

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE  
REPORT OF THE NEONATAL KIDNEY OFFERING GROUP  
TO THE KIDNEY ADVISORY GROUP**

## **INTRODUCTION**

At its meeting in June 2016, the Kidney Advisory Group (“KAG”) of NHS Blood and Transplant agreed that:

1. It was reasonable to establish centres to transplant kidneys from small donors.

*‘The data suggest that the use of very small kidneys, including neonatal kidneys, is probably best centralized to a limited number of centres with defined protocols in order to gain the necessary expertise to achieve good outcomes.’ – KAG(M)(16)1(Am), minute 5.1.*

2. *‘A small short-life Sub-Group be established to consider the issues.’*

A Sub-Group was set up named “The Neonatal Kidney Offering Group” (“The Group”), with the following Members:

Mrs Kathleen Preston Chair - Lay Member Kidney Advisory Group  
Mr Jon Gulliver - NHS England (Specialist Commissioning) Representative  
Mrs Julia Mackisack - Lay Member, Kidney Advisory Group  
Ms Roseanne McDonald - NSD Scotland Representative  
Ms Lisa Mumford - Statistics & Clinical Studies, NHSBT  
Mr Keith Rigg - Consultant Surgeon, Nottingham University Hospitals NHS Trust

The Terms of Reference for the Group as set by KAG were to make **recommendations** with respect to the following questions:

- Is it reasonable to establish a small number of centres to transplant small donor kidneys?
- If so, how many centres should there be and where should they be?
- How should ‘small donors’ be defined, that is, what weight or age?

This is the Group’s Report to KAG.

## **SUMMARY OF RECOMMENDATIONS**

### **1. DEFINITION OF “SMALL” KIDNEYS**

For the purposes of this Report, we **recommend** that “small” kidneys are defined as kidneys from a donor aged 1 year and 364 days or less. (This consequently includes kidneys from donors aged 28 days and less.) The other **recommendations** in this Report accordingly refer to donated kidneys from such donors.

## 2. TRANSPLANTING TEAMS

2.1 Given the very low numbers of “small” kidneys currently transplanted, we consider that this is not an area which is suitable for “occasional practice”. Surgeons and other members of the Teams transplanting “small” kidneys require the appropriate skills and experience for this specialised area of practice. The development of those skills and experience to maximise use of these organs, balanced with achieving good outcomes for recipients, requires that transplantation of these kidneys is concentrated in a very small number of centres. We accordingly **recommend** that transplantation of these “small” kidneys is initially carried out at only two transplant centres in the UK. For reasons explained in the Report, we **recommend** that these centres are at St James’s University Hospital Leeds, the centre currently with the most experience and expertise in this area of transplantation, and Guy’s and St Thomas’ NHS Foundation Trust, London (whose transplant surgeons also cover Great Ormond Street Hospital) a centre with very close links with two large neonatal units, ELCH and Great Ormond Street Hospital.

## 3. RETRIEVAL

3.1 There is a need for NORS teams retrieving “small” kidneys to have the appropriate specialist skills and experience required. We accordingly **recommend** that NHSBT agrees the number of NORS teams that should retrieve these organs, and, in conjunction with the lead transplanting centres, the training, skills and experience required by them.

3.2 We also **recommend** that a surgeon from the transplanting team is always involved in the retrieval (whether physically present, or available for consultation).

## 4 OFFERING OF “SMALL” ORGANS

We **recommend** that the Offering sequence for these “small” organs is set out clearly, and is consistently adhered to by all involved.

## 5 RECIPIENTS

5.1 We **recommend** that further work is done to agree the criteria for selecting suitable potential recipients of these “small” kidneys.

5.2 We **suggest** that the selected centres may wish to consider working with other local centres to widen their recipient “pool” to maximise the potential use of these organs.

## 6 DEVELOPMENT OF THE SERVICE

6.1 We **recommend** that the selected centres develop and demonstrate Leadership and commitment to this area of transplantation.

6.2 We **recommend** that the selected centres develop a shared programme of Learning and Training in this area of practice to ensure there at least two

surgeons in each centre who are competent to undertake transplantation of all “small” kidneys. This Programme should include joint working with the designated NORS teams. This Programme could also, over time, with appropriate planning, be shared with other transplant centres.

6.3 We **recommend** that over time the selected centres establish good and consistent communications with neo-natal units, and agree relevant guidelines.

6.4 In particular, we **recommend** that guidelines are developed for SNODs and CLODs in donating centres with neonatal units to ensure good consistent communication and support in this developing area of practice.

6.5 We **recommend** that an Evidence Base is developed to follow up the Outcomes from the selected centres to inform the further development of the Service.

## 7 REVIEW

The aim should be to retain flexibility to expand the number of Transplant Centres transplanting these “small” organs over time as the number of these organs made available for donation increases.

7.1 We therefore **recommend** that there is a review of the development of the service and outcomes 12 months after the **recommendations** in this Report are implemented.

7.2 We **suggest** that to coincide with the 12 month review the lead centres should present audit data to KAG covering the details and outcomes of cases undertaken, lessons learned and proposals for future development.

## AIMS, OBJECTIVES AND METHODOLOGY

The Group agreed that the overarching aim of its work and Report should be to facilitate the maximum use of kidneys donated by “small” donors for the benefit of patients waiting for a kidney transplant. To further this aim, the Group considered:

- How should the weights of donors be categorised?
- Should weights or age be categorised?
- Should all kidney transplant centres be allowed to carry out these transplants, and if not, which centres/how many centres should be carrying out these transplants?

In considering these questions, the Group:

- (i) studied relevant Data, as tabled in the Annex to this Report, including Centre transplant activity by donor weight and age, and the waiting list size of centres;
- (ii) considered the Skills, Experience and Training required to transplant “small” kidneys;
- (iii) had meetings with Mr Niaz Ahmad, Consultant Transplant Surgeon at St James’s University Hospital, Leeds and his Team, and Mr Chris Callaghan, Consultant Transplant Surgeon, Guy’s and St Thomas’ NHS

Foundation Trust, London and his Team, and a telephone discussion with Mr Argiris Asderakis, Consultant Transplant Surgeon, University Hospital of Wales, Cardiff, to gather information on their experience in carrying out these transplants to date, and the issues which have arisen. (The Group decided that a visit to St James's University Hospital, Leeds, was clearly required as the Transplant Unit there has done by far the most transplants of "small" kidneys to date. The decision to contact Guy's and St Thomas' NHS Foundation Trust and University Hospital of Wales was taken because the data shows that, after Leeds, those centres have the most experience of transplanting "small" kidneys).

- (iv) had discussions with NHSBT staff;
- (v) considered the Articles Optimizing the Recovery, Utilization and Transplantation Outcomes for Kidneys from Small Pediatric Donors by Maluf et al American Journal of Transplantation 2013<sup>1</sup>, and (ii) Dave R et al Transplantation 2015<sup>2</sup>, and also
- (vi) discussed the issues at 3 "face to face" meetings and one tele-conference.

We hope that this Report and its **recommendations** will provide a sound basis to achieve the aim of enabling the maximum use of these small organs for the benefit of those waiting for a kidney transplant.

## CONCLUSIONS AND RECOMMENDATIONS

The Group identified a number of key Issues to be addressed, as follows:

### DEFINITION OF "SMALL" KIDNEYS

The first and fundamental issue is "What is a small kidney for the purposes of this Report?"

The available data breaks donors into categories based on age and/or weight. [See Tables 1 and 2]. We were advised that the centre at St James's University Hospital, Leeds, considers a "small" donor to be a donor under 2 years of age, and this categorisation seems to have worked well in practice. From our discussions, we also think that categorisation of the donor by age is likely to be more consistent and more practicable than categorisation by weight. In practice the average weight (50<sup>th</sup> centile) for a two year old is around 12kg based on the Early Years UK WHO charts.

Accordingly, we consider that the evidence and data support categorization of a "small" donor as being a donor aged 1 year, 364 days or less, which we accordingly consider to be the most robust basis for the definition.

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<sup>1</sup> D. G. Maluf, R. J. Carrico, J. D. Rosendale, R. V. Perez and S. Feng. Optimizing Recovery, Utilization and Transplantation Outcomes for Kidneys From Small, 20 kg, Pediatric Donors. American Journal of Transplantation 2013; 13: 2703–2712

<sup>2</sup> Rajiv V. Dave, Abdul R. Hakeem, Michael J. Dawrant, Clare L. Ecuier, Andrew J.P. Lewington, Magdy S. Attia, Lutz Hostert, Eric Finlay, and Niaz Ahmad. Renal Transplantation From Pediatric Donors in the United Kingdom. Transplantation 2015; 99: 1968–1975

**Recommendation:** For the purposes of this Report, we **recommend** that “small” kidneys are defined as kidneys from a donor aged 1 year and 364 days or less. (This consequently includes kidneys from donors aged 28 days and less.) The other **recommendations** in this Report accordingly refer to donated kidneys from such donors.

## TRANSPLANTING TEAMS

The Group has considered:

- (i) How many centres should be selected to carry out transplants of these “small” kidneys and
- (ii) The most relevant Criteria for selecting which those Centres should be.

Table 1 shows that only 58 kidney transplants from all donors aged less than 5 years were carried out in the UK between 1 April 2011 and 31 March 2017. Table 2 shows that only 36 kidney transplants were carried out in the UK from donors aged under 2 years of age during that period. Of those, only 9 were from neonatal (under 28 days old) donors.

Given the very low numbers of “small” kidneys currently transplanted, we consider that this is not an area which is suitable for “occasional practice”. Surgeons and other members of the Teams transplanting “small” kidneys require the appropriate skills and experience for this specialised area of practice. The development of those skills and experience to maximise use of these organs, balanced with achieving good outcomes for recipients, requires that transplantation of these kidneys is concentrated in a very small number of centres to maximise the development of the expertise required within those centres. We consider that, given the very low current numbers of these transplants, the optimum number of selected centres is 2.

We consider that the most relevant criteria which centres require to demonstrate are:

Previous experience of transplanting kidneys from donors aged less than 2 years;  
 Team-based surgical expertise in transplanting *en bloc* kidneys;  
 Team-based surgical expertise in paediatric transplantation;  
 Expertise in working with paediatric donors;  
 A sufficient waiting list and pool of suitable recipients;  
 Necessary supporting infrastructure-surgeons, theatres, other clinical and support staff;

Based on the Data and other information available to the Group, we consider that the 2 centres which currently best meet these Criteria are St James’s University Hospital Leeds, and Guy’s and St Thomas’ NHS Foundation Trust Hospital (whose transplant surgeons also cover Great Ormond Street Hospital), London.

The Data demonstrated that, in comparison with every other centre, St James’s University Hospital Leeds has carried out by far the most *en bloc* kidney transplants from donors under 2 years of age in the period from 1 April 2011 to 31 March 2017 and is clearly the Centre which has the most experience and expertise in these

transplants. It is the only centre which has transplanted kidneys from donors under 28 days of age.

The Transplant Unit at Guy's and St Thomas' NHS Foundation Trust, with transplant surgeons also covering Great Ormond Street Hospital, and which has very close links with two paediatric units (GOSH and ELCH) in our opinion, after the Leeds unit, best meets the Criteria detailed above. We recognise, however, that this centre has not carried out transplants from children under 1 year and so will have to liaise with Leeds to acquire the skills to do so.

Our **recommendation** on the location of the centres also takes account of their geographical location as regards the whole of the UK population, which will help to optimise cold ischemia times.

It is important to note that the Offering and Allocation of kidneys from donors aged 2 to 5 years will remain as at present.

**Recommendation:** We accordingly **recommend** that transplantation of these "small" kidneys is initially carried out at only two transplant centres in the UK. For reasons explained in the Report, we **recommend** that these centres are at St James's University Hospital Leeds, the centre currently with the most experience and expertise in this area of transplantation, and Guy's and St Thomas' NHS Foundation Trust, London (whose transplant surgeons also cover Great Ormond Street Hospital) a centre with very close links with two large neonatal units, ELCH and Great Ormond Street Hospital.

## RETRIEVAL

Although the issue of retrieval is not specifically included in the Group's Terms of Reference, we heard about distressing (in one case very recent) cases in which kidneys donated from small children could not be transplanted because of damage at retrieval, resulting in the loss of these kidneys for a recipient, and even more distress for the bereaved families. We were told that specialised skills are needed to retrieve kidneys from very small children, as they cannot be treated simply as small adults. There are also difficult emotional issues involved for the Retrieval Team and donor hospital. There is a need for NORS teams retrieving "small" kidneys to have the appropriate special training, skills and experience required. We also heard that, because of the particular challenges of these retrievals, a surgeon from the transplanting team should be present, or available for consultation, throughout the retrieval.

**Recommendations:** We accordingly **recommend** that NHSBT agrees the number of NORS teams that should retrieve these organs, and, in conjunction with the lead transplanting centres, the training, skills and experience required by them.

We also **recommend** that a surgeon from the transplanting team is always involved in the retrieval (whether physically present, or available for consultation).

## OFFERING OF “SMALL” ORGANS

During our investigations, various people involved in the Transplant Pathway gave us differing accounts of their experience of how the offering system and sequence works in practice for different categories of donors under 5 years of age. This is clearly an unsatisfactory situation, as the offering sequence and system should be consistent and clearly understood.

**Recommendation:** We **recommend** that the offering sequence for these “small” organs is set out clearly, and is consistently adhered to by all involved.

## RECIPIENTS

We heard during our investigations that there is a relatively small number of patients awaiting kidney transplantation at any one time who are considered to be suitable to receive these “small” kidneys and that it takes extra time, investigation and discussion to select and consent them. This means that a centre needs to have a sufficiently large waiting list to provide suitable potential recipients. We heard of cases of kidneys from infant donors not being transplanted as the centre which had accepted them some time later said it had “no suitable recipients”. We heard differing views as to whether it was desirable or practicable for centres to develop a system for them to create a “pool” of suitable potential recipients with other transplant centres, but we consider that this is an idea worth exploring. We also heard different views as to what the criteria for selection should be.

### Recommendation and Suggestion

We accordingly **recommend** that further work is done to agree the criteria for selecting suitable potential recipients of these “small” kidneys.

We **suggest** that the selected centres may wish to consider working with other centres to widen their recipient “pool” to maximise the potential use of these organs.

## DEVELOPMENT OF THE SERVICE

We consider that it is essential that the centres which are initially selected to carry out transplants of these organs provide the leadership and commitment required to develop this area of transplantation.

We recognise that despite the low numbers of these “small” donors it is important that the transplanting centre is not reliant on a single surgeon for transplantation. We would like to see the selected centres develop a Programme of Training and Learning, which can be spread within these centres, and which could also, over time, with appropriate planning, be shared with other transplant centres. We also consider that it is essential that they develop good and consistent communications with each other and with neo-natal units, as we heard that this is a very important factor in maximising the success of transplants.

**Recommendations:**

We **recommend** that the selected centres develop and demonstrate Leadership and commitment to this area of transplantation.

We **recommend** that the selected centres develop a shared Programme of Learning and Training in this area of practice to ensure there are at least two surgeons in each centre who are competent to undertake transplantation of all “small” kidneys. This programme should include joint working with the designated NORS teams. This programme could also, over time, with appropriate planning, be shared with other transplant centres.

We **recommend** that over time the selected centres establish good and consistent communications with neo-natal units, and agree relevant guidelines.

In particular, we **recommend** that guidelines are developed for SNODs and CLODs in donating centres with neonatal units to ensure good consistent communication and support in this developing area of practice.

We **recommend** that an Evidence Base is developed to follow up the outcomes from the selected centres to inform the further development of the Service.

**REVIEW**

The aim should be to retain flexibility to expand the number of Transplant Centres transplanting these “small” organs over time as the evidence of favorable outcomes accrues and the number of these organs made available for donation increases. The Group recognises that the **recommendations** in this Report are not a final or fixed solution, and accordingly considers that the position should be reviewed after 12 months of implementation. This is a relatively recent and developing area of transplant practice, with specific complexities and sensitivities. We see the ultimate aim being the spread of skills to carry out these transplants to more Transplant Centres across the UK, and to be an international exemplar of good practice and research in this area of transplantation.

As the Offering and Allocation of kidneys from donors aged 2 to 5 years will remain as at present, there are opportunities for other centres to develop their skills and expertise in transplanting organs from these smaller children.

**Recommendation and Suggestion:**

We **recommend** that there is a review of the development of the service and outcomes 12 months after the **recommendations** in this Report are implemented.

We **suggest** that to coincide with the 12 month review the lead centres should present audit data to KAG covering the details and outcomes of cases undertaken, lessons learned and proposals for future development.



## ANNEX

Neonatal kidneys

**Cohort:** All kidney only transplants performed in the UK from UK donors aged less than 5, between 1 April 2011 – 31 March 2017. (Over last 6 financial years, N=58)

Table 1: Transplant type by centre

Transplant centre	Transplant type		TOTAL
	Kidney	En-bloc kidney	
Cambridge	0	1	1
Cardiff	0	5	5
Edinburgh	0	3	3
GOSH*	0	3	3
Guy's*	0	4	4
Glasgow	0	2	2
Leeds	0	24	24
Leicester	0	1	1
Liverpool <sup>1</sup>	1	2	3
Manchester	0	1	1
Oxford <sup>1</sup>	5	0	5
Portsmouth	0	3	3
The Royal Free	0	1	1
The Royal London	0	2	2
<b>Total</b>	<b>6</b>	<b>52</b>	<b>58</b>

\*Guy's transplant team routinely carry out transplants at GOSH

<sup>1</sup> additional one kidney transplanted as SPK

Table 2: Transplant centre by donor age and weight

Transplant centre	Number of neonatal donors (≤28 days)	Donor weight of non-neonatal donors (kg) (28 days < donor age < 5 yrs)												Total
		<10	10- <11	11- <12	12- <13	13- <14	14- <15	15- <16	16- <17	17- <18	18- <19	19- <20	20+	
Cambridge	0	0	0	0	0	0	0	0	0	0	0	0	1	1
Cardiff	0	3	0	0	1	0	1	0	0	0	0	0	0	5
Edinburgh	0	1	1	0	0	0	0	1	0	0	0	0	0	3
GOSH*	0	1	0	0	0	1	1	0	0	0	0	0	0	3
Guy's*	0	0	0	0	2	1	0	0	0	0	0	0	1	4
Glasgow	0	0	0	1	0	0	0	0	0	0	0	0	1	2
Leeds	9	10	0	0	2	0	0	0	1	2	0	0	0	24
Leicester	0	0	0	1	0	0	0	0	0	0	0	0	0	1
Liverpool	0	0	0	0	1	1	0	0	1	0	0	0	0	3
Manchester	0	0	0	1	0	0	0	0	0	0	0	0	0	1
Oxford	0	0	0	0	1	0	0	0	4	0	0	0	0	5
Portsmouth	0	1	0	0	1	1	0	0	0	0	0	0	0	3
The Royal Free	0	0	0	1	0	0	0	0	0	0	0	0	0	1
The Royal London	0	1	0	0	1	0	0	0	0	0	0	0	0	2
<b>Total</b>	<b>9</b>	<b>17</b>	<b>1</b>	<b>4</b>	<b>9</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>6</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>3</b>	<b>58</b>

\* Guy's transplant team routinely carry out transplants at GOSH

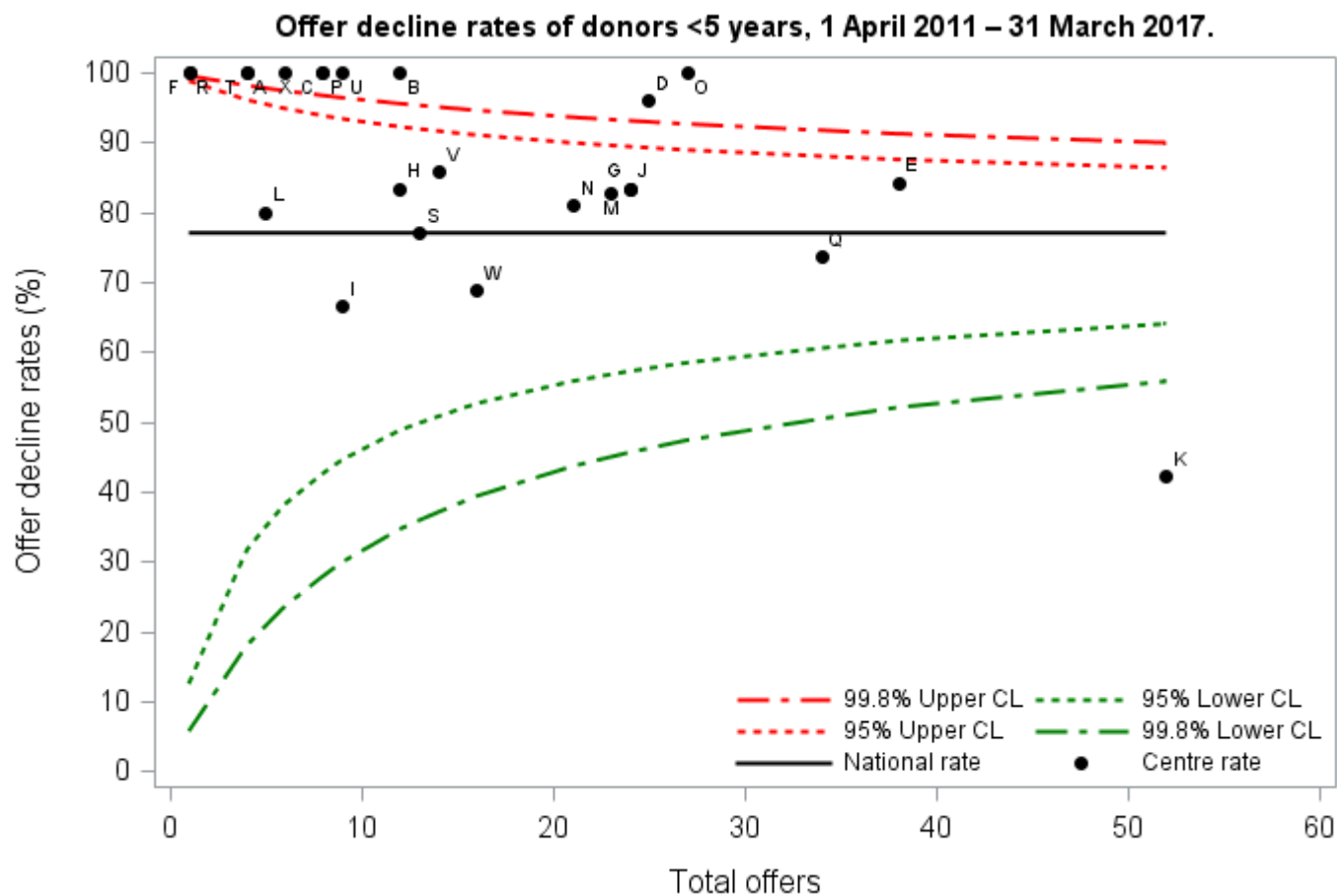
Transplant centre	Number of neonatal donors (≤28 days)	Donor age					Total
		28 days – 1 yr	1yr - <2yrs	2 yrs - <3yrs	3 yrs - <4yrs	4 yrs - <5yrs	
Cambridge	0	0	0	0	0	1	1
Cardiff	0	3	1	0	1	0	5
Edinburgh	0	1	1	1	0	0	3
GOSH*	0	0	2	0	2	1	3
Guy's*	0	0	1	1	0	2	4
Glasgow	0	0	0	1	1	0	2
Leeds	9	10	1	1	0	3	24
Leicester	0	0	1	0	0	0	1
Liverpool	0	0	1	0	0	2	3
Manchester	0	0	0	1	0	0	1
Oxford	0	0	1	0	2	2	5
Portsmouth	0	0	2	1	0	0	3
The Royal Free	0	0	1	0	0	0	1
The Royal London	0	0	1	1	0	0	2
<b>Total</b>	<b>9</b>	<b>14</b>	<b>13</b>	<b>7</b>	<b>5</b>	<b>10</b>	<b>58</b>

\* Guy's transplant team routinely carry out transplants at GOSH

Table 3: Current kidney only waiting list size by centre, as at 01/05/2017.

<b>Transplant centre</b>	<b>Number currently active on the kidney only waiting list</b>	<b>%</b>
Belfast	119	2.4
Birmingham	393	7.9
Bristol	224	4.5
Cambridge	194	3.9
Cardiff	122	2.5
Coventry	79	1.6
Edinburgh	143	2.9
GOSH	14	0.3
Guy's	292	5.9
Glasgow	274	5.5
Leeds	213	4.3
Leicester	146	2.9
Liverpool	163	3.3
Manchester	375	7.5
Newcastle	233	4.7
Nottingham	138	2.8
Oxford	218	4.4
Plymouth	87	1.8
Portsmouth	187	3.8
Sheffield	150	3.0
St George's	272	5.5
The Royal Free	235	4.7
The Royal London	292	5.9
WLRTC	418	8.4
UK	4981	100

Table 4: Kidney offer decline rates of donors &lt;5 years by transplant centre, 1 April 2011 – 31 March 2017.



Centre	Code	Kidney offers declined	
		N	% of all offers from donors <5
Belfast	A	4	100
Birmingham	B	12	100
Bristol	C	8	100
Cambridge	D	25	96
Cardiff	E	38	84
Coventry	F	1	100
Edinburgh	G	24	83
GOSH	I	9	83
Guys	J	24	83
Glasgow	H	12	67
Leeds	K	52	42
Leicester	L	5	80
Liverpool	M	23	83
Manchester	N	21	81
Newcastle	O	27	100
Nottingham	P	8	100
Oxford	Q	34	74
Plymouth	R	1	100
Portsmouth	S	13	77
Royal Free	V	14	86
Royal London	W	16	67
Sheffield	T	4	100
St Georges	U	9	100
WLRTC	X	6	100
UK	-	390	80

Transplant centre	Number of neonatal donor offers, % declined (≤28 days)		Donor age of non-neonatal donor offers, % declined									
			28 days – 1yr		1yr - <2yr		2yr - <3yr		3yr - <4yr		4yr - <5yr	
	N	%	N	%	N	%	N	%	N	%	N	%
Belfast	0		1	100	1	100	2	100	0		0	
Birmingham	2	100	1	100	2	100	4	100	1	100	2	100
Bristol	0		5	100	0		0		2	100	1	100
Cambridge	7	100	9	100	4	100	1	100	2	100	2	50
Cardiff	7	100	15	80	8	88	1	100	4	50	3	100
Coventry	0		0		0		0		0		1	100
Edinburgh	7	100	8	88	5	60	1	0	1	100	2	100
GOSH	0		2	100	2	0	1	100	1	0	3	100
Glasgow	3	100	3	100	3	100	1	0	2	50	0	
Guys	5	100	7	100	4	75	3	67	1	100	4	50
Leeds	20	45	20	30	5	80	1	0	3	100	3	0
Leicester	1	100	1	100	2	50	1	100	0		0	
Liverpool	4	100	9	89	3	67	2	100	3	100	2	0
Manchester	7	100	7	100	0		2	50	4	50	1	0
Newcastle	6	100	9	100	6	100	1	100	3	100	2	100
Nottingham	3	100	1	100	2	100	1	100	0		1	100
Oxford	7	100	11	100	6	67	0		7	29	3	33
Plymouth	0		1	100	0		0		0		0	
Portsmouth	0		5	100	5	60	1	0	1	100	1	100
Royal Free	3	100	3	100	3	67	2	100	1	100	1	100
Royal London	3	100	5	100	3	0	2	0	1	100	2	100
Sheffield	1	100	1	100	1	100	1	100	0		0	
St Georges	1	100	4	100	1	100	1	100	2	100	0	
WLRTC	0		3	100	2	100	0		0		1	100
Total	87	90	131	85	68	75	29	72	39	72	35	69

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Table 5

Distribution of CIT\_HRS

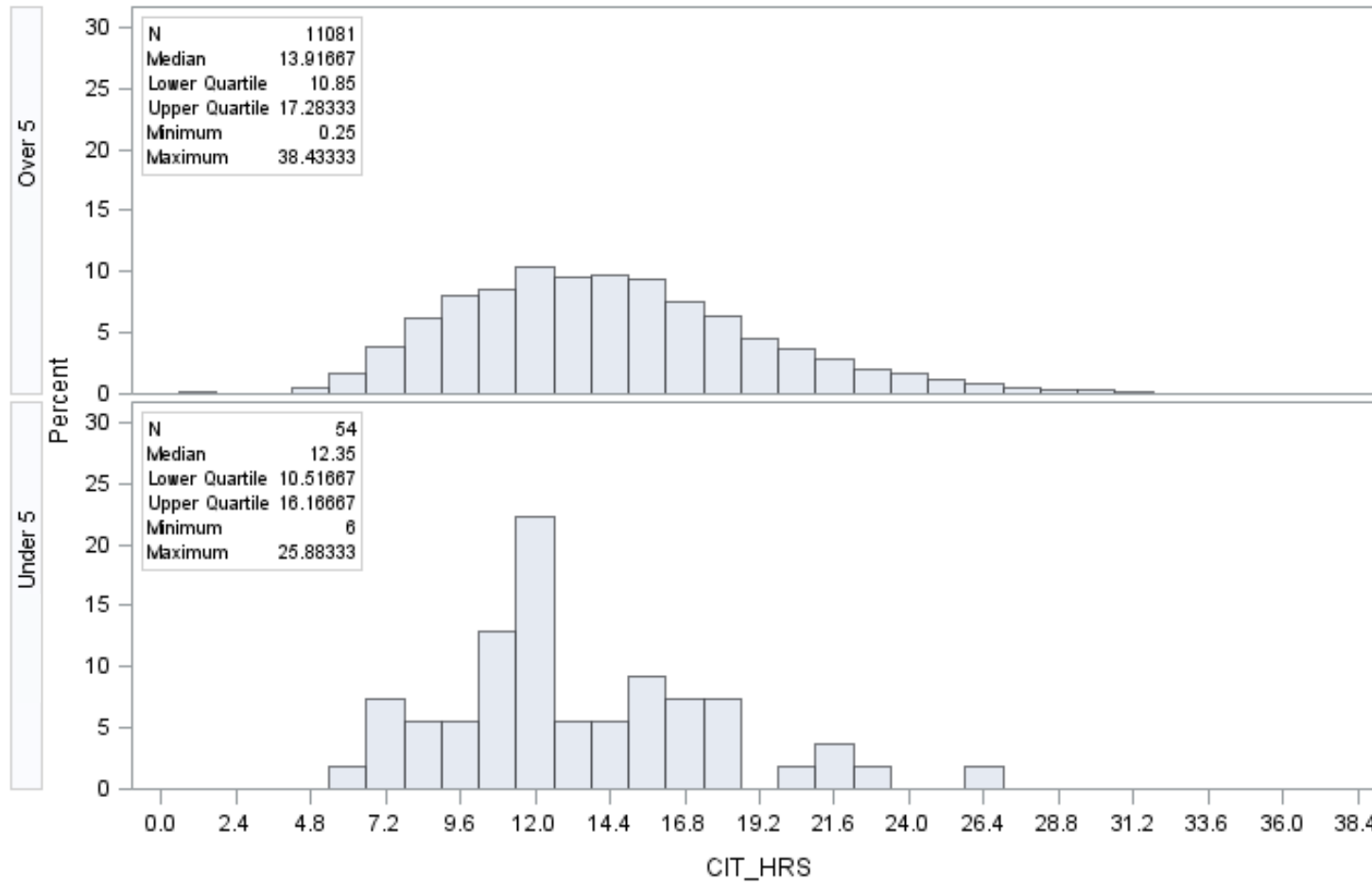


Table 6: 1 year graft and patient survival following deceased donor kidney only transplant from donors aged less than 5 years, 1 April 2011 – 31 March 2017

