# NHS BLOOD AND TRANSPLANT ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

#### KIDNEY ADVISORY GROUP

### SUSPENDED RECIPIENTS DEEP DIVE

#### INTRODUCTION

1 The active kidney transplant waiting list has decreased from 6,036 in 2013 to 4,643 in 2022. Over this time period the number of recipients suspended on the kidney transplant list has increased from 2727 in 2013 to 3,440 in 2022 (**Figure 1**). This paper looks at the characteristics of suspended recipients.

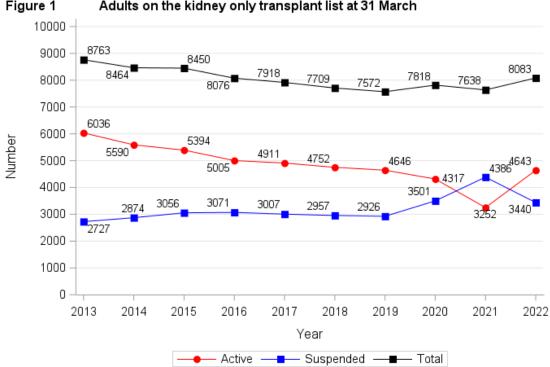


Figure 1 Adults on the kidney only transplant list at 31 March

2 As stated in POL186: Kidney Transplantation: Deceased Donor Organ Allocation, suspended time is taken into account for waiting time in the following way:

# Waiting times

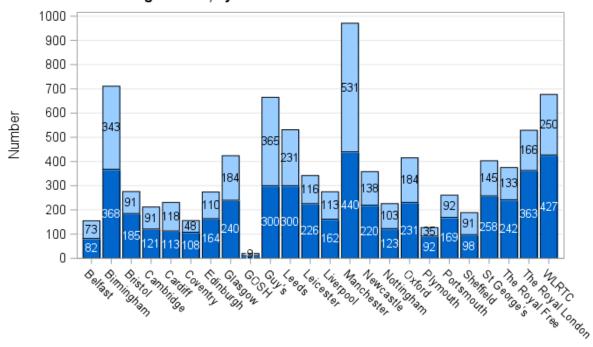
Number of days waiting time accrued.

Waiting time is determined from date of starting permanent dialysis (HD or PD) or date of first active listing for a graft, whichever is earliest. Each day accrues 1 point, including all days of suspension from the list.

#### **DATA**

- Data were obtained from the UK Transplant Registry on recipients on the UK kidney transplant list between 31 March 2013 and 31 August 2022.
- Figure 2 shows the number of recipients on the kidney only transplant list at 31 March 2022 by registration status and centre. 43% of all recipients were recorded as suspended at 31 March 2022 and this ranged from 28% in Plymouth to 55% in Guy's and Manchester.

Figure 2 Recipients on the suspended kidney only transplant list at 31 August 2022, by centre



Transplant centre

# **RESULTS**

Table 1 shows the number of recipients suspended at 31 August 2017 and 2022, who were suspended within their first 3 or 6 months of becoming active on the transplant list. This is based on recipients who are currently suspended and includes recipients who were activated in previous years, suspended within the first 3/6 months and are still suspended at the time of analysis. The data shows that the number of recipients suspended within the first 3 months has increased by 186. This equates to a 4% increase as a proportion of all suspended recipients. A breakdown of suspensions in the first 3 months is shown in Appendix Table 1. The number of recipients who were suspended prior to activation on the transplant list increased from 629 in 2017 to 711 in 2022.

Table 1 Point of suspension for recipie	nts on trans	plant list 31	August 2017	and 2022
	2017		202	
	N	%	N	%
Suspended Prior to activation	629	20	711	19
Suspended in first 3 months	423	12	609	16
Suspended in first 6 months	665	20	964	26
Total number of suspended recipients	3165		3760	

Table 2 shows the number of recipients who were suspended for more than 2 years (post activation) at 31 August 2017 and 2022. The number of recipients who were suspended for more than 2 years has increased by 322. In 2022, 35% of recipients suspended for more than 2 years were reported as not on dialysis. While it is likely that many of these recipients had started dialysis since registration, it gives an indication of the proportion who joined the list prior to starting dialysis and would potentially lose points if removed from the list. Pre-emptive listing rates between April 2020 and March 2021 were 45% for the UK overall. A breakdown of the data for long term suspensions by centre is shown in Appendix Table 2.

Table 2 Long term suspensions, post-activation 31 August 2017 and 2022							
	201	7	202	2			
	N	%	N	%			
Suspended for more than 2 years	583	18	903	24			
Suspended for more than 5 years	118	4	180	5			
Total number of suspended recipients	3165		3760				

Table 3 shows the reasons for suspension along with summary data on the length of suspension, for all recipients suspended at 31 August 2017 and 2022. The length of suspension is defined from the start date of suspension to 31 August in the respective years. The proportion observed for each reason has changed little over the 5 year period. The total numbers have increased but the median length of suspension has decreased from 301 days to 282 days.

Table 3 Reason give 2022	en for	recipi	ent suspen	sions as at 31 Auç	gust 201	7 and
2017						
Reason	N	%	Median	Length of Suspending-Range	sion Min	Max
Condition Improved Condition Deteriorated Medical Investigations Patient/Parent request Patient non-compliant Live transplant work up Patient temporarily unavailable Other Unknown	77 1000 401 125 34 55 99 111 1263	2 32 13 4 1 2 3 4 40	434 304 260 283 627 38 49 254 331	204-841 105-658 92-645 41-687 127-1100 17-114 13-357 80-861 119-799	6 0 1 0 24 1 0 0	3838 4077 3144 2131 2131 1148 2739 3816 5433
2022						
Reason	N	%	Median	Length of Suspending IQ-Range	sion Min	Max
Condition Improved	56	2	841	223.5- 1812.5	21	5398
Condition Deteriorated Medical Investigations Patient/Parent request Patient non-compliant Live transplant work up Patient temporarily unavailable Other Unknown	1152 412 170 25 90 73 251 1531	31 11 5 1 2 2 7 41	207 314 420 1203 59 79 329 383	65-542 113.5-908.5 97-968 287-1630 33-201 20-745 71-880 92-841	0 0 0 23 0 0 5	5903 4520 3291 3122 2240 4565 3730 6319
Total	3760		282	75.5-832	0	6319

Table 4 shows the demographics of recipients suspended on the kidney only transplant list at 31 August 2017 and 2022. The proportion of patients suspended by age group are similar across age groups.

Table 4				recipients su August 2017 a		
		2017		20	022	
Factor		N	%	N	%	
Age	0-17	34	1	61	2	0.25
J	18-34	294	9	373	10	
	35-49	770	24	889	24	
	50-59	919	29	1035	28	
	60-69	820	26	1003	27	
	70+	328	10	399	11	
Sex	Male	1934	61	2203	59	0.01
	Female	1234	39	1551	41	
	Unknown			6	0	
Ethnicity	White	2212	69	2498	66	0.02
	Asian	491	16	628	17	
	Black	325	10	436	12	
	Other	99	3	140	4	
	Unknown	38	1	58	1	
Risk Group*	R1	630	23	901	29	
	R2	745	27	860	27	
	R3	844	30	799	25	
	R4	576	21	599	19	
	Missing	370		601		

<sup>\*</sup>Risk groups are based on the last calculated value and are missing where the recipient has not been active

Table 5 shows the number of recipients who were suspended in the first wave of the pandemic by centre as well as their outcome.

	Outcomes of recipients suspended from the transplant list between March 2020 and June 2020, as at 19 September 2022						
Transplant Centre	Total active Feb 2020	N suspended Mar-Jun 2020	% Suspended	N Not Reactivated	% Not Reactivated	P-value	
Belfast	79	8	(10)	0	(0)	<0.001	
Birmingham	353	345	(98)	12	(3)		
Bristol	151	141	(93)	3	(2)		
Cambridge	164	84	(51)	1	(1)		
Cardiff	147	146	(99)	13	(9)		
Coventry	109	107	(98)	1	(1)		
Edinburgh	161	159	(99)	10	(6)		
Glasgow	254	167	(66)	9	(5)		
Leeds	285	152	(53)	4	(3)		
Leicester	174	165	(95)	4	(2)		
Liverpool	141	135	(96)	3	(2)		
London, Great			` '		, ,		
<b>Ormond Street</b>	17	16	(94)	0	(0)		
London, Guy's	237	231	(97)	35	(15)		
London, St George's	230	223	(97)	20	(9)		
London, The Royal Free London, The	234	221	(94)	11	(5)		
Royal London	318	310	(97)	21	(7)		
London, WLRT		354	(93)	14	(4)		
Manchester	416	400	(96)	9	(2)		
Newcastle	206	197	(96)	7	(4)		
Nottingham	127	124	(98)	5	(4)		
Oxford	189	122	(65)	2	(2)		
Plymouth	96	89	(93)	0	(0)		
Portsmouth	143	139	(97)	11	(8)		
Sheffield	112	107	(96)	4	(4)		

### **SUMMARY**

The suspended transplant list has increased by 26% over the last 10 years. The reasons for this are unclear. More recipients are now being suspended soon after first activation. In addition, more recipients are being suspended for longer periods of time and it is likely that a combination of these factors contributes to the higher number of suspended recipients.

#### RECOMMENDATIONS

- 1. Should POL186 change from "each day accrues 1 point, including all days of suspension" to "each day accrues 1 point to a maximum of 30 days of suspension from the list" to remove perverse incentives for inappropriate listing followed by immediate or prolonged periods of suspension?
- 2. Should we remove the option of suspension immediately after activation?
- 3. Should patients suspended for >2yrs (or 5 years or any fixed time point) be routinely de-listed with no restriction to re-join when deemed medically fit? Patients on dialysis would still earn time credit from date they started dialysis if/when re-activated
- 4. Should we remove the option of centres reporting 'Unknown' reason for suspension?
- 5. Should patients with wave one pandemic suspensions followed by noreactivation to date have urgent review to decide on reactivation/continued suspension/removal from the list?
- 6. Should there be centre specific performance metrics associated with suspended patients list maintenance?

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September 2022

# **APPENDIX TABLE 1 – Early suspensions by centre**

Centre	Total list size (Act + Susp)	Suspended in first 3 months	%
Belfast	155	23	15
Birmingham	711	48	7
Bristol	276	23	8
Cambridge	212	30	14
Cardiff	231	26	11
Coventry	156	2	1
Edinburgh	274	22	8
Glasgow	424	60	14
Leeds	531	28	5
Leicester	342	26	8
Liverpool	275	18	7
London, Guy's	665	53	8
London, St George's	403	25	6
London, The Royal Free	375	23	6
London, The Royal London	529	21	4
London, WLRTC	677	37	5
Manchester	971	47	5
Newcastle	358	21	6
Nottingham	226	15	7
Oxford	415	28	7
Plymouth	127	6	5
Portsmouth	261	14	5
Sheffield	189	13	7
UK	8783	609	7

# APPENDIX TABLE 2 – Long term suspensions by centre

	Total list size				
	(Act +	Suspended		Suspended	
Centre	Susp)	2 years	%	5 years	%
Belfast	155	6	4	0	0
Birmingham	711	53	7	10	1
Bristol	276	31	11	6	2
Cambridge	212	19	9	6	3
Cardiff	231	40	17	8	3
Coventry	156	11	7	2	1
Edinburgh	274	29	11	2	1
Glasgow	424	53	13	16	4
Leeds	531	27	5	4	1
Leicester	342	22	6	2	1
Liverpool	275	26	9	9	3
London, Guy's	665	139	21	32	5
London, St George's	403	46	11	5	1
London, The Royal Free	375	45	12	9	2
London, The Royal	529	68	13	10	2
London					
London, WLRTC	677	60	9	14	2
Manchester	971	98	10	29	3
Newcastle	358	38	11	5	1
Nottingham	226	18	8	2	1
Oxford	415	26	6	2	0
Plymouth	127	4	3	1	1
Portsmouth	261	21	8	1	0
Sheffield	189	23	12	5	3
UK	8783	903	10	180	2