

UK Renal Registry Inequity of access to the UK kidney transplant waiting list

Data on patients who initiated kidney replacement therapy between March 2017 and February 2020

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UK Renal Registry

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Executive Summary

As part of its remit the UK Renal Registry regularly evaluates the care and outcomes of all patients eligible for dialysis and kidney transplantation. The evaluation of the patient's health is necessary before adding a patient to the waiting list for kidney transplantation and is an area where disparities based on age, ethnicity, sex, and socioeconomic status could potentially lead to inequities. This report has been compiled to examine inequities in access to listing for kidney transplantation. Although there have not been significant changes in this report compared with what we reported in the previous UK Renal Registry Annual report, periodically scrutinising the disparities remains crucial due to its clinical importance and significant public interest.

Analyses have revealed that individuals' characteristics, and features of the renal centres that deliver their care, contribute to variations in access to transplantation in the UK. Patients of Asian ethnicity were more likely, and patients of Black ethnicity less likely, to be listed for transplantation than patients of White ethnicity. The level of social deprivation in the area where people live has a strong association with their likelihood of being on the transplant list. When considered together, these disparities did not appear to be chance findings or explained by other known characteristics. At a system level, kidney centres with in-house kidney transplantation services had on average higher listing rates than kidney centres that refer their patients to other centres for transplantation.

Here, we report on patients who initiated kidney replacement therapy between March 2017 and February 2020, and follow them up for listing outcomes until February 2022. Our analyses therefore spanned the COVID-19 pandemic. We observed that patients who initiated kidney replacement therapy between March 2019 and February 2020 were less likely to be listed for transplantation than March 2017 to February 2019. Despite this, the effects of ethnicity, social deprivation and in-house transplantation services remained significant through all time periods.

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Introduction

Aims

Kidney transplantation involves the implantation of a donor organ into a recipient with kidney failure. Deceased donors, both donors after brain death (DBD) and donors after circulatory death (DCD), are allocated through a National Allocation Scheme managed by NHS Blood and Transplant (NHSBT). A critical step in the receipt of a deceased donor kidney is transplant 'listing' - where an individual becomes fully activated on the organ waiting list due to an irreversible decline in kidney function. Individuals may be 'listed' and receive a kidney transplant before or after starting dialysis. Generally, patients would have reached chronic kidney disease (CKD) stage five or be within 6 months of predicted kidney replacement therapy (KRT) to be listed. The National Allocation Scheme prioritises individuals who have spent more time on the transplant waiting list. However, listing is not automatic, and depends upon administration by kidney centres and completion of clinical investigations to document eligibility. Listing is thus sensitive to patient and institutional factors. Being listed earlier increases the likelihood of finding a suitable match sooner, thereby increasing the chances of avoiding dialysis if the match is identified before kidney function deteriorates further, compared to the same person being listed with a delay.

This report aims to evaluate whether access to listing is disparate for adults in the UK. Rates of listing and time to listing were analysed according to patient characteristics. Differences between kidney centres and between kidney centres with in-house kidney transplantation services (hereafter transplant centres) and kidney centres that refer their patients to other units for transplantation (non-transplant centres) were examined, with adjustment for patient characteristics.

In this report, we focus on access to *deceased* donor kidney listing. Access to live donor transplants is not considered here as it depends on the availability of a willing and compatible living donor, often a family member or friend. Live donor organs are not allocated through the national kidney allocation scheme, and there is no 'list' for live donation. Living Kidney Donation (LKD) is instead orchestrated by kidney centres, including, where necessary, liaison between transplant and non-transplant centres.

What is already known, and what does this report add?

The UK Renal Registry (UKRR) previously published a chapter on access to transplant in the annual report for patients on KRT. However, historical UKRR reports have only included patients up to 65 years old. An increasing number of older patients have been listed/transplanted in recent years, so this report includes adults up to 75 years of age. In previous reports (19th and 21st UKRR annual reports), females were shown to be less likely to be listed after adjusting for age, ethnicity, and primary kidney disease. This report is, in part, provided to investigate trends in inequity of access to kidney listing (see appendix A3 for more details).

Previous UKRR annual reports showed patients had higher odds of being listed in transplant centres within 2 years of KRT start, compared to patients who were treated in a non-transplant centre. It was speculated in some studies, that it was because of having easier access to transplant specialists.

There is more information on the Organ Donation and Transplantation (ODT) website that is maintained by NHSBT, including their annual report on kidney transplantation, and documents regarding kidney offering, selection and allocation policies (see appendix A5).

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The UK Kidney Association (UKKA) Patient Council has worked with clinicians and researchers at the UKKA to produce a series of reports on the impact of key patient characteristics on kidney disease and kidney care in the UK. These 'disparities reports' are available at https://ukkidney.org/audit-research/disparities-report and include analysis of the effects of age, ethnicity, sex, and socioeconomic factors upon the likelihood of transplantation. Whilst these reports each include one analysis of transplant listing, the data for these analyses comes directly from this report, which provides greater detail.

UK Kidney Association guidelines

UKKA guidelines (https://ukkidney.org/health-professionals/guidelines/guidelines-commentaries) provide audit measures relevant to the care of patients on KRT. Where data permit, attainment of guideline standard by UK kidney centres is reported by the UKRR (table 1).

Table 1 The UK Kidney Association audit measures relevant to listing and transplantation in this report

The UK Kidney Association guideline	Audit criteria	Related analysis/analyses
Planning, initiating and withdrawal of	Proportion of incident patients on UK transplant waiting list at KRT initiation	Table 3
KRT (2014)	Proportion of incident KRT patients transplanted pre-emptively from living donors and deceased donors	Table 3, also reported in chapters 2 and 5 of UKRR annual report

This report addresses the following key aspects of care of patients on KRT for which there are UKKA guidelines (table 1):

- Listing this includes the proportion of patients listed at KRT start, the proportion listed two years after KRT start and the time of listing from KRT start.
- Pre-emptive transplant this is the proportion of patients who start KRT by receiving a kidney transplant from either a living or a deceased donor.

Variation in access to listing by kidney centre has been reported in previous UKRR annual reports (https://ukkidney.org/audit-research/annual-report). Whilst there is no standard to assess the optimum time to listing, nor a measure to determine the proportion of the population suitable for listing, comparing access between centres serves as a valuable tool for fostering shared learning amongst healthcare institutions.

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Analyses cohort

This report includes all patients aged between 18 and 75 who started dialysis or received a transplant between 01/03/2017 and 29/02/2020. Patients were followed-up for two years after starting dialysis or receiving a transplant, up to 28/02/2022. Paediatric patients are not included as the process for transplant assessment and organ allocation is often different to adults. In the previous UKRR annual report analysis, the upper age threshold was set at 65 due to challenges in estimating the median waiting time, with many centres failing to list 50% of patients within a 2-year timeframe. In this report, we extend the age threshold from 65 to 75, recognising the overall aging trend in the KRT cohort, and provide additional waiting time information for listing one-third of the population instead of just 50%. Until a time when we have information about which patients have been locally assessed as unsuitable to receive a kidney transplant, those over 75 have been excluded due to concerns about potential frailty that might legitimately prevent transplant listing. Patients listed for multi-organ transplants other than kidney and pancreas, and patients who were suspended for 30 days within 90 days of listing, were excluded. The latter exclusion avoided any potential bias from centres that may activate patients on the transplant waiting list, and then immediately suspend them before reactivation after a medical assessment of the patient's fitness for transplantation.

Individuals were categorised by whether they were listed before starting dialysis (pre-emptive listing) or transplanted without first receiving any dialysis (pre-emptive transplant). Those who received dialysis were categorised by whether they were listed within two years of starting dialysis. Patients who received an LKD transplant within two years of starting dialysis were considered to have been pre-emptively listed, irrespective of deceased donor listing status. Time from dialysis start to listing was calculated as:

Time from starting dialysis to listing for patients listed after starting dialysis.

Patients who were listed before starting dialysis were recorded as listed on the day of dialysis initiation, i.e. time from starting KRT to listing was zero days.

Patients who received pre-emptive transplants (living or deceased donor) were recorded as listed on the day of transplantation, i.e. time from starting KRT to listing was zero days.

Patients who received an LKD after starting dialysis who had not been listed on the National Allocation System prior to transplantation were recorded as listed six months before the date of their transplant. This aimed to account for the time needed to prepare patients for an LKD.

The proportion of patients receiving a pre-emptive transplant and the proportion listed at KRT start (including those with a pre-emptive transplant) was calculated by kidney centre, with centres stratified as transplant and non-transplant centres. The time (days) to listing half of all patients (i.e. median time to listing), and to listing one-third of patients, is provided at centre level. Patients transplanted after starting dialysis were assigned to the kidney centre recorded by the UKRR as the centre providing dialysis. For patients transplanted pre-emptively, there may be instances where the kidney centre recorded was the transplant centre, even when work-up took place in a non-transplant centre – for further discussion of the methods used to assign patients to centres, and the potential influence this may have on centre listing rates, see appendix A2.

Patient characteristics were investigated to examine access across age groups, ethnicities, sex, and socio-economic status. Socioeconomic status was measured by the Index of Multiple Deprivation (IMD) quintile of the patient's area of residence published by the Office for National Statistics (ONS). Analyses were adjusted for age group, sex, ethnicity, socioeconomic status, and primary kidney disease (diabetic nephropathy) to account for the known associations between patient characteristics and comorbidities. For the purpose of this report, primary kidney disease was categorised only by whether kidney failure was caused by diabetes, as the most commonly attributed cause. Logistic regression was used to adjust the odds of transplant listing within two years of starting KRT by patient characteristics (age, ethnicity, sex, socioeconomic status, and primary kidney disease/diabetic nephropathy); for full methods, see appendix A1. The impact of the COVID-19 pandemic was investigated in a sensitivity analysis by splitting the cohort into 3 time periods and modelling the periods in addition to other patient characteristics.

Cohort composition: Initial overview

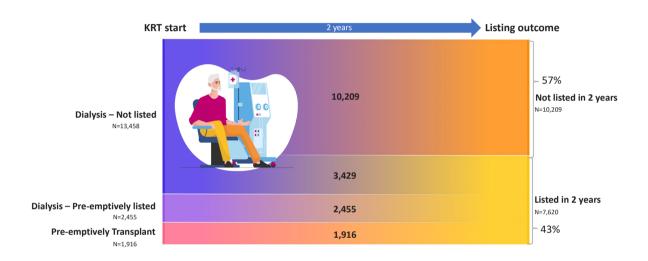


Figure 1 Diagram depicting patients in this cohort (N=17,829)

Overall, in this cohort 43% (N=7,620) of the patients were listed (or pre-emptively transplanted) within 2 years from the start of KRT (figure 1). Three quarters of the cohort started dialysis before being listed (13,458, 75%). The remaining 25% comprised patients who were pre-emptively listed (N=2,455, 14%) or pre-emptively transplanted (N=1,916, 11%).

Within the cohort, 57% (N=10,209) were not listed within 2 years of starting kidney replacement therapy, including patients deemed not fit for transplantation.

Access to listing by patient characteristics

Unadjusted analyses

The crude (unadjusted) proportion of patients who were listed within two years after starting KRT by age group, ethnicity, sex, socioeconomic status, and primary kidney disease (diabetic nephropathy) are shown in figure 2 to figure 6.

Age group

The younger the patients, the higher the proportion listed within 2 years from the start of KRT. 80% of patients under 30 were listed within 2 years, while only 17% of patients between 70 and 75 years old were listed. The median age of kidney patients in this cohort is 59 years old. There is no evidence of a threshold effect – every age group is listed for transplant less often than those who are younger, but more frequently than those who are older.

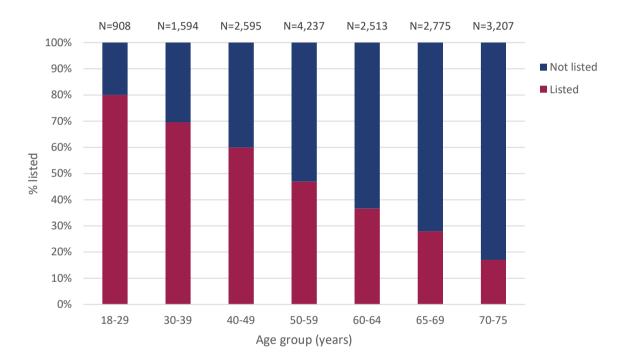


Figure 2 Percentage of patients listed within 2 years of KRT start by age group

Ethnicity

Ethnicity data were missing for 10% of patients and missing ethnicity was included as a category in the analysis because the data may not be missing at random. Crude listing rates are approximately 40% for all ethnic groups, except for patients of Asian ethnicity, for whom rates are higher, at 50%.

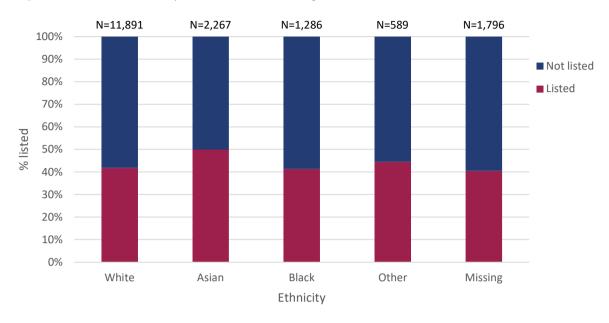


Figure 3 Percentage of patients listed within 2 years of KRT start by ethnicity

Sex

There are more male than female kidney patients. Crude listing rates are approximately 43% for both males and females 2 years after KRT start.

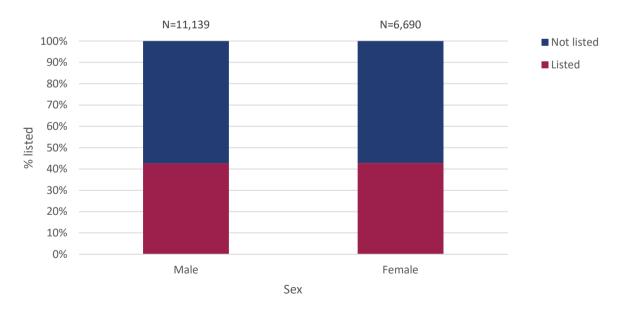


Figure 4 Percentage of patients listed within 2 years of KRT start by sex

Socioeconomic status

There is a higher proportion listed amongst those residing in more affluent areas: 51% of patients who lived in the most affluent areas were listed within 2 years of starting KRT, compared to only 36% of patients who lived in most deprived areas. There is no evidence of a threshold effect – every group is listed for transplant more frequently than those residing in more deprived areas, but less frequently than those living in more affluent areas.

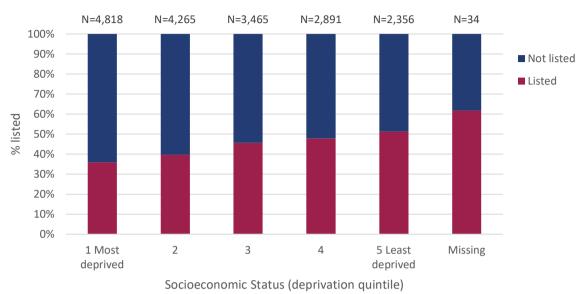


Figure 5 Percentage of patients listed within 2 years of KRT start by socioeconomic status

Primary kidney disease (diabetic nephropathy)

Similarly to ethnicity, missing primary kidney disease was included as a category in the analysis because the data may not be missing at random. Only 30% of patients with diabetic nephropathy were listed within 2 years of starting KRT, while 49% patients with other primary kidney diseases were listed within 2 years. Patients with no information on primary kidney disease also had a lower listing rate at 31%.

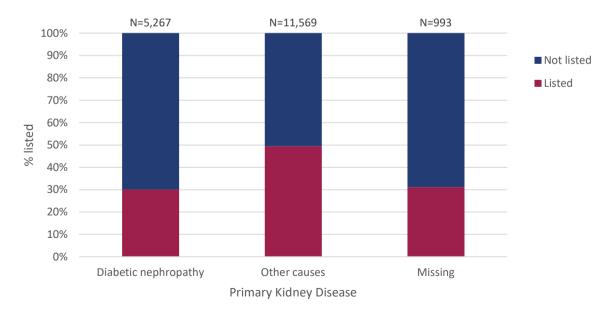


Figure 6 Percentage of patients listed within 2 years of KRT start by primary kidney disease

Adjusted analysis

In this section, we examined the adjusted analysis of the proportion of patients who were listed within two years after initiating KRT. The adjustment factors included age group, ethnicity, sex, socioeconomic status, and primary kidney disease (diabetic nephropathy). This adjustment aims to consider the potential influence of these variables, allowing us to establish the independent impact of each factor on the likelihood of being listed. Unlike the preceding unadjusted analysis, this approach provides a more detailed understanding of the factors associated with access to transplant listing, revealing disparities that may arise from demographic and clinical differences among patients.

Table 2 Multivariable logistic regression model showing the relationship between adult patient characteristics and odds ratio of transplant listing within 2 years of starting KRT (cohort incident to KRT between March 2017 and February 2020)

Cl		D-4:4- NI (0/)	Transplant listing within 2 years of KRT start		
Characteristic		Patients N (%)	Odds ratio	95% CI	
Age group	18-29	908 (5%)	3.93	3.29-4.7	
	30-39	1,594 (9%)	2.54	2.24-2.88	
	40-49	2,595 (15%)	1.68	1.51-1.86	
	50-59	4,237 (24%)	1.00	reference	
	60-64	2,513 (14%)	0.63	0.56-0.69	
	65-69	2,775 (16%)	0.39	0.35-0.43	
	70-75	3,207 (18%)	0.19	0.17-0.21	
Ethnicity	White	11,891 (67%)	1.00	reference	
	Asian	2,267 (13%)	1.66	1.5-1.84	
	Black	1,286 (7%)	0.86	0.76-0.98	
	Other	589 (3%)	0.94	0.78-1.13	
	Missing	1,796 (10%)	0.96	0.85-1.07	
Sex	Male	11,139 (62%)	1.00	reference	
	Female	6,690 (38%)	0.95	0.89-1.02	
Socioeconomic Status	1 (most deprived)	4,818 (27%)	0.56	0.5-0.61	
(deprivation quintile)	2	4,265 (24%)	0.70	0.64-0.78	
	3	3,465 (19%)	1.00	reference	
	4	2,891 (16%)	1.20	1.08-1.34	
	5 (least deprived)	2,356 (13%)	1.47	1.31-1.65	
	Missing	34 (0%)	1.87	0.87-4.02	
Primary kidney disease	Diabetic	5,267 (30%)	0.44	0.41-0.48	
	Not diabetic	11,569 (65%)	1.00	reference	
	Missing	993 (6%)	0.43	0.37-0.5	

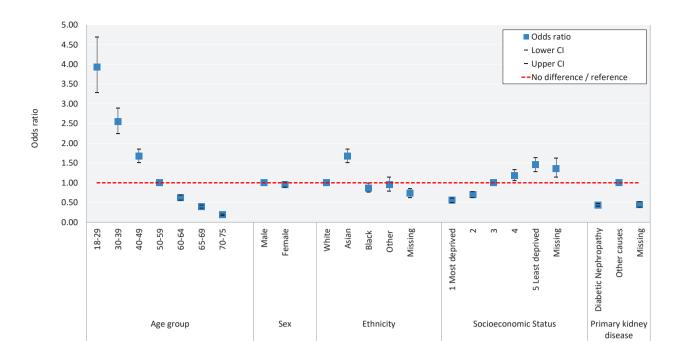


Figure 7 Odds ratios of listing within 2 years of starting KRT by age group, sex, ethnicity, socioeconomic status, and primary kidney disease

After adjusting for patient characteristics, 18-29 year olds have 3.9-fold higher odds of being listed within 2 years of starting KRT compared to 50-59 year olds, whereas 70-75 year-olds have 81% lower odds compared to 50-59 year olds. Patients of Asian ethnicity remained more likely to be listed than those of White ethnicity, even once other patient factors are considered. Patients of Black ethnicity were less likely to be listed than those of White ethnicity.

There might be a perception that females were less likely to be listed compared to males. In the 21st UKRR annual report (patients from January 2012 to December 2014) we showed that females had 13% lower odds of listing than males once other factors were considered. However, in this analysis the odds of being listed was similar between males and females when other factors were considered. (see appendix A3 for more details on the trend of sex disparities).

Overall, the cohort is more deprived than the general population, as over half (51%) of the cohort falls into socioeconomic status quintiles 1 and 2, representing the most deprived categories (table 3). This adjusted analysis shows that the kidney patients who live in the most affluent quintile have 47% higher odds of being listed compared to the patients in the middle quintile, whereas patients who live in the most deprived quintile have 44% lower odds of being listed compared to the middle quintile.

Access to listing by kidney centre

The proportion of patients listed within two years of starting KRT by kidney centre is shown, unadjusted and after adjusting for patient characteristics. In some centres (e.g. Belfast), almost 50% of patients were either preemptively transplanted or listed before starting KRT, hence giving a median time to listing of zero days.

Table 3 Proportion of incident adult patients in each kidney centre listed or transplanted at KRT start and proportion of patients listed for a transplant prior to or within 2 years of starting KRT (cohort incident to KRT between March 2017 and February 2020)

				% pre-		% listed			
				emptive	% listed	within			
			% LKD	listing/	within 2	2 years	Time to	Time to	
		% pre-	pre-	transplant	years of	of KRT	listing 1/3	listing 50%	Final event
	KRT	emptive	emptive	before/at	KRT start,	start, risk	patients**	patients**	time***
Centre	number	transplant	transplant	KRT start	unadjusted	adjusted*	days	days	days
				TRANSP	LANT CENTRE	S			
Bham	838	7.0	3.3	20.5	36.2	36.5	509	n/a	1,697
Belfast	154	32.5	25.3	49.4	68.2	63.8	0	7	
Bristol	351	12.0	6.0	24.8	39.3	36.8	263	n/a	1,497
Camb	244	32.4	12.7	43.4	61.9	52.6	0	94	
Cardff	410	9.3	5.9	19.0	32.9	34.1	725	n/a	1,435
Covnt	295	12.5	6.8	27.1	46.1	44.4	168	1,006	
Edinb	281	24.9	12.8	41.3	57.3	52.7	0	277	
Glasgw	480	14.6	8.1	35.8	52.3	54.4	0	506	
L Barts	767	8.3	5.0	22.0	44.6	45.0	224	n/a	1,484
L Guys	436	14.7	7.6	28.2	43.4	41.8	189	1,171	
L Rfree	595	10.8	4.7	28.2	43.2	44.9	127	n/a	1,666
L St.G	206	13.1	7.3	28.6	45.6	40.6	113	n/a	1,191
L West	886	9.9	6.0	22.6	50.3	48.9	222	709	
Leeds	439	12.3	4.1	33.0	54.0	50.3	0	417	
Leic	718	11.4	5.3	29.4	47.2	46.8	83	1,164	
Liv Roy	239	21.3	13.0	28.9	37.7	40.2	255	n/a	1,520
M RI	483	13.7	5.2	25.9	46.0	50.0	239	1,108	
Newc	309	17.5	12.3	30.7	45.0	45.5	107	n/a	1,494
Nottm	274	13.1	5.8	22.6	42.3	42.2	176	n/a	1,333
Oxford	434	22.6	10.8	37.6	59.0	52.7	0	249	
Plymth	138	13.8	7.3	26.1	42.8	47.0	139	n/a	1,529
Ports	490	11.8	4.9	27.4	44.9	47.7	142	n/a	1,576
Sheff	368	7.3	3.5	18.8	35.6	38.3	425	n/a	1,246
				DIALY	SIS CENTRES				
Abrdn	115	0.0	0.0	13.9	36.5	35.6	472	n/a	1,573
Airdrie	145	0.0	0.0	20.7	42.8	47.0	309	n/a	1,272
Antrim	86	22.1	17.4	37.2	48.8	50.0	0	932	
Bangor	52	5.8	3.9	21.2	38.5	35.7	412	n/a	881
Bradfd	216	8.3	2.3	19.4	39.4	38.2	356	n/a	1,403
Brightn	324	8.6	3.1	21.0	34.0	32.5	579	n/a	1,213
Carlis	91	5.5	2.2	8.8	31.9	35.4	n/a	n/a	698
Carsh	513	6.2	4.3	17.5	33.3	29.9	704	n/a	1,505
Clwyd	62	8.1	3.2	12.9	21.0	22.2	n/a	n/a	997
Colchr	77	0.0	0.0	11.7	37.7	41.3	371	n/a	1,045
D&Gall	35	0.0	0.0	31.4	48.6	51.4	44	n/a	558
Derby	190	5.3	1.6	24.2	40.5	39.3	244	n/a	1,072
Donc	103	1.0	1.0	17.5	36.9	42.6	464	n/a	1,244
Dorset	192	10.9	4.7	28.7	44.8	44.5	114	1,105	•

			% LKD	% pre- emptive listing/	% listed within 2	% listed within	Time to	Time to	
		% pre-	% LKD pre-	transplant	years of	2 years of KRT	listing 1/3	listing 50%	Final event
	KRT	% pre-	emptive	before/at	KRT start,		patients**	patients**	time***
Comtra	number	*		KRT start		start, risk	*	*	
Centre		transplant	transplant		unadjusted	adjusted*	days	days	days
Dudley	119	8.4	2.5	19.3	35.3	38.9	480	n/a	1,002
Dundee	81	0.0	0.0	21.0	43.2	42.3	126	n/a	955
EssexMs	280	5.4	2.5	16.4	39.6	40.5	397	n/a	1,528
Exeter	267	8.6	6.4	19.5	36.0	37.5	511	n/a	1,393
Glouc	140	6.4	3.6	22.1	47.9	46.6	234	837	
Hull	246	7.7	4.9	22.4	35.4	35.0	551	n/a	1,315
Inverns	60	0.0	0.0	20.0	35.0	36.3	457	n/a	1,104
Ipswi	106	12.3	2.8	22.6	39.6	42.2	239	n/a	1,165
Kent	331	9.4	4.5	19.9	36.6	37.8	398	n/a	1,754
Klmarnk	86	0.0	0.0	14.0	29.1	35.0	1,065	n/a	1,087
Krkcldy	100	0.0	0.0	16.0	32.0	31.8	829	n/a	1,068
L Kings	383	2.4	1.3	10.7	27.7	25.8	1,055	n/a	1,676
Liv Ain	117	0.9	0.9	21.4	34.2	40.4	574	n/a	1,480
Middlbr	282	9.9	8.2	23.8	42.9	44.5	246	n/a	1,190
Newry	69	18.8	14.5	27.5	53.6	53.0	54	391	
Norwch	181	6.1	2.2	13.8	35.9	37.0	511	1,699	
Prestn	364	18.1	8.2	32.4	51.1	50.1	23	637	
Redng	221	14.5	4.5	25.8	48.4	45.7	194	823	
Salford	393	13.7	5.9	30.5	50.6	52.0	82	662	
Shrew	114	5.3	0.9	14.9	29.8	30.1	n/a	n/a	1,132
Stevng	396	6.3	1.3	23.0	42.7	41.2	217	n/a	1,211
Stoke	208	8.2	3.9	25.5	37.5	40.2	351	n/a	1,275
Sund	189	8.5	4.8	21.7	34.4	37.7	571	n/a	1,294
Swanse	283	7.1	2.8	15.9	30.7	34.2	1,075	n/a	1,306
Truro	111	5.4	4.5	18.0	39.6	43.8	425	n/a	1,366
Ulster	60	16.7	13.3	25.0	48.3	47.9	85	n/a	599
West NI	89	16.9	14.6	33.7	52.8	51.4	0	486	
Wirral	129	3.1	1.6	14.0	35.7	38.9	658	n/a	747
Wolve	205	2.0	0.5	12.2	28.8	30.6	1,425	n/a	1,578
Wrexm	63	4.8	0.0	17.5	31.8	30.4	704	n/a	861
York	120	14.2	6.7	28.3	53.3	53.2	84	618	
					TOTALS				
England	15,118	10.6	5.1	24.2	42.6	42.5	243		1,815
N Ireland	458	23.4	18.6	37.6	56.8	55.3	0	258	
Scotland	1,383	10.1	5.4	29.1	46.7	47.4	83	1,087	
Wales	870	7.9	4.1	17.6	31.6	33.1	933		1,435
UK	17,829	10.8	5.5	24.6	42.7	42.7	230		1,815

^{*} Risk adjusted by age, ethnicity, sex, socioeconomic status and primary kidney disease (diabetic nephropathy), modelled by logistic regression (see details in Appendix A1 Methods)

Pre-emptive transplanted patients in Scotland were all allocated to the 2 transplanting centres, as the information on referring centre was not available. From next year these patients will be allocated to the expected referring centre based on patient postcode, in accordance with the Scottish Renal Registry Annual Report https://www.srr.scot.nhs.uk/

^{**} Time to listing is estimated by Kaplan Meier. In centres with fewer events and/or longer waiting times, median values could not be estimated (see details in Appendix A1 Methods)

^{***}Final event times are shown if median values could not be estimated

Access to listing by transplant and non-transplant centres

The funnel plot below (figure 8) provides a visual representation of the variation in risk-adjusted centre listing rates at two years after starting KRT across multiple centres, while also considering the influence of various demographic factors (age, ethnicity, sex, primary kidney disease (diabetic nephropathy), socioeconomic status).

Transplant centres demonstrated a higher listing rate in general when compared to non-transplant/dialysis centres. However, those centres that fall outside of the confidence limits indicate listing rates that significantly deviate from what would be expected by chance alone. Such deviations suggest the presence of potential variability in performance among these centres.

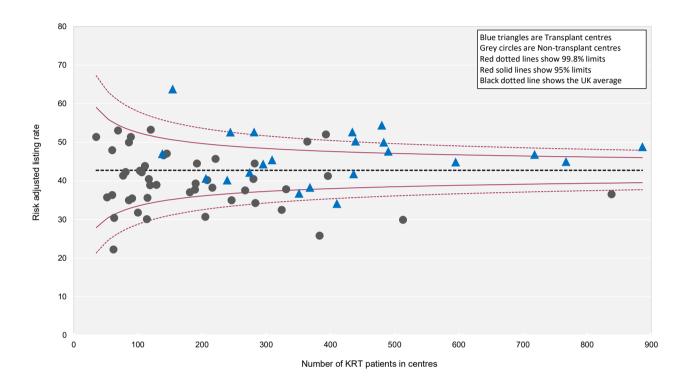


Figure 8 Centre listing rate with confidence limits, adjusted by age, sex, ethnicity, primary kidney disease, socioeconomic status

The following caterpillar plot shows the centre listing rate within 2 years of starting of KRT, adjusting for age, sex, ethnicity, socioeconomic status, and primary kidney disease (diabetic nephropathy). The centre listing rate is sorted from low to high listing %, by non-transplant centre on the left and transplant centres on the right. It ranged from 23% to 54% in non-transplant centres, compared to a higher listing rate of 34% to 64% in transplant centres.

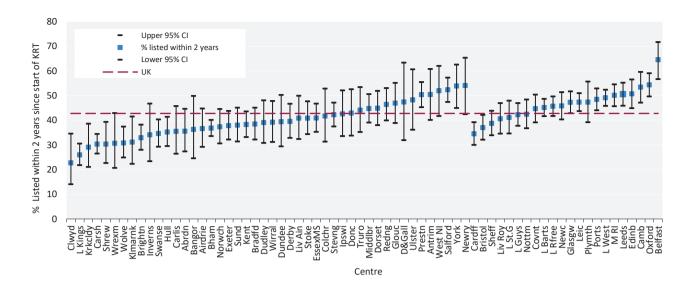


Figure 9 Centre listing rate within 2 years of starting KRT, adjusted by age, ethnicity, sex, socioeconomic status, primary kidney disease, by transplant and non-transplant centres

Adjusting for age, ethnicity, sex, socioeconomic status, and primary kidney disease (diabetic nephropathy), the odds ratio plot (figure 10) showed there was 50% higher odds of being listed within 2 years of starting KRT if patients were having treatment in a transplant compared to non-transplant centre.

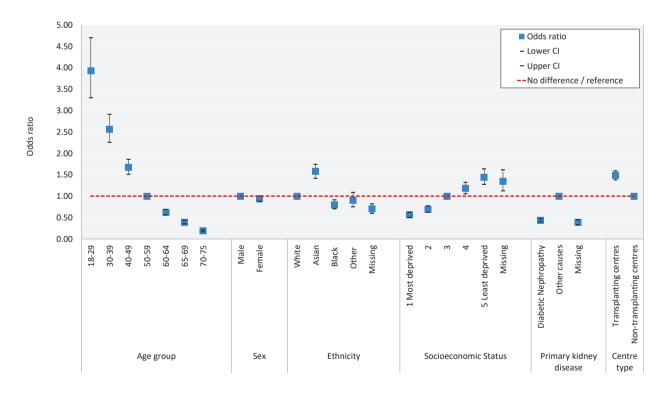


Figure 10 Odds ratio of listing within 2 years of starting KRT by centre type, adjusted for age, sex, ethnicity, socioeconomic status and primary kidney disease

Patients transplanted after starting dialysis were assigned to the kidney centre recorded by the UKRR as the centre providing dialysis. For patients transplanted pre-emptively, there may be instances where the kidney centre recorded was the transplant centre, even when work-up took place in a non-transplant centre.

As a result, the incident KRT population of a non-transplant centre might appear smaller as some pre-emptive transplants may have been allocated to the transplant centre. The remaining KRT population of non-transplant centres are predominantly on dialysis and are perhaps less likely to be suitable for transplant or require a longer time to work up for transplantation. This could be another reason why transplant centres have a higher access to listing rate than non-transplant centre in general (see figure 9 and 10). Currently just over a quarter of adult kidney centres report CKD4/5 patients to the UKRR. As more kidney centres report CKD data to the UKRR and the patient pathway becomes clearer, the UKRR will have better information of where the patient was treated before transplantation. A sensitivity analysis was performed by excluding patients who had a pre-emptive transplant, and evaluating whether this group of patients could explain the effect of transplant vs non-transplant centre. There were still 30% higher odds of being listed within 2 years of starting KRT for patients who were having treatment in a transplant compared to non-transplant centre, however the effect size was reduced. For details of the analysis please see appendix A2.

COVID-19 and access to listing

The impact of the COVID-19 pandemic was investigated in a sensitivity analysis by dividing the cohort into 3 time periods and modelling the time periods in addition to other patient characteristics. Patients who started KRT during the period March 2019 to February 2020 had 10% lower odds of being listed within 2 years during the period of the pandemic. However, there was no evidence that the temporal changes, presumably related to changes in practice during the pandemic, varied by ethnicity or by type of centre. A more detailed analysis on the impact of the pandemic will be done once a more up-to-date cohort and more information becomes available.

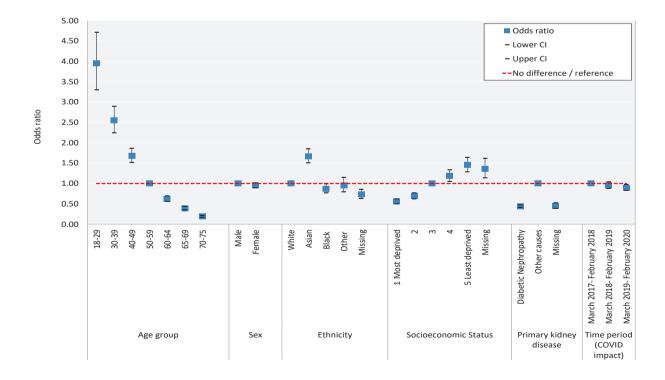


Figure 11 Odds ratio of listing by time period, adjusted for age, ethnicity, sex, socioeconomic status and primary kidney disease (diabetic nephropathy)

Discussion

This report updates the analysis last performed by the UK Renal Registry on 2017 data (21st UKRR Annual report Chapter 6), and before that the findings from the Access to Transplantation and Transplant Outcome (ATTOM) study which performed a detailed analysis of factors affecting transplant listing (1). In general, the findings are consistent.

In this report the social determinants of health were assessed using the area that a patient lives in and the Office of National Statistics 'Index of Multiple Deprivation'. In the ATTOM study several social determinants were considered separately (1). It is likely that the rate of car ownership in ATTOM, and the impact of living in a deprived postcode considered here represent the same finding – that there is a clear gradient in access to transplant listing associated with level of deprivation.

Also consistent with previous analysis, this report shows higher odds of transplant listing by 2 years in people of Asian ethnicity (1), and this appears distinct from age and level of deprivation. The explanation for this is unclear.

In different reports, there have been weak statistical associations between access to transplantation and sex (2,3) and/or ethnicity (1). Previous analyses reported ethnicity association as White and non-White but in this report, there is a statistically significant lower odds of access to listing for transplantation for Black ethnicity, but not female sex as reported elsewhere. Again, as both age and local area deprivation are considered simultaneously, the reason for these weak associations is unclear.

It is a common finding between these analyses that access to kidney transplant listing is lower in several non-transplant centres (1,2,3). Figure 9 shows that approximately half of non-transplant centres were indistinguishable from transplant centres in their rates of listing – showing that it is not an immutable fact that listing rates have to be lower in non-transplant centres. The reasons for differences in the listing rate between transplant and non-transplant centres are not known. There could be logistical barriers to streamlining the assessment process in the centres with lower listing rates. Our modelling includes key patient characteristics but there could be other unmeasured characteristics which vary between centres that affect the listing rate.

Currently the UKRR does not collect information on other factors which may affect listing such as assessment for kidney transplantation or patient treatment choice. It is hoped that more information will be available on preparation for chronic kidney treatment in the future when transplant assessment decisions will be routinely returned to the UKRR as part of the latest version (version 5) of the UKRR dataset.

References

- 1. Rishi Pruthi, Matthew L. Robb, Gabriel C. Oniscu, Charles Tomson, Andrew Bradley, John L. Forsythe, Wendy Metcalfe, Clare Bradley, Christopher Dudley, Rachel J. Johnson, Christopher Watson, Heather Draper, Damian Fogarty, Rommel Ravanan, Paul J. Roderick and on behalf of the ATTOM Investigators: Inequity in Access to Transplantation in the United Kingdom. CJASN June 2020, 15 (6) 830-842; DOI: https://doi.org/10.2215/CJN.11460919
- 2. UK Renal Registry (2019) UK Renal Registry 21st Annual Report data to 31/12/2017, Bristol, UK. Chapter 6 Access to transplantation P.147-160. Available from https://ukkidney.org/audit-research/annual-report
- 3. Byrne C, Caskey F, Castledine C, Dawnay A, Ford D, Fraser S, Lambie M, Maxwell H, Steenkamp R, Wilkie M, Williams AJ, NEPHRON 2017;137 (suppl1), UK Renal Registry 19th Annual Report of the Renal Association, UK Renal Registry, Bristol, UK

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Appendix

A1 Methods

UKRR data include start date of KRT and patient characteristics including age group (18-29, 30-39, 40-49, 50-59, 60-64, 65-69, 70-75), sex (male, female), ethnicity (White, Asian, Black, Other, missing), primary kidney disease (diabetic nephropathy, other, missing) and socioeconomic status quintile (1 - Most deprived, 2, 3, 4, 5 - Least deprived). Note that the socioeconomic status quintile is an area-level measure recorded by Lower Layer Super Output area, and was constructed using the national Index of Multiple Deprivation score (reference: https://assets.publishing.service.gov.uk/media/5dfb3d7ce5274a3432700cf3/IoD2019_FAQ_v4.pdf). Date of listing and date of transplantation are provided by the UK Transplant Registry (UKTR), held by the Organ Donation and Transplantation Directorate of NHS Blood and Transplant. The UKRR maintains its own record of transplantation dates and conducts regular audits to validate these dates against the information in the UKTR.

To identify factors which influence the likelihood of listing for transplantation, an incident KRT cohort was analysed. All adult patients starting KRT between 1 March 2017 and 28 February 2020 at kidney centres returning data to the UKRR were considered for inclusion. Paediatric patients, patients over 75 years old, patients listed for multi-organ transplants other than kidney and pancreas and patients who were suspended for 30 days within 90 days of listing were excluded. The remaining patients were followed up for two years after starting KRT, to assess the proportion of patients registered on the waiting list for a kidney transplant alone or kidney and pancreas transplant.

Logistic regression models were fitted to examine the relationship between patient characteristics (age group, ethnicity, sex, primary kidney disease, socioeconomic status) and transplant listing (or pre-emptive transplant) within two years of starting KRT. The proportion of all incident KRT patients listed for transplantation within two years of starting KRT were calculated for each kidney centre, with adjustment for the above patient characteristics.

The risk-adjusted % listed at 2 years from KRT start estimates were obtained through indirect standardisation. The same logistic regression model described above was used to determine the probability of being listed for each patient based on their individual patient characteristics values. The sum of these probabilities for all patients at a centre is denoted E, and represents the expected number of patients listed within 2 years after starting KRT at that centre. The number of patients who were actually listed at 2 years after the start of KRT at the centre is given by O. The risk-adjusted estimate is then calculated by multiplying the ratio O/E by the overall unadjusted % listed at 2 years across all kidney centres in the UK.

The odds ratio from the logistic regression model was used to assess the impact of age, sex, ethnicity, PRD, and socioeconomic status on the odds of the patients being listed within two years after KRT start. The odds of patients who were treated at non-transplant centres being listed within 2 years after KRT start was compared to those treated at transplant centres, adjusted by age, sex, ethnicity, primary kidney disease and socioeconomic status. The distinction between transplant and non-transplant centres is not factored into the primary model. We intentionally refrain from adjusting for this factor from the primary model because we aim to highlight any disparities in outcomes between the types of centres. By not adjusting for centre type, we can effectively demonstrate the differences in listing rates. Centre type is not intended to serve as an explanatory factor for the observed variation.

Funnel plots were used to present results for the proportion of patients being listed within two years after KRT, providing a visual comparison of the relative performance of kidney centres, based on the results of the logistic regression models described above.

Waiting time from starting KRT to listing at each kidney centre was estimated by Kaplan Meier (KM) analysis, censored at death or on 28 February 2022, whichever was earlier. We have chosen to report time to listing for one-third of patients, as well as the traditional at 50% median time to listing, because for many centres the KM estimate did not reach 50% (i.e. after 2 years of starting KRT, less than 50% of population was listed). This was not presented in the previous UKRR annual report because we only reported patients up to 65 years old, while in this report we extended the cohort to include 65 to 75 year old patients. This is because the KRT population has been getting older over time. It will be more relevant to include the older population, despite an expectation that older KRT patients might plausibly be less likely to be listed within 2 years. In centres where the KM curve did not reach 50% (and therefore median time could not be calculated), the final event time point was reported.

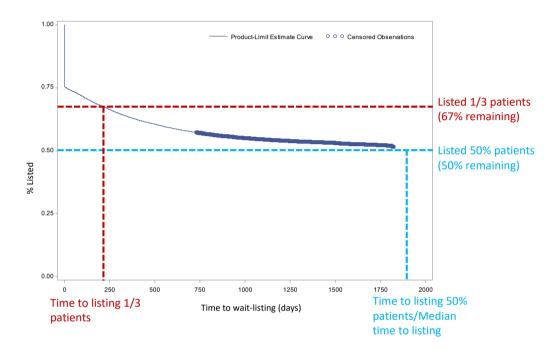


Figure A1 Kaplan Meier plot of overall time to listing within 2 years of KRT start

A2 Access to listing by transplant vs non-transplant centre – excluding preemptive transplant patients

A subgroup sensitivity analysis was performed on the dialysis patients (N=15,913) by excluding patients who had a pre-emptive transplant, using the same logistic regression model adjusting for age, sex, ethnicity, socioeconomic status, and primary kidney disease (diabetic nephropathy). Below, figure A2a shows that the centre listing rate ranged from 15% to 50% in non-transplant centres (23% to 54% including pre-emptive transplant, figure 9), compared to a higher listing rate of 25% to 56% in transplant centres (34% to 64% including pre-emptive transplant, figure 9).

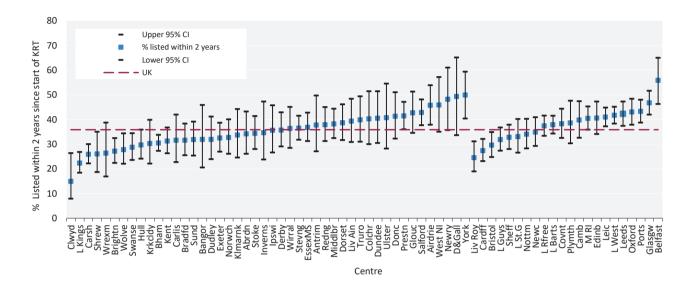


Figure A2a Centre listing rate within 2 years of KRT start excluding pre-emptive transplants, adjusted for age, sex, ethnicity, socioeconomic status, primary kidney disease, by transplant and non-transplant centre

Using the same logistic regression model, in addition to adjustment for patient characteristics, there is a 30% higher odds (figure A2b) of being listed within 2 years if patients were having treatment in a transplant compared to a non-transplant centre (compared to 50% higher odds of being listed within 2 years including preemptive transplant patients, figure 10).

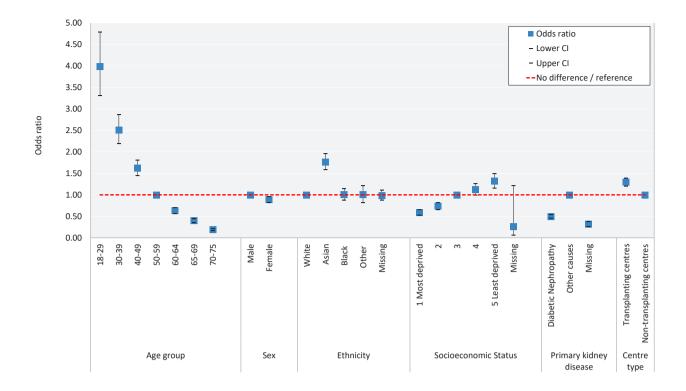


Figure A2b Odds ratio of listing within 2 years of KRT start, excluding pre-emptive transplants by centre type, in addition to adjusting for age group, sex, ethnicity, socioeconomic status, and primary kidney disease

By excluding patients with a pre-emptive transplant, the effect size of the transplant vs non-transplant centre has been reduced (50% vs 30% higher odds of being listed within 2 years of KRT start in a transplant centre), which means that the method used to assign a treatment centre to a pre-emptive transplant partially explained why transplant centres have a higher access to listing rate than non-transplanting centres in general, but having easier access to transplant specialists in transplant centres could still play an important role in a high listing rate.

A3 Trend in kidney listing and sex disparities

We have investigated the trend in the proportion of female patients listed for kidney transplantation within two years of KRT start from 2008 to 2019. There is no obvious increasing or decreasing trend.

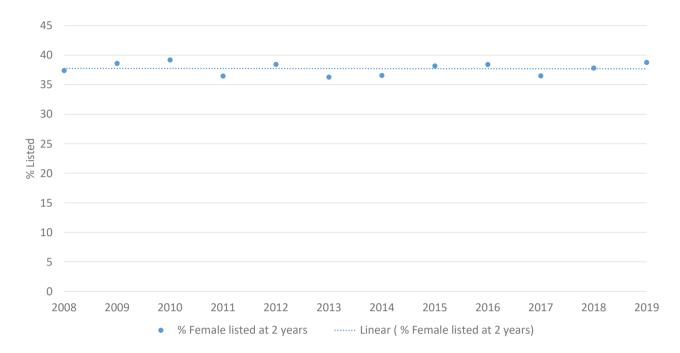


Figure A3 Trend in % female sex listed for kidney transplantation 2 years after KRT start (unadjusted)

In addition, the interaction of sex and year of starting KRT on the odds of listing was modelled through logistic regression, adjusted for age group, ethnicity, socioeconomic status, and primary kidney disease (diabetic nephropathy). The interaction was not statistically significant, i.e. the combination of sex and the year of starting KRT did not have a significant impact on the likelihood of being listed.

A4 Links to relevant NHSBT documents

Table A4 Links to relevant documents for reports from NHSBT regarding kidney transplantation, offering, selection and allocation policies

Document name	Link to website for the document:
Kidney transplantation annual report	https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/
Kidney offering scheme from ODT website	https://www.odt.nhs.uk/odt-structures-and-standards/odt-hub-programme/kidney-offering-scheme/
Kidney Selection Policy - POL184	https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/18170/pol184.pdf
Kidney Allocation Policy - POL186 (PDF 764KB)	https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/26155/pol18612-kidney-allocation-policy.pdf

Abbreviations

ATTOM Access to Transplantation and Transplant Outcome

CI Confidence Interval

CKD Chronic Kidney Disease

COVID-19 Coronavirus disease

DBD Donation after brain death

DCD Donation after circulatory death

IMD Index of Multiple Deprivation

KM Kaplan Meier

KRT Kidney Replacement Therapy

LKD Living kidney donor

N Number

NHSBT NHS Blood and Transplant

ODT Organ Donation and Transplantation

ONS Office for National Statistics

UKKA UK Kidney Association

UKRDC UK Renal Data Collaboration

UKRR UK Renal Registry

UKTR UK Transplant Registry

Abbreviations 27

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