ANNUAL REPORT ON DONATION AND TRANSPLANTATION IN PAEDIATRICS SUMMARY REPORT FOR THE 12 MONTH PERIOD 1 APRIL 2017 - 31 MARCH 2018

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2017 to 31 March 2018 and summaries of the following are provided:-

- POTENTIAL DONOR AUDIT
- TRANSPLANT LIST
- TRANSPLANT ACTIVITY

The dataset used to compile this report includes all audited paediatric deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 8 November 2018. Paediatric patients have been defined as all patients under 18 years of age. Neonatal patients who die in a neonatal unit have been excluded from the report and patients who die on a ward have not been audited.

This report summarises the main findings of the PDA over the 12-month period, in particular the reasons why patients were lost during the donation process.

Data on the paediatric transplant list and transplant activity have been obtained from the UKTR. Organ specific paediatric definitions are provided with the data.

2 DEFINITIONS

Eligible donors after brain death (DBD) are defined as patients for whom death was confirmed following neurological tests and who had no absolute medical contraindications to solid organ donation.

Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.

Absolute medical contraindications to organ donation are listed here: http://www.odt.nhs.uk/pdf/contraindications_to_organ_donation.pdf

Further definitions to aid interpretation are given in **Appendix 1**.

3 BREAKDOWN OF AUDITED DEATHS IN PICUs AND PAEDIATRIC CARIOTHORACIC ICUs

In the 12-month period from 1 April 2017 to 31 March 2018, there were a total of 1,204 audited patient deaths in paediatric ICUs in the UK. A detailed breakdown for both the DBD and DCD data collection flows is given in **Figure 1** and **2**, and **Table 1** summaries the key percentages.

Figure 1 Donation after brain death

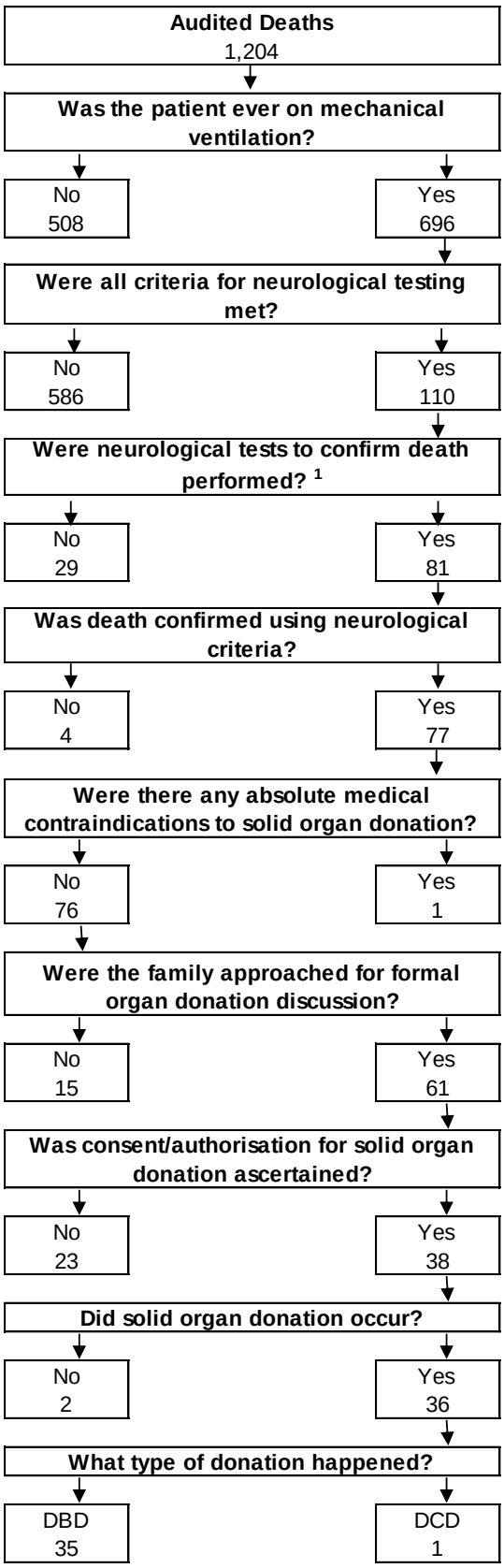
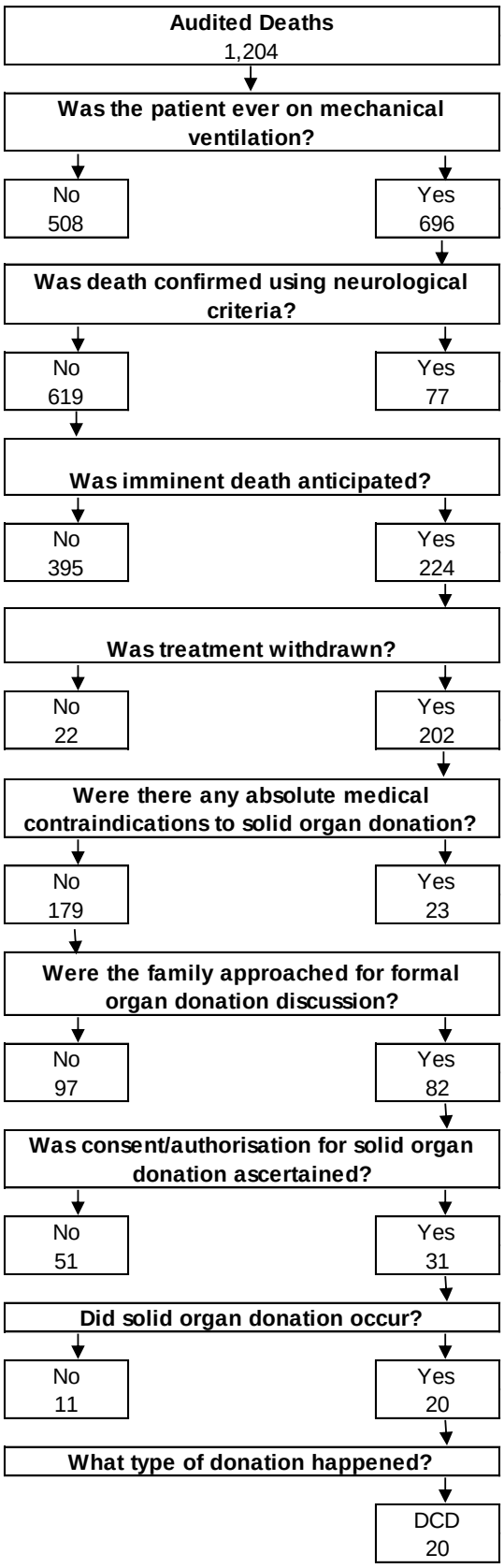


Figure 2 Donation after circulatory death



1 Patients for whom tests were not performed due to; cardiac arrest despite resuscitation occurred or brainstem reflexes returned, are excluded from the calculation of the neurological death testing rate

Table 1 Key numbers and rates

	DBD	DCD
Patients meeting organ donation referral criteria[1]	110	224
Referred to SN-OD	104	187
Referral rate %	*94.5%*	*83.5%*
Neurological death tested	81	-
Testing rate %	*73.6%*	-
Eligible donors[2]	76	179
Family approached	61	82
Family approached and SN-OD present	51	60
% of approaches where SN-OD present	*83.6%*	*73.2%*
Consent/authorisation given	38	31
Consent/authorisation rate %	*62.3%*	*37.8%*
Actual donors from each pathway	36	20
% of consented/authorised donors that became actual donors	*94.7%*	*64.5%*

[1] DBD - A patient with suspected neurological death excluding those that were not tested due to reasons: cardiac arrest occurred despite resuscitation or brainstem reflexes returned.
DCD - A patient in whom imminent death is anticipated, ie a patient receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within 4 hours

[2] DBD - Death confirmed by neurological tests and no absolute contraindications to solid organ donation
DCD - Imminent death anticipated and treatment withdrawn with no absolute contraindications to solid organ donation

4 NEUROLOGICAL DEATH TESTING RATE

The neurological death testing rate was 74% and is the percentage of patients for whom neurological death was suspected that were tested. To be defined as neurological death suspected, the patients were indicated to have met the following four criteria - apnoea, coma from known aetiology and unresponsive, ventilated and fixed pupils. Patients for whom tests were not performed due to; cardiac arrest occurred despite resuscitation, brainstem reflexes returned were not possible to test meaning these reasons were excluded. Neurological death tests were not performed in 29 patients (26%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 6 (21%) patients not tested, the reason stated clinical reason/clinicians' decision. Haemodynamic instability, 5 (17%), continuing effects of sedatives, 5 (17%) and biochemical/endocrine abnormality, 5 (17%) were other reasons given.

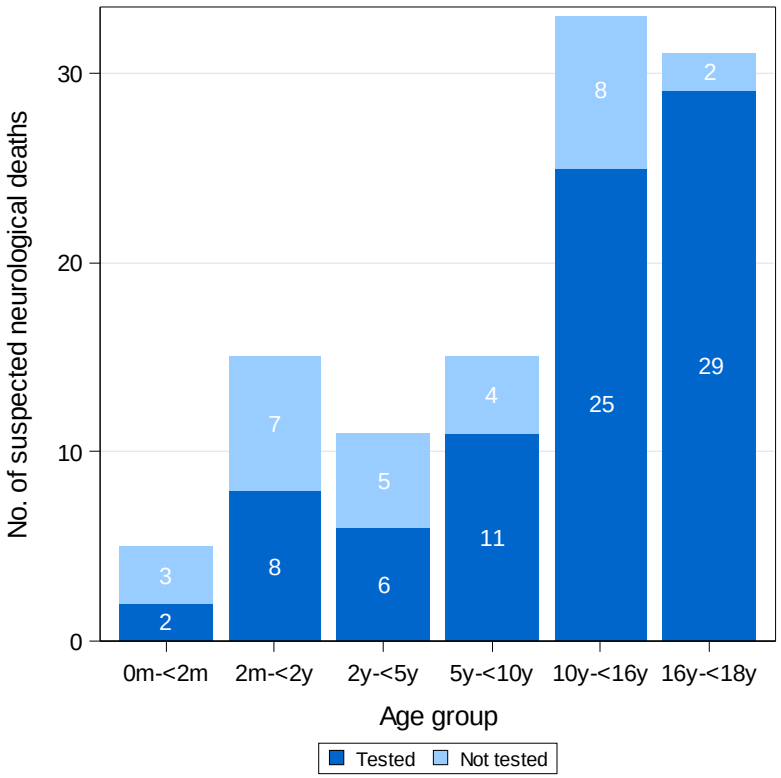
Table 2 Reasons given for neurological death tests not being performed

	N	%
Clinical reason/Clinicians' decision	6	20.7
Patient haemodynamically unstable	5	17.2
Continuing effects of sedatives	5	17.2
Biochemical/endocrine abnormality	5	17.2
Family declined donation	2	6.9
Other	2	6.9
Family pressure not to test	1	3.4
Medical contraindication to donation	1	3.4
SN-OD advised that donor not suitable	1	3.4
Unknown	1	3.4
Total	**29**	**100.0**

4.1. NEUROLOGICAL DEATH TESTING RATE BY PATIENT AGE

Age is represented by a categorical variable with intervals <2 months, 2 months - <2 years, 2-<5 years, 5-<10 years,10-<16 years and 16-<18 years. There were a total of 110 neurological deaths suspected in paediatric patients in the UK from 1 April 2017 to 31 March 2018 and a total of 81 deaths where neurological tests were performed (74%). **Figure 3** shows the number of neurological death tests performed by age group. The 16 - <18 year old age group had the highest testing rate, 94%.

Figure 3 Neurological death testing by age group



5 REFERRAL RATE

A patient for whom neurological death is suspected or for whom imminent death is anticipated, i.e. receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within four hours, should be referred to a Specialist Nurse - Organ Donation (SN-OD). The DBD referral rate was 95% and the DCD referral rate was 84%. **Table 3** shows the reasons given why such patients were not referred. One patient can meet the referral criteria for both DBD and DCD and therefore some patients may be counted in both columns. Referral criteria are defined in **Appendix 1**.

Of the patients who met the referral criteria and were not referred, the reason given for 2 (33%) DBD patients was the family declined donation after neurological testing. The reason given for 14 (38%) DCD patients was the patient was not identified as a potential donor/organ donation was not considered. A further 12 (32%) DCD patients were not referred for 'Other/unknown' reasons.

Table 3 Reasons given why patient not referred

	DBD		DCD	
	N	**%**	**N**	**%**
Family declined donation after neurological testing	2	33.3	-	-
Coroner/Procurator Fiscal Reason	1	16.7	1	2.7
Family declined donation prior to neurological testing	1	16.7	1	2.7
Neurological death not confirmed	1	16.7	-	-
Other/unknown	1	16.7	12	32.4
Not identified as a potential donor/organ donation not considered	-	-	14	37.8
Thought to be medically unsuitable	-	-	4	10.8
Family declined donation following decision to withdraw treatment	-	-	2	5.4
Medical contraindications	-	-	3	8.1
Total	**6**	**100.0**	**37**	**100.0**

6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 80% and 46% of DBD and DCD cases, respectively. The DCD approach rate is considerably lower than the DBD approach rate as the DCD assessment process identifies a large number of eligible DCD donors which are unsuitable for organ donation prior to the approach. Consequently, families of these patients are never approached for the formal organ donation discussion and the reason for not approaching is recorded as 'Patient's general medical condition', 'Other medical reason' or 'Other'. The information in **Table 4** shows the reasons given why the families were not approached.

The main reason given for not approaching families of eligible DBD donors, in 6 (40%) cases, was Coroner/Procurator Fiscal refused permission.

The reason stated for not approaching families of eligible DCD donors, were patient's general medical condition 29 (30%) and patient was not identified as a potential donor / organ donation was not considered 22 (23%). The majority of these cases are due to the DCD assessment process which identifies patients unsuitable for donation prior to the approach.

Table 4 Reasons given why family not formally approached

	DBD		DCD	
	N	**%**	**N**	**%**
Coroner / Procurator Fiscal refused permission	6	40.0	10	10.3
Family stated that they would not support donation before they were formally approached	4	26.7	1	1.0
Family considered too upset to approach	2	13.3	1	1.0
Other	2	13.3	21	21.6
Patient's general medical condition	1	6.7	29	29.9
Not identified as a potential donor / organ donation not considered	-	-	22	22.7
Resource failure	-	-	1	1.0
Other medical reason	-	-	12	12.4
Total	**15**	**100.0**	**97**	**100.0**

7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose families were formally approached for formal organ donation discussion. The consent/authorisation rate is the proportion of eligible donors for whom consent/authorisation for solid organ donation was ascertained.

During the financial year, the DBD consent/authorisation rate was 62% and the 95% confidence limits for this percentage are 50% - 74%. The DCD consent/authorisation rate was 38% and the 95% confidence limits for this percentage are 27% - 48%. The overall consent/authorisation rate was 48% and the 95% confidence limits for this percentage are 37% - 59%.

Three children were known to have registered their wish to donate on the Organ Donor Register (ODR) at the time of the formal organ donation discussion. All three of these children were greater than 16 years old. Consent/authorisation was ascertained for two of the donors registered on the ODR (67%) and 1 family overruled their loved one's known wish to be an organ donor.

The consent/authorisation rate was 48% when a patient's ODR status was not known at the time of approach.

Of the 10 DBD families approached for formal organ donation discussion, where the SN-OD was not present, consent/authorisation was ascertained for just three donors. For DCD patients, consent/authorisation was not ascertained for any of the 22 eligible DCD patients when the SN-OD was not present. The overall consent/authorisation rate was 59% when the SN-OD was present compared to 9% when the SN-OD was not present.

The reasons why the family did not support organ donation are shown in **Table 5**. The main reason that families of eligible DBD patients did not support organ donation was other/unknown reason, 5 (22%). The main reason that families of eligible DCD patients did not support organ donation was the family did not want surgery to the body, 14 (28%).

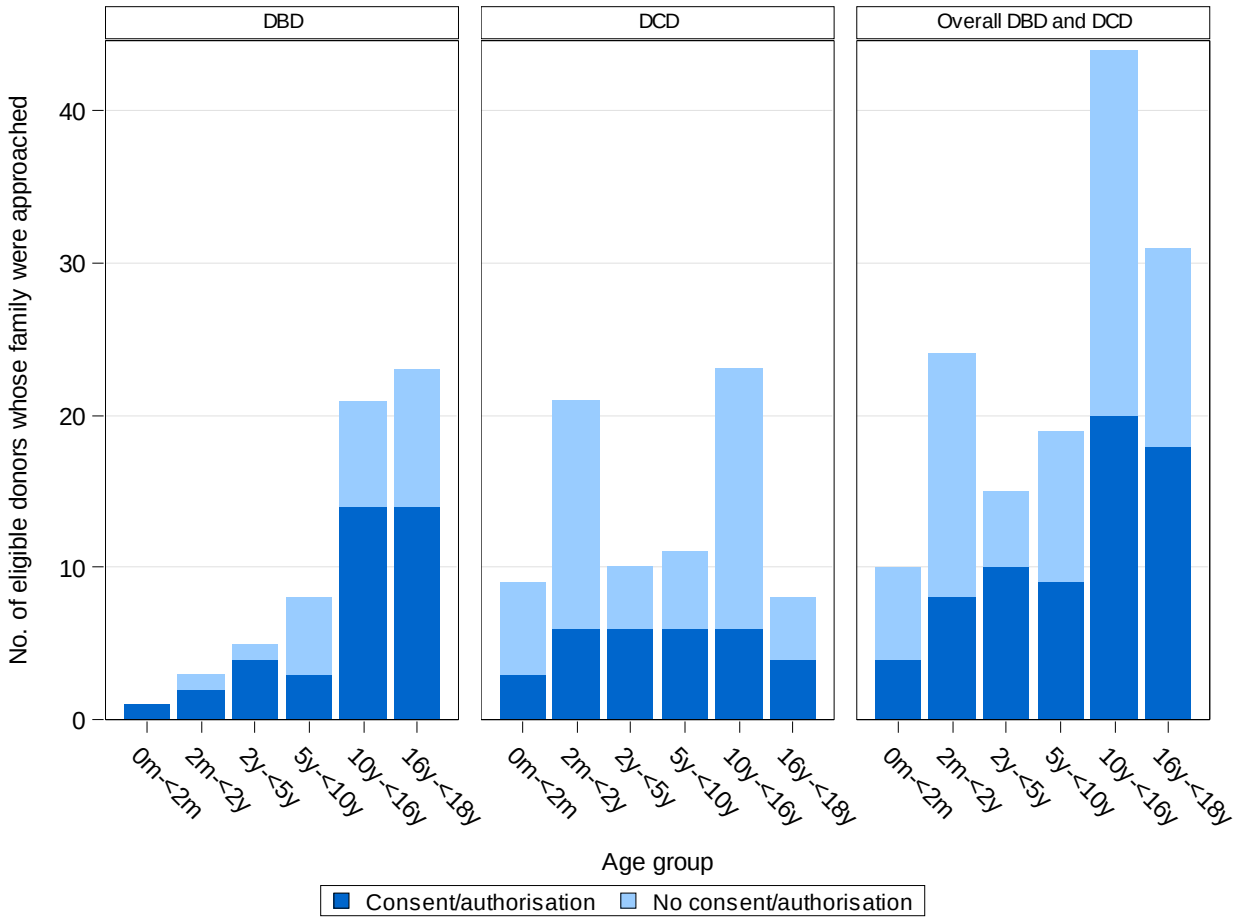
Table 5 Reasons given why family did support organ donation

	DBD		DCD	
	N	**%**	**N**	**%**
Other	5	21.7	13	25.5
Family did not want surgery to the body	4	17.4	14	27.5
Family felt it was against their religious/cultural beliefs	4	17.4	1	2.0
Family felt the patient had suffered enough	3	13.0	11	21.6
Strong refusal - probing not appropriate	3	13.0	-	-
Family felt the length of time for donation process was too long	1	4.3	5	9.8
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	1	4.3	3	5.9
Family were not sure whether the patient would have agreed to donation	1	4.3	1	2.0
Family were divided over the decision	1	4.3	1	2.0
Family wanted to stay with the patient after death	-	-	1	2.0
Families concerned about organ allocation	-	-	1	2.0
Total	**23**	**100.0**	**51**	**100.0**

7.1 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

The consent/authorisation rates for the six age groups (for the 61 eligible DBD and 82 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest overall consent/authorisation rate for eligible donors occurred in the 2 - <5 year old age group (67%) the lowest consent/authorisation rate was in the 2 months – < 2 years age group (33%).

Figure 4 Number of families approached by age group

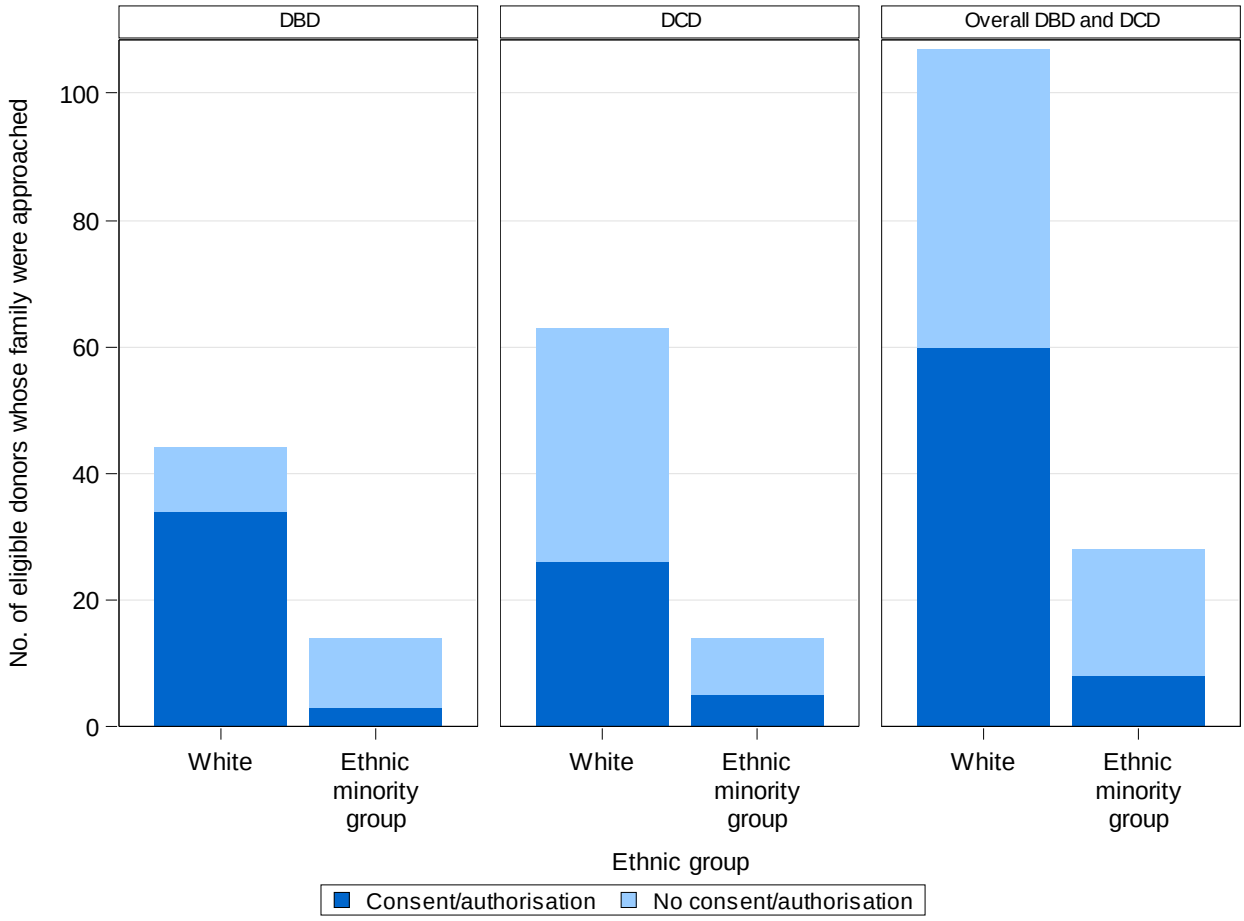


Consent/authorisation rates for patients from the white ethnic community are compared with patients from the Black, Asian and Minority Ethnic (BAME) community and are shown in **Figure 5**. Note that there were an additional 3 DBD and 5 DCD families approached where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 77% for eligible white donors and 21% for eligible BAME donors. For eligible DCD, the consent/authorisation rates were 41% for eligible white DCD and 36% for eligible BAME DCD.

The overall consent/authorisation rates were 56% for eligible white donors and 29% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 47% - 65% for eligible white donors and 12% - 45% for eligible BAME donors.

Figure 5 Number of approaches by patient ethnicity



8 SOLID ORGAN DONATION

Of the eligible donors whose family consented to/authorised donation, 95% of the eligible DBD and 65% of the eligible DCD went on to become actual solid organ donors. **Table 6** shows the reasons why consented/authorised eligible donors did not become actual solid organ donors.

The main reason given for consented/authorised eligible DCD not proceeding to become a solid organ donor was prolonged time to asystole, 4 (36%). There were 2 DBD consented/authorised eligible DBD who did not proceed, one due to Coroner / Procurator Fiscal refusal and one due to positive virology.

Table 6 Reasons why solid organ donation did not happen following consent

	DBD		DCD	
	N	%	N	%
Coroner/ Procurator Fiscal refusal	1	50.0	2	18.2
Positive virology	1	50.0	-	-
Family changed mind	-	-	3	27.3
Organs deemed medically unsuitable by recipient centres	-	-	1	9.1
Prolonged time to asystole	-	-	4	36.4
Logistic reasons	-	-	1	9.1
Total	**2**	**100.0**	**11**	**100.0**

9 TRANSPLANT LIST

Table 7 shows the number of paediatric patients on the active transplant list as at 31 March 2018. In total there were 130 patients waiting for a transplant, 62 (48%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant was slightly lower than as at 31 March 2017, with 172 waiting.

Table 7 Active paediatric transplant list in the UK, as at 31 March 2018 (2017)

	Active transplant list	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Heart	26	(29)
Lung	4	(8)
Heart and lung	0	(2)
Total cardiothoracic	**30**	**(39)**
Renal paediatric patients (< 18 years at time of registration)		
Kidney	62	(80)
Liver paediatric patients (< 17 years at time of registration)		
Liver	32	(42)
Intestinal paediatric patients (< 18 years at time of registration)		
Intestinal	4	(7)
Total	**130**	**(172)**

10 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2017 to 31 March 2018, are presented in **Table 8**. In the 12-month period, there were a total of 283 transplants performed. Of these, 192 were deceased donor transplants and 91 were from living donors. Nearly half of all the paediatric transplants were kidney transplants.

Table 8 Paediatric transplants in the UK, 1 April 2017 – 31 March 2018 (2016/2017)

	Transplant numbers	
Cardiothoracic paediatric patients (< 16 years at time of transplant)		
Deceased heart	36	(33)
Heart and lung	0	(0)
Lung only – DBD	5	(9)
Lung only – DCD	1	(1)
Total cardiothoracic	**42**	**(43)**
Renal paediatric patients (< 18 years at time of transplant)		
Kidney – DBD	57	(52)
Kidney – DCD	3	(3)
Kidney – living donor	70	(72)
Total kidney	**130**	**(127)**
Liver paediatric patients (< 17 years at time of transplant)		
Liver – DBD	72	(81)
Liver – DCD	7	(5)
Liver – living donor	20	(20)
Total liver	**99**	**(106)**
Intestinal paediatric patients (< 18 years at time of transplant)		
Intestinal	1	(1)
Total	**283**	**(284)**

11 SUMMARY

In the year 1 April 2017 to 31 March 2018, there were 1,204 paediatric deaths audited for the PDA. Of these deaths, 110 and 224 patients met the referral criteria for DBD and/or DCD, respectively and 95% and 84% were referred to a SN-OD.

Of the 110 patients for whom neurological death was suspected, 74% were tested and there were 76 and 179 eligible DBD and DCD, respectively.

Of the families approached, consent/authorisation was ascertained for 62% eligible DBD donors and 38% of eligible DCD donors. Of these, 95% and 65%, respectively, became actual solid organ donors. One family overruled their loved one's known wish to be an organ donor.

At 31 March 2018, there were a total of 130 paediatric patients on the transplant list. In the year 1 April 2017 to 31 March 2018, 283 paediatric patients received a transplant. The number of paediatric patients on the transplant list at the end of the year decreased by 42 patients compared with the end of 2017. The number of paediatric patients transplanted during 2017/18 was similar to 2016/17.

Chloe Brown & Sue Madden **November 2018**
NHS Blood and Transplant

Appendix I - Definitions

POTENTIAL DONOR AUDIT / REFERRAL RECORD	
Data excluded	Patients who did not die on a critical care unit or an emergency department and patients aged over 80 years are excluded.
Donors after brain death (DBD)	
Suspected Neurological Death	A patient who meets all of the following criteria: Apnoea, coma from known aetiology and unresponsive, ventilated, fixed pupils. Excluding cases for which cardiac arrest occurred despite resuscitation, brainstem reflexes returned, and neonates - less than 37 weeks corrected gestational age
Potential DBD donor	A patient who meets all four criteria for neurological death testing (ie suspected neurological death, as defined above)
DBD referral criteria	A patient with suspected neurological death. Excluding cases for which cardiac arrest occurred despite resuscitation, brainstem reflexes returned, and neonates - less than 37 weeks corrected gestational age
Discussed with Specialist Nurse – Organ Donation	A patient with suspected neurological death discussed with the Specialist Nurse – Organ Donation (SN-OD)
Neurological death tested	Neurological death tests were performed
Eligible DBD donor	A patient confirmed dead by neurological death tests, with no absolute medical contraindications to solid organ donation
Family approached for formal organ donation discussion	Family of eligible DBD asked to support patient's expressed or deemed consent/authorisation, informed of an appointed representative, asked to make a decision on donation on behalf of their relative, or informed of a patient's opt-out decision via the ODR
Consent/Authorisation ascertained	Family supported expressed or deemed consent/authorisation, appointed representative gave consent, or where applicable the family gave consent/authorisation
Actual donors: DBD	Neurological death confirmed patients who became actual DBD as reported through the PDA
Actual donors: DCD	Neurological death confirmed patients who became actual DCD as reported through the PDA
Neurological death testing rate	Percentage of patients for whom neurological death was suspected who were tested
Referral rate	Percentage of patients for whom neurological death was suspected who were discussed with the SN-OD
Consent / authorisation rate	Percentage of families or nominated/appointed representative approached for formal organ donation discussion where consent/authorisation was ascertained
SN-OD presence rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was present
SN-OD consent / authorisation rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was present and consent/authorisation was ascertained

Donors after circulatory death (DCD)	
Imminent death anticipated	A patient, not confirmed dead using neurological criteria, receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within 4 hours
DCD referral criteria	A patient in whom imminent death is anticipated (as defined above)
Discussed with Specialist Nurse – Organ Donation	Patients for whom imminent death was anticipated who were discussed with the SN-OD
Potential DCD donor	A patient who had treatment withdrawn and death was anticipated within four hours
Eligible DCD donor	A patient who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation
Family approached for formal organ donation discussion	Family of eligible DCD asked to support patient's expressed or deemed consent/authorisation, informed of an appointed representative, asked to make a decision on donation on behalf of their relative, or informed of a patient's opt-out decision via the ODR
Consent/Authorisation ascertained	Family supported expressed or deemed consent/authorisation, appointed representative gave consent, or where applicable the family gave consent/authorisation
Actual DCD	DCD patients who became actual DCD as reported through the PDA
Referral rate	Percentage of patients for whom imminent death was anticipated who were discussed with the SN-OD
Consent / authorisation rate	Percentage of families or nominated/appointed representative approached for formal organ donation discussion where consent/authorisation was ascertained
SN-OD presence rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was present
SN-OD consent / authorisation rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was present and consent/authorisation was ascertained