

**ANNUAL REPORT ON DONATION AND TRANSPLANTATION IN PAEDIATRICS
SUMMARY REPORT FOR THE 12 MONTH PERIOD
1 APRIL 2016 - 31 MARCH 2017**

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2016 to 31 March 2017 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 May 2017. 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Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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 2016 to 31 March 2017, there were a total of 1,159 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** summarises the key percentages.

Figure 1 Donation after brain death

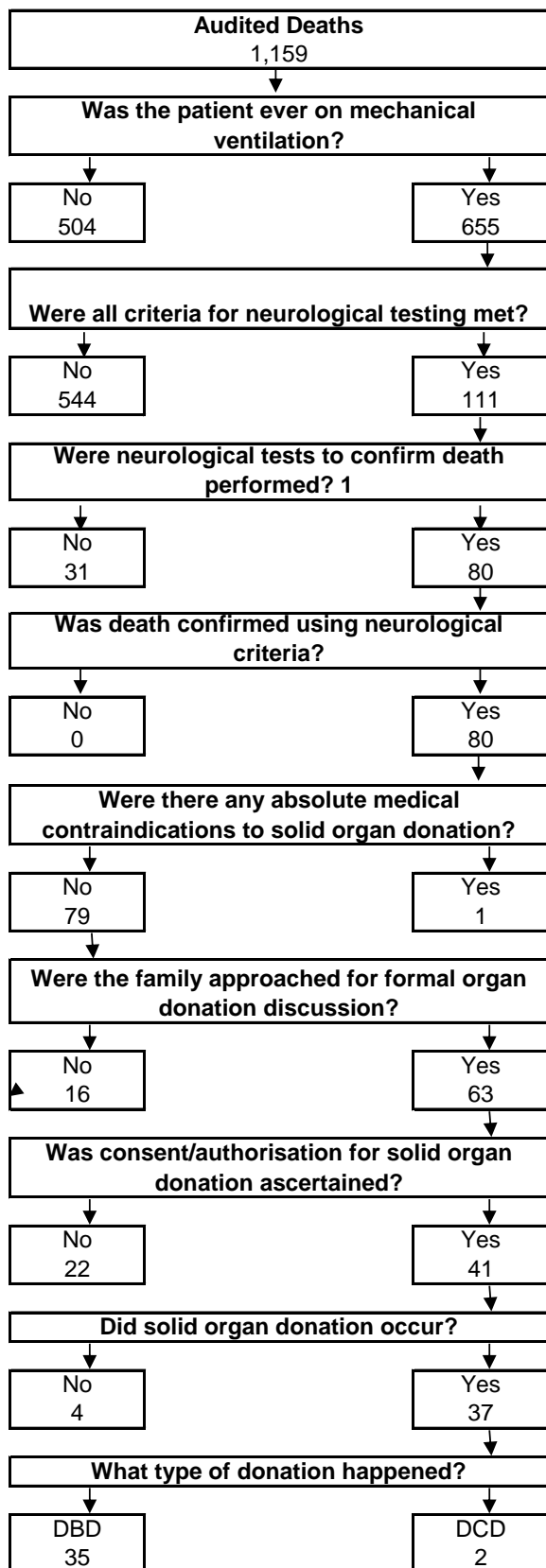
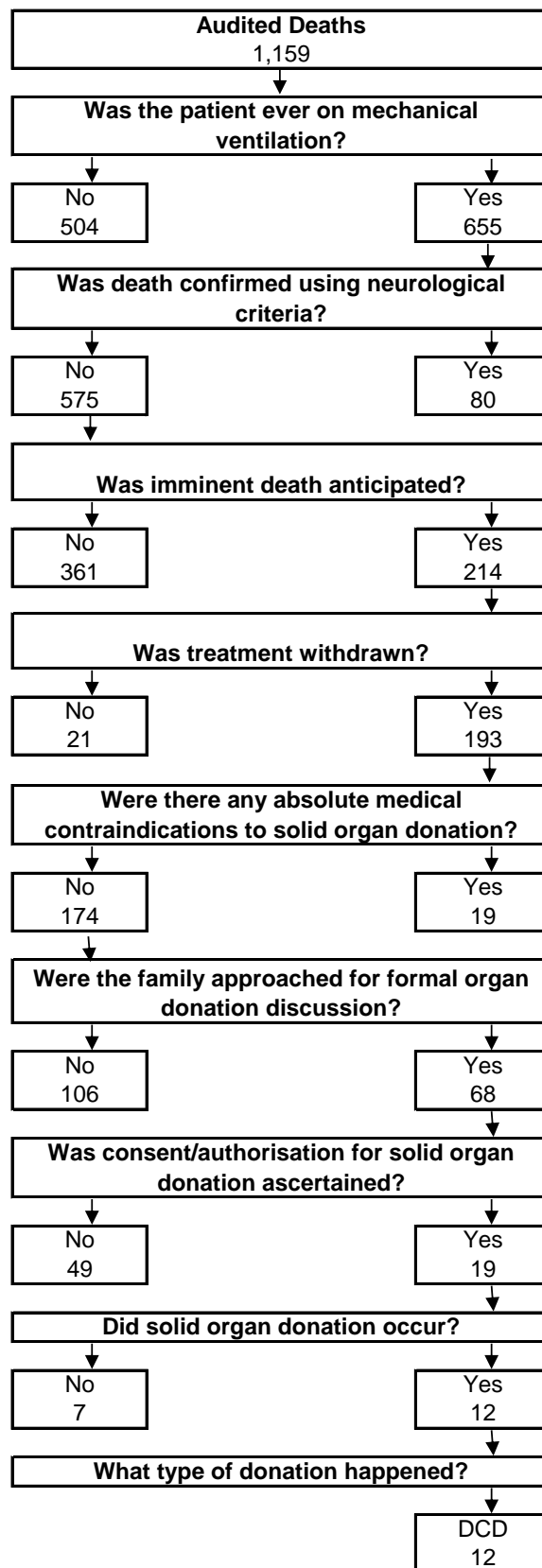


Figure 2 Donation after circulatory death



1 Patients for whom tests were not performed due to; cardiac arrest despite resuscitation occurred, brainstem reflexes returned, or neonates - less than 37 weeks corrected gestational age 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	111	214
Referred to SN-OD	99	162
<i>Referral rate %</i>	<i>89.2%</i>	<i>75.7%</i>
Neurological death tested	80	-
<i>Testing rate %</i>	<i>72.1%</i>	-
Eligible donors ²	79	174
Family approached	63	68
Family approached and SN-OD involved	51	46
<i>% of approaches where SN-OD involved</i>	<i>81.0%</i>	<i>67.6%</i>
Consent/authorisation given	41	19
<i>Consent/authorisation rate %</i>	<i>65.1%</i>	<i>27.9%</i>
Actual donors from each pathway	37	12
<i>% of consented/authorised donors that became actual donors</i>	<i>90.2%</i>	<i>63.2%</i>
¹ DBD - A patient with suspected neurological death excluding those that were not tested due to reasons: cardiac arrest occurred despite resuscitation, brainstem reflexes returned, neonates - less than 37 weeks corrected gestational age 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 72% 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. Patients less than 37 weeks corrected gestational age were not possible to test and therefore not included in this data. Neurological death tests were not performed in 31 patients (28%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 11 (36%) patients not tested, the reason stated, was that the patient was haemodynamically unstable and 7 (23%) patients were not tested for clinical reason/clinicians decision.

	N	%
Patient haemodynamically unstable	11	35.5
Clinical reason/Clinicians decision	7	22.6
Family pressure not to test	4	12.9
Family declined donation	2	6.5
Continuing effects of sedatives	2	6.5
Biochemical/endocrine abnormality	2	6.5
Inability to test all reflexes	2	6.5
SN-OD advised that donor not suitable	1	3.2
Total	31	100.0

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 89% and the DCD referral rate was 76%. **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 but were not referred, 25% of DBD and 25% of DCD cases were because the patient was not identified as a potential donor/organ donation. A further 25% of DBD patients were not referred for coroner/Procurator Fiscal reasons and 42% of DCD patients were not referred for 'Other/unknown' reasons.

	DBD		DCD	
	N	%	N	%
Not identified as a potential donor/organ donation not considered	3	25.0	13	25.0
Coroner/Procurator Fiscal Reason	3	25.0	1	1.9
Thought to be medically unsuitable	2	16.7	7	13.5
Family declined donation prior to neurological testing	1	8.3	1	1.9
Reluctance to approach family	1	8.3	1	1.9
Medical contraindications	1	8.3	7	13.5
Other/unknown	1	8.3	22	42.3
Total	12	100.0	52	100.0

6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 80% and 39% 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 63% of cases, was Coroner/Procurator Fiscal refused permission.

The reason stated for not approaching families of eligible DCD donors, were patient's general medical condition (31%) and 'other' (31%). The majority of these cases are due to the DCD assessment process which identifies patients unsuitable for donation prior to the approach.

	DBD		DCD	
	N	%	N	%
Coroner / Procurator Fiscal refused permission	10	62.5	12	11.3
Family considered too upset to approach	3	18.8	1	0.9
Other	1	6.3	33	31.1
Not identified as a potential donor / organ donation not considered	1	6.3	11	10.4
Patient had previously expressed a wish not to donate	1	6.3	-	-
Family stated that they would not support donation before they were formally approached	-	-	9	8.5
Patient's general medical condition	-	-	33	31.1
Other medical reason	-	-	7	6.6
Total	16	100.0	106	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 65% and the 95% confidence limits for this percentage are 53% - 77%. The DCD consent/authorisation rate was 28% and the 95% confidence limits for this percentage are 17% - 39%. The overall consent/authorisation rate was 46% and the 95% confidence limits for this percentage are 34% - 58%.

Five 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. Three of these children were less than 16 years old. Consent/authorisation was ascertained for all five DBD donors registered on the ODR. There were no DCD donors known to have registered their wish to donate on the ODR

The consent/authorisation rate was 100% when a patient’s ODR status was known, compared to 44% when a patient's ODR status was not known at the time of approach.

During the financial year, no families overruled their loved one's known wish to be an organ donor.

Of the 12 DBD families approached for formal organ donation discussion, where the SN-OD was not involved, consent/authorisation was ascertained for just two donors. Similarly, for DCD patients, consent/authorisation was ascertained for only one of the 22 eligible DCD patients when the SN-OD was not involved. The overall consent/authorisation rate was 59%, when the SN-OD was involved compared to 9% when the SN-OD was not involved.

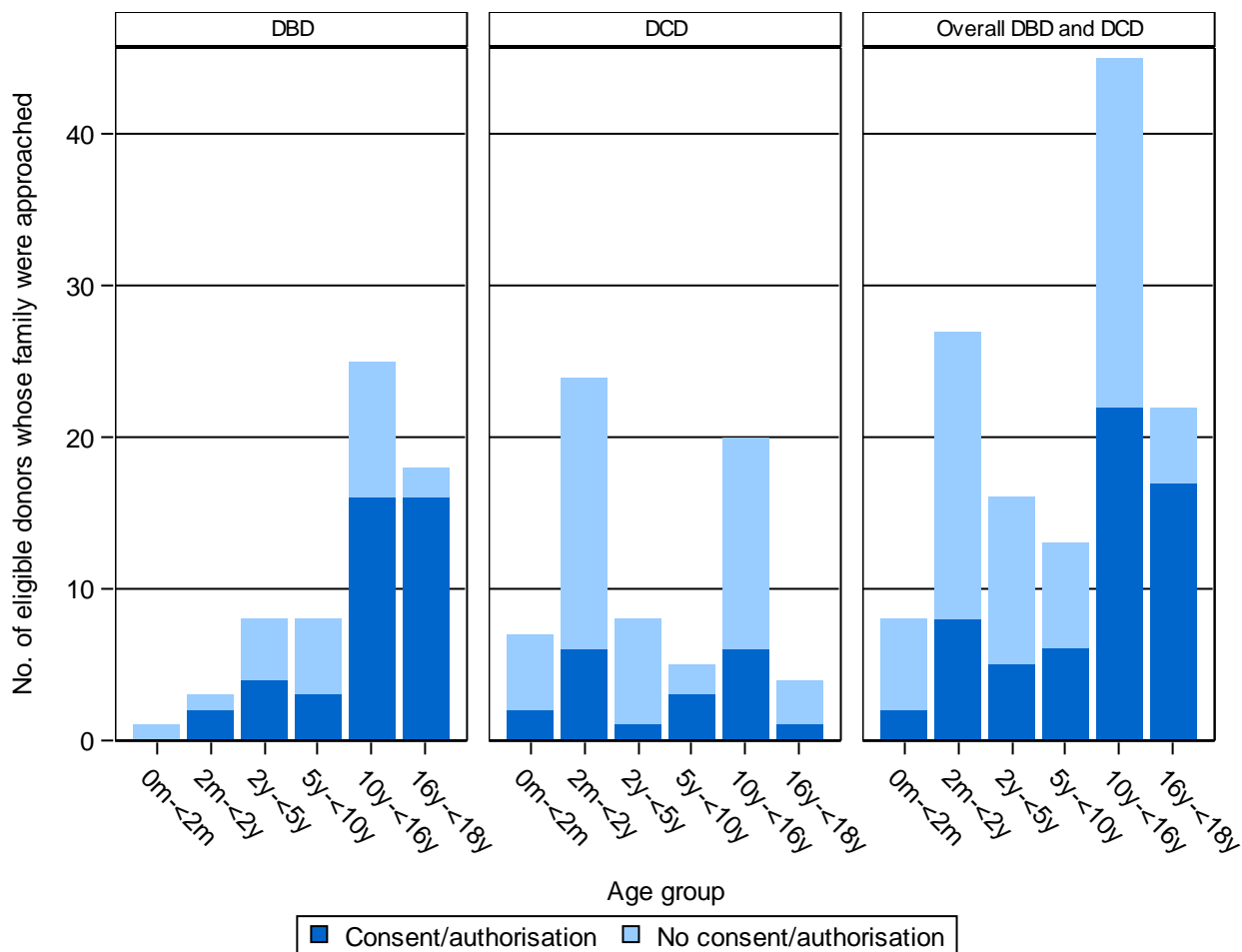
The reasons why the family did not support organ donation are shown in **Table 5**. The main reason that families of eligible DBD patients did not support organ donation was the family did not want surgery to the body (27%). The main reason that families of eligible DCD patients did not support organ donation was the family felt the length of time for the donation process was too long (29%).

	DBD		DCD	
	N	%	N	%
Family did not want surgery to the body	6	27.3	8	16.3
Family felt it was against their religious/cultural beliefs	3	13.6	3	6.1
Family felt the patient had suffered enough	3	13.6	5	10.2
Family felt the length of time for donation process was too long	3	13.6	14	28.6
Other	3	13.6	7	14.3
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	2	9.1	5	10.2
Family were not sure whether the patient would have agreed to donation	1	4.5	-	-
Family did not believe in donation	1	4.5	2	4.1
Family were divided over the decision	-	-	1	2.0
Family wanted to stay with the patient after death	-	-	2	4.1
Family concerned that organs may not be transplanted	-	-	1	2.0
Strong refusal - probing not appropriate	-	-	1	2.0
Total	22	100.0	49	100.0

8 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

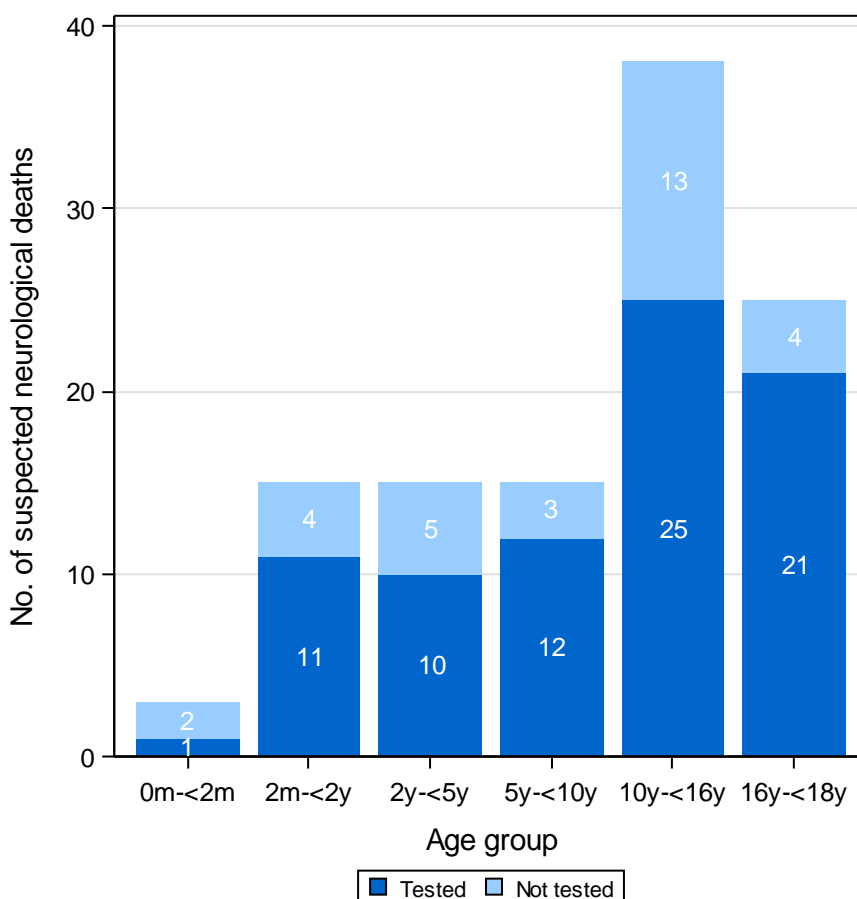
Age is represented by a categorical variable with intervals <2 months, 2 months - <2 years, 2-<5 years, 5-<10 years, 10-<16 years and 16-<18 years. The consent/authorisation rates for the six age groups (for the 63 eligible DBD and 68 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest consent/authorisation rate for eligible donors occurred in the 16 - <18 year old age group (77%) the lowest consent/authorisation rate was in the 0 – < 2 month age group (25%).

Figure 4 Age variation in consent/authorisation rate



There were a total of 111 neurological deaths suspected in paediatric patients in the UK from 1 April 2016 to 31 March 2017 and a total of 80 deaths where neurological tests were performed (72%). **Figure 5** shows the number of neurological death tests performed by age group. The 16 - <18 year old age group had the highest testing rate, 84%.

Figure 5 Age distribution where neurological death tests performed

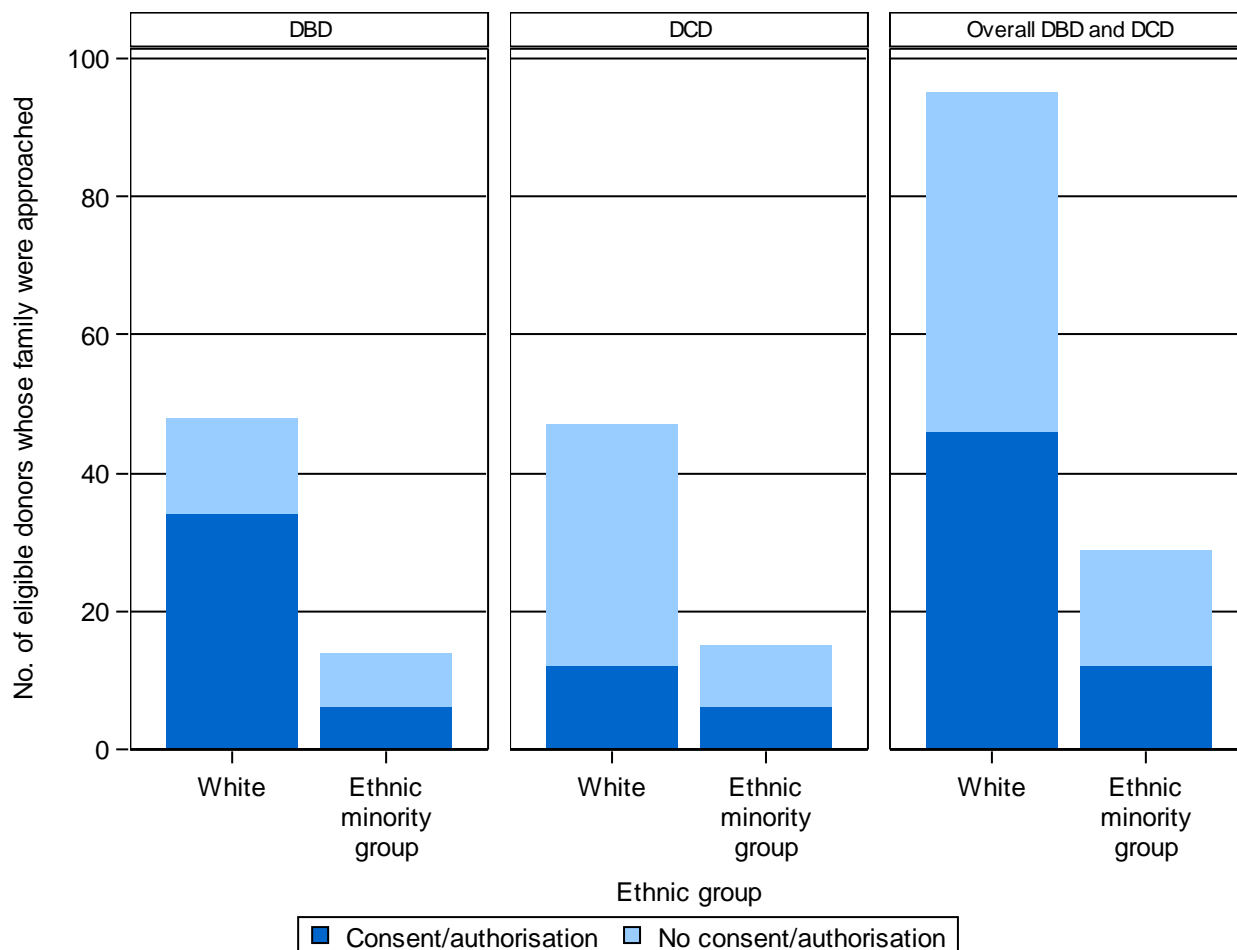


To conduct a meaningful analysis on ethnicity, patients have been categorised as white or in an ethnic minority group and the consent/authorisation rates are shown in **Figure 6**. Note that there were an additional 1 DBD and 6 DCD families approached where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 71% for white eligible donors and 43% for eligible donors from an ethnic minority group. For eligible DCD, the consent/authorisation rates were 26% for white eligible DCD and 40% for eligible DCD from an ethnic minority group.

The overall consent/authorisation rates were 48% for white eligible donors and 41% for eligible donors from an ethnic minority group. The 95% confidence limits for overall consent/authorisation rates are 38% - 58% for white eligible donors and 23% - 59% for eligible donors from an ethnic minority group.

Figure 6 Ethnic group variation in consent/authorisation rate



10 SOLID ORGAN DONATION

Of the eligible donors whose family consented to/authorised donation, 90% of the eligible DBD and 63% 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, 43%. There were 4 DBD consented/authorised eligible DBD who did not proceed, each for different reasons.

	DBD		DCD	
	N	%	N	%
Family changed mind	1	25.0	1	14.3
Coroner/ Procurator Fiscal refusal	1	25.0	1	14.3
Cardiac arrest	1	25.0	-	-
Other	1	25.0		
Organs deemed medically unsuitable by recipient centres	-	-	1	14.3
Prolonged time to asystole	-	-	3	42.9
General instability	-	-	1	14.3
Total	4	100.0	7	100.0

11 TRANSPLANT LIST

Table 7 shows the number of paediatric patients on the active transplant list as at 31 March 2017. In total there were 172 patients waiting for a transplant, 80 (47%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant was slightly higher than as at 31 March 2016, with 165 waiting.

	Active transplant list	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Heart	29	(35)
Lung	8	(7)
Heart and lung	2	(0)
Total cardiothoracic	39	(42)
Renal paediatric patients (< 18 years at time of registration)		
Kidney	80	(69)
Kidney/pancreas	0	(1)
Total kidney	80	(70)
Liver paediatric patients (< 17 years at time of registration)		
Liver	46	(49)
Intestinal paediatric patients (< 18 years at time of registration)		
Intestinal	7	(4)
Total	172	(165)

12 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2016 to 31 March 2017, 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 2016 – 31 March 2017 (2015/2016)		Transplant numbers	
Cardiothoracic paediatric patients (< 16 years at time of transplant)			
Deceased heart	33	(34)	
Heart and lung	0	(0)	
Lung only – DBD	9	(7)	
Lung only – DCD	1	(2)	
Total cardiothoracic	43	(43)	
Renal paediatric patients (< 18 years at time of transplant)			
Kidney – DBD	52	(47)	
Kidney – DCD	3	(4)	
Kidney – living donor	71	(78)	
Total kidney	126	(129)	
Liver paediatric patients (< 17 years at time of transplant)			
Liver – DBD	85	(72)	
Liver – DCD	5	(5)	
Liver – living donor	20	(19)	
Total liver	110	(96)	
Intestinal paediatric patients (< 18 years at time of transplant)			
Intestinal	4	(3)	
Total	283	(271)	

13 SUMMARY

In the year 1 April 2016 to 31 March 2017, there were 1,159 deaths audited for the PDA. Of these deaths, 111 and 214 patients met the referral criteria for DBD and/or DCD, respectively and 89% and 76% were referred to a SN-OD.

Of the 111 patients for whom neurological death was suspected, 72% were tested and there were 79 and 174 eligible DBD and DCD, respectively. Families of these eligible DBD and DCD were approached for formal organ donation discussion in 80% and 39% of cases, respectively.

Of the families approached, consent/authorisation was ascertained for 65% eligible DBD donors and 28% of eligible DCD donors. Of these, 90% and 63%, respectively, became actual solid organ donors. No families overruled their loved one's known wish to be an organ donor

At 31 March 2017, there were a total of 172 paediatric patients on the transplant list. In the year 1 April 2016 to 31 March 2017, 283 paediatric patients received a transplant. The number of paediatric patients on the transplant list at the end of the year increased by 7 patients compared with the end of 2016. The number of paediatric patients transplanted during the 12-month period, also increased, by 12 transplants.

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May 2017

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
Approach rate	Percentage of eligible DBD families or nominated/appointed representatives approached for formal organ donation discussion
Consent / authorisation rate	Percentage of families or nominated/appointed representative approached for formal organ donation discussion where consent/authorisation was ascertained
SN-OD involvement rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was involved
SN-OD consent / authorisation rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was involved 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
Approach rate	Percentage of eligible DCD families or nominated/appointed representatives approached for formal organ donation discussion
Consent / authorisation rate	Percentage of families or nominated/appointed representative approached for formal organ donation discussion where consent/authorisation was ascertained
SN-OD involvement rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was involved
SN-OD consent / authorisation rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SN-OD was involved and consent/authorisation was ascertained