5.13). Once listed, diabetic patients were more likely to be temporarily suspended from the waiting list (28% vs 20%,  $p < 0.005$ ).

The time to activation on the national transplant waiting list was compared between diabetic and non-diabetic patients who started RRT in 1998/1999 (Figure 5.13). The most striking difference was seen in the proportion of patients activated before starting dialysis.

**Table 5.6: Percentage of new patients starting RRT in 2003 according to primary renal diagnosis and age**

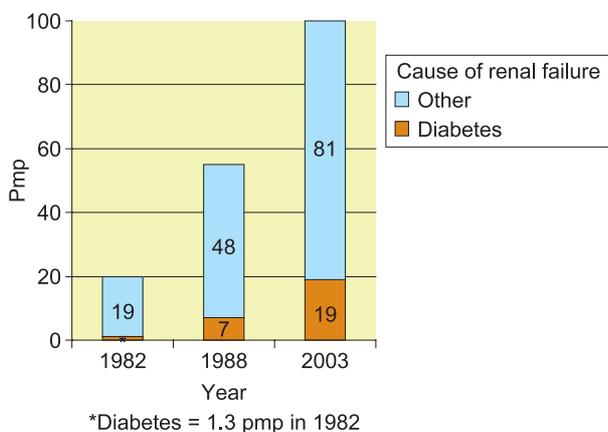
Diagnosis	Age ≤ 65 years (N = 1,992)	Age > 65 years (N = 1,942)	All ages (N = 3,934)
Aetiology uncertain	19.7	29.6	24.6
Glomerulonephritis	12.9	5.9	9.4
Pyelonephritis	7.8	7.4	7.6
<b>Diabetes</b>	<b>20.9</b>	<b>14.9</b>	<b>17.9</b>
Reno-vascular disease	2.4	13.2	7.7
Hypertension	4.7	5.6	5.1
Polycystic kidney disease	9.4	2.7	6.1
Other	15.7	13.4	14.6
Not recorded	6.6	7.3	6.9



**Figure 5.13: Time to transplant listing for patients starting RRT in 1998/1999 according to diabetic status and age group**

Patients under the age of 65 years without diabetes mellitus were twice as likely to be listed pre-emptively for a renal transplant.

Over time an increasing number of diabetic patients have received a renal transplant (Figure 5.14). The proportion of diabetic transplant recipients has increased from 2.1% of the total in 1988 to 9.1% in 2003. Furthermore, Renal Registry data show that an additional 2.6% of transplant recipients have diabetes mellitus but not recorded as the primary cause of ERF. Combined kidney/pancreas transplantation has also increased from 4 in 1988 to 42 in 2003.



**Figure 5.14: Number of adult patients receiving a renal transplant by year according to diabetic status**

The percentage of diabetic ERF patients less than 65 years old with a transplant was examined by renal units to explore whether there was a difference between centres in their approach to transplanting patients with this diagnosis (Figure 5.15). There is a very wide variation (3–62%) between centres in the proportion of diabetic patients less than 65 years old with established renal failure that have a transplant (35% overall mean for England and Wales). Adjustment for patient mix (eg age, ethnicity) only partially explains these differences and may indicate variation between centres in their policy of listing diabetic patients.

### Outcome after transplantation

For diabetic patients remaining on dialysis, there is a significant increased risk of death at one year of 1.87 (95% CI 1.58–2.22) compared to patients with glomerulonephritis ( $p < 0.001$ ). Although there is an increased risk of death one year after transplantation for diabetic patients, this does not reach statistical significance. However, the risk of death five years after transplantation is more than twice that observed in the reference group with glomerulonephritis, a highly significant statistical difference ( $p < 0.001$ ). After renal transplantation, one and five year allograft survival is no different for patients with diabetes mellitus than for patients with glomerulonephritis (Table 5.7).

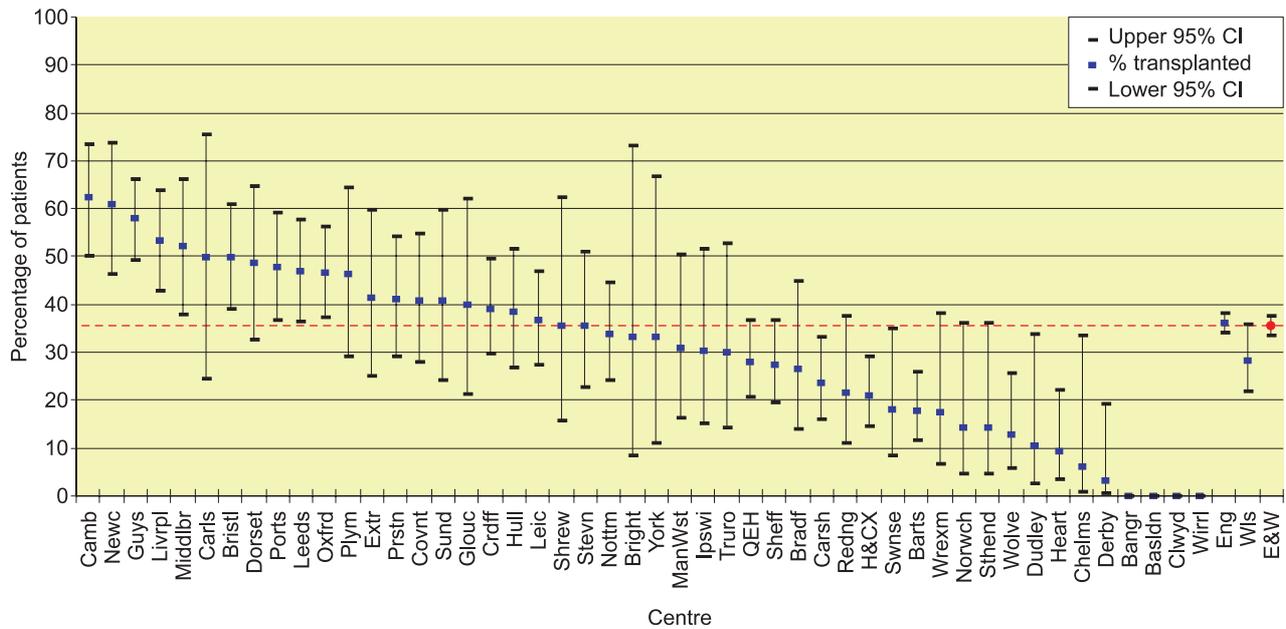


Figure 5.15: Proportion of diabetic patients with ERF aged less than 65 years with a functioning renal transplant by renal centre

Table 5.7: Outcome after renal transplantation comparing diabetic patients with patients with glomerulonephritis

Outcome		Relative Risk	95% CI	p value
Graft survival (death with function censored)	1 year	0.72	0.37–1.39	p = 0.33
	5 year	1.02	0.78–1.32	p = 0.91
Patient survival	1 year	1.85	0.99–3.46	p = 0.06
	5 year	2.22	1.71–2.87	p ≤ 0.001

**Conclusion**

An increasing proportion of patients with ERF due to diabetic nephropathy are receiving renal transplants compared with previous years. Diabetic patients are less likely to be listed for a transplant than non-diabetic patients and when listed are more likely to be temporarily suspended from the transplant waiting list. Pre-emptive listing before the start of dialysis is much less common in diabetic patients.

There is centre variation in the proportion of diabetic patients with a functioning transplant that can only partially be accounted for by differences in case-mix across centres and may indicate differences in the policy of listing diabetic patients.

The short and medium term graft outcome after transplantation for diabetic recipients is similar to other patient groups although there is

an increased risk of death that at 5 years is more than double that for patients with glomerulonephritis.

**The influence of socio-economic deprivation on renal transplantation**

The influence of socio-economic deprivation on renal transplantation has not been well studied in the UK. In the Registry Report 2000 the first analysis was reported on a prevalent cohort of renal replacement therapy patients using deprivation data from the 1991 Census. The Registry had been waiting for the new 2001 Census data before repeating these analyses on the much larger incident cohort now available. Further analyses on dialysis patients using the 2001 Census data were included in Report 2003 (Chapter 17).

**Table 5.8: Townsend scores by postcode quintile**

Townsend quintile	1 Least deprived	2	3	4	5 Most deprived
Townsend score range	≤ -3.35	-3.34 to -1.97	-1.96 to -0.16	-0.15 to 2.59	>2.60

### Calculating the Townsend deprivation score

The Townsend index was used as the scoring system for social deprivation, which was derived from the patient’s postcode. The Townsend index (calculated for the Registry from the 2001 Census data, by Hannah Jordan of Southampton University) is a composite measure of deprivation based on total unemployment rate, no car households, overcrowded households and not owner occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater the deprivation.

Using 2001 Census data, a profile was created for all 1.25 million postcodes in England and Wales. The postcodes were ordered by Townsend score from lowest to highest and then divided into quintiles of Townsend scores (Table 5.8). For those postcodes with more than one Townsend score (5% of postcode areas cross a census boundary), the mean Townsend score was calculated.

For all patients with a recorded postcode it was therefore possible to allocate;

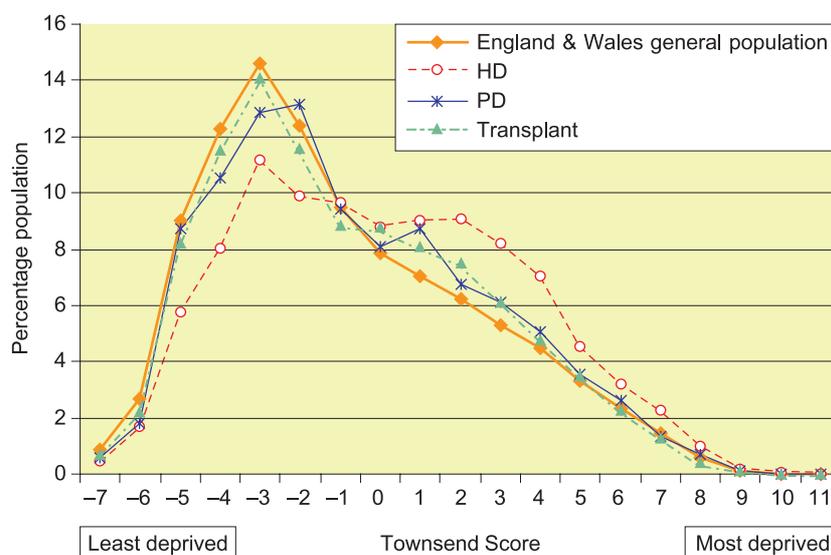
1. A Townsend score for the postcode area in which they lived; and
2. A national Townsend quintile, the lowest quintile representing the least deprived one fifth of postcodes.

This approach was based on the assumption that each area with a postcode covers approximately the same number of residents.

### Results

The distribution of Townsend deprivation scores in prevalent patients is shown in Figure 5.16 for each RRT modality and compared with that in the general population for England and Wales. Transplant recipients and PD patients appear to have a similar distribution of social deprivation to that of the non-RRT general population. Patients on HD are from the more socially deprived group. This may relate to higher rates of co-morbidity (especially diabetes) in this population. The prevalent transplant patients also largely reflect a more ‘historical’ dialysis population than the current one.

The Townsend index for each RRT modality across age groups is shown in Figure 5.17. At



**Figure 5.16: Population distribution of Townsend deprivation scores in prevalent RRT patients by modality**

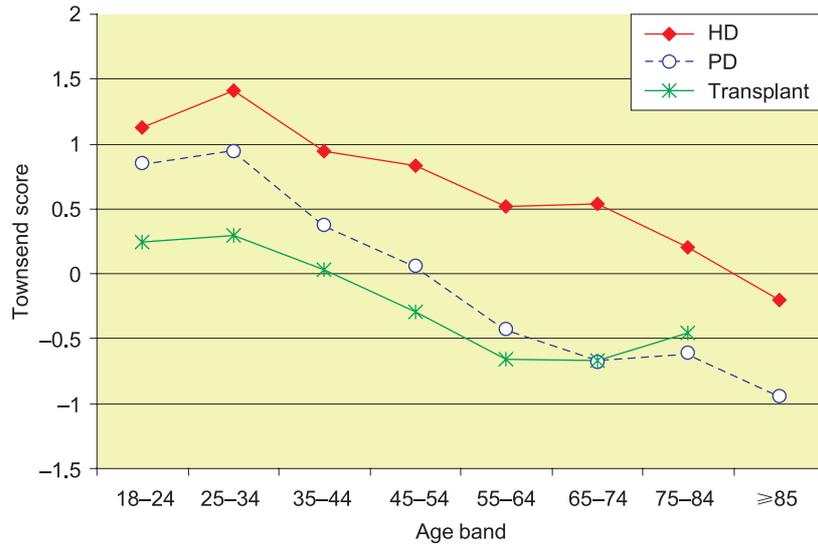


Figure 5.17: The Townsend index for each RRT modality across age groups

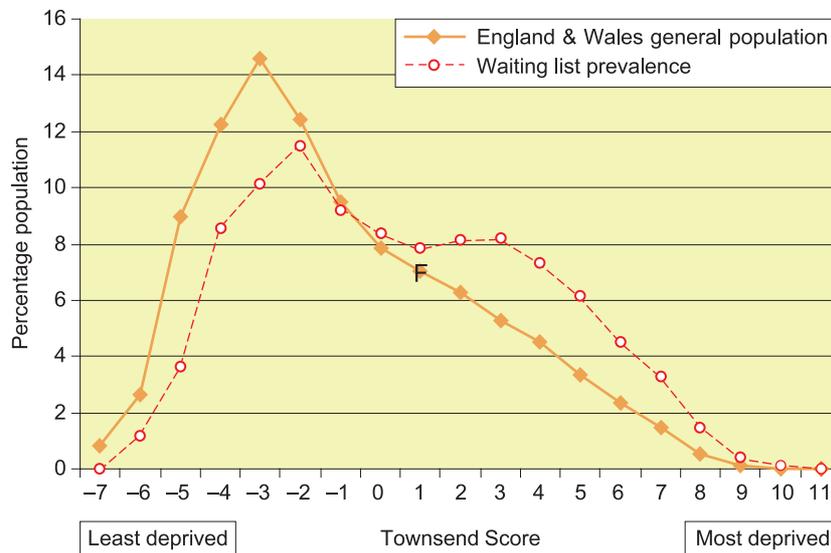


Figure 5.18: Population distribution of Townsend deprivation scores in wait listed dialysis patients

almost every age band, the Townsend index for transplanted patients is lower than for patients treated by peritoneal or haemodialysis. In addition, the index falls with increasing age in all modalities. The observed differences may be accounted for by a number of factors including differences in co-morbidity and ethnicity.

Figure 5.18 illustrates that the current waiting list population more closely resembles the prevalent dialysis population than the prevalent transplant population. Part of this difference will be related to the longer waiting time for patients from an ethnic minority background (who also live in more socially deprived areas) and the lower donor rates with a matching blood group and tissue type.

Figure 5.19 shows that transplanted patients have lower social deprivation than new registrants to the transplant waiting list (incident patients) and prevalent patients already on the waiting list. Ethnicity and also increased employment opportunities and hence income in transplanted patients may account for these observations.

For transplanted patients, the recipients of living donor transplants are less socially deprived than deceased donor transplants across all age groups (Figures 5.20 and 5.21).

Table 5.9 shows the influence of ethnicity on the deprivation scores for prevalent patients on the transplant waiting list. African-Caribbean

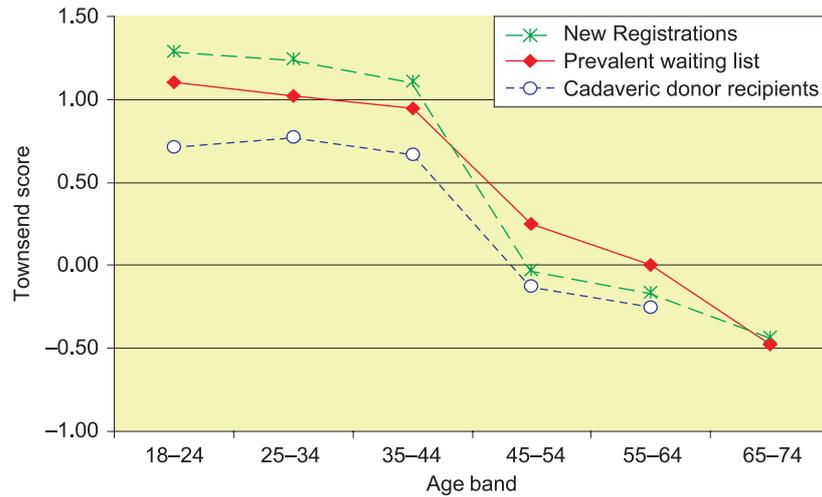


Figure 5.19: Townsend index for new registrants to the transplant waiting list, prevalent patients on the waiting list and transplanted patients (deceased donor)

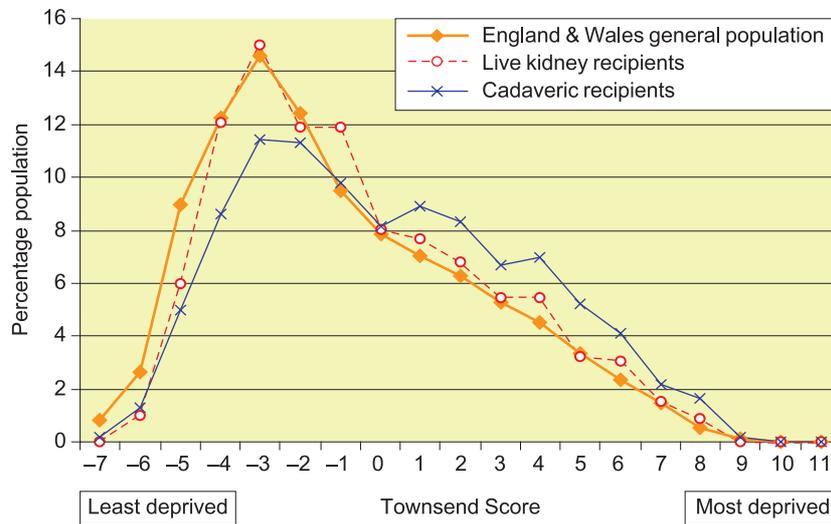


Figure 5.20: Population distribution of Townsend deprivation scores in cadaveric and live transplant recipients

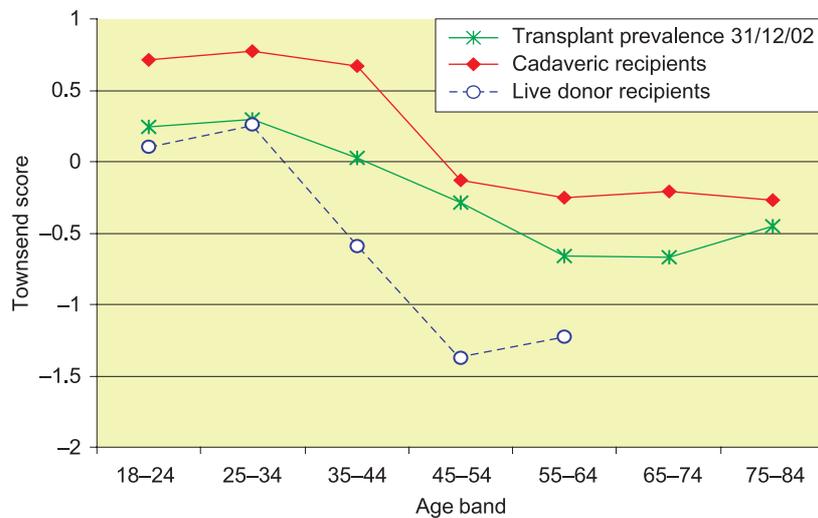


Figure 5.21: Social deprivation scores for transplant type by age groups for prevalent patients on 31 December 2002

**Table 5.9: Mean Townsend index of waiting list patients by ethnicity**

<b>Ethnicity</b>	<b>N</b>	<b>Townsend index (mean)</b>
White	2,583	-0.17
Chinese	40	1.00
Other	53	2.18
South Asian	553	2.19
African-Caribbean	306	3.69
Unknown	52	1.34

**Table 5.10: Mean Townsend index by time spent on waiting list**

<b>Time on list (days)</b>	<b>N</b>	<b>Townsend index (mean)</b>
1-1,000	2,583	-0.17
1,001-2,000	908	1.00
2,001-3,000	303	2.18
>3,000	253	2.19

patients had the highest social deprivation score.

There was also a relationship between the length of time spent on the transplant waiting list and deprivation (Table 5.10). This probably

reflects the effect of ethnicity in that patients from ethnic minorities are likely to wait longer for a transplant because of their less common blood group and tissue type.

## Conclusions

Combining data with UK Transplant provides important insights into patient and centre specific factors that influence patients' access to the transplant waiting list. The time it takes to list patients for transplantation can also be studied. The variation observed between centres may be explained by differences in policy and organisational arrangements. The reasons for the differences in social deprivation between live related recipients and deceased donor recipients, requires further investigation.

## Acknowledgement

We would like to acknowledge the significant contribution made to this chapter by Helen Thomas, Samantha Armstrong, Rachel Johnson and Dave Collett of UK Transplant.

