



Blood and Transplant

**ANNUAL REPORT ON DECEASED DONATION
AND TRANSPLANTATION IN PAEDIATRICS**

**SUMMARY REPORT FOR THE 12 MONTH PERIOD
1 APRIL 2018 – 31 MARCH 2019**

PUBLISHED SEPTEMBER 2019

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2018 to 31 March 2019 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 9 May 2019. 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Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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:
https://nhsbtdeb.blob.core.windows.net/umbraco-assetscorp/4376/contraindications_to_organ_donation.pdf

SNOD Specialist Nurse in Organ Donation, including Specialist Requesters

The consent/authorisation rate is the percentage of eligible donor families approached for organ donation discussion where consent/authorisation for donation was ascertained.

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

3 BREAKDOWN OF AUDITED PAEDIATRIC DEATHS

In the 12-month period from 1 April 2018 to 31 March 2019, there were a total of 1,075 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

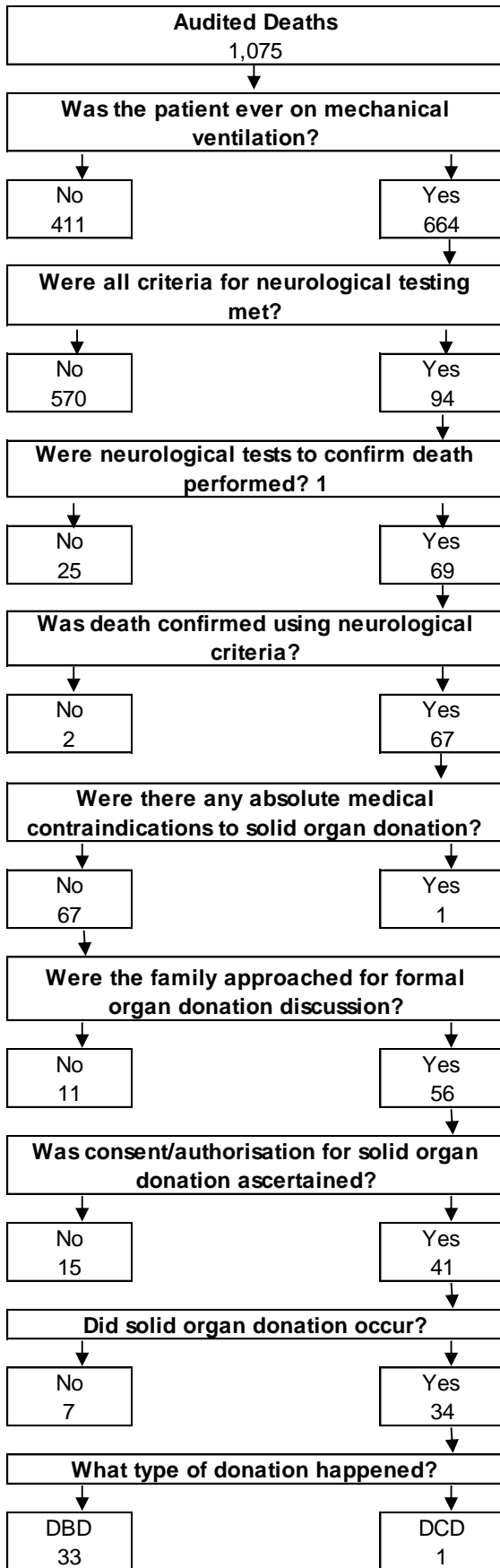
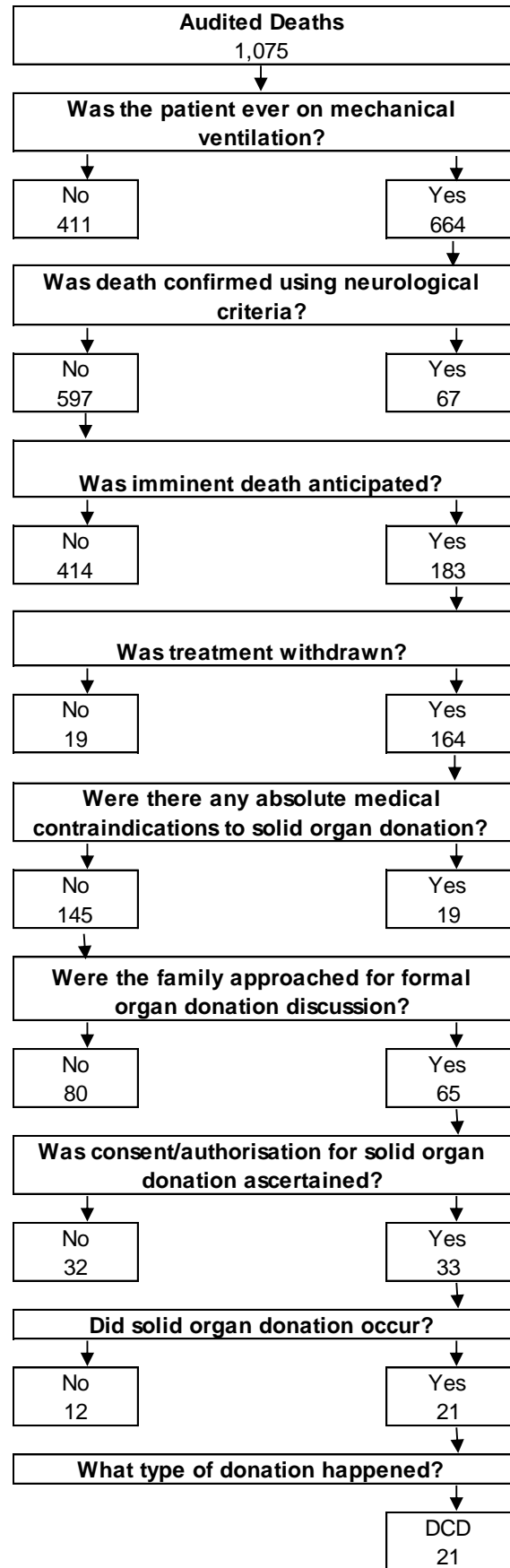


Figure 2 Donation after circulatory death



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

Table 1 Key numbers and rates

	DBD	DCD	All
Patients meeting organ donation referral criteria ¹	94	183	252
Referred to SN-OD	92	154	222
<i>Referral rate %</i>	<i>97.9</i>	<i>84.2</i>	<i>88.1</i>
Neurological death tested	69		69
<i>Testing rate %</i>	<i>73.4</i>		<i>73.4</i>
Eligible donors ²	67	145	212
Family approached	56	65	121
Family approached and SN-OD present	49	47	96
<i>% of approaches where SN-OD present</i>	<i>87.5</i>	<i>72.3</i>	<i>79.3</i>
Consent/authorisation given	41	33	74
<i>Consent/authorisation rate %</i>	<i>73.2</i>	<i>50.8</i>	<i>61.2</i>
Actual donors from each pathway	34	21	55
<i>% of consented/authorised donors that became actual donors</i>	<i>82.9</i>	<i>63.6</i>	<i>74.3</i>

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 73% 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 25 patients (27%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 6 (24%) patients not tested, the reason stated was family pressure not to test. Biochemical/endocrine abnormality, 4 (16%), haemodynamic instability, 3 (12%) and clinical reason/clinician's decision, 3 (12%) were other reasons given.

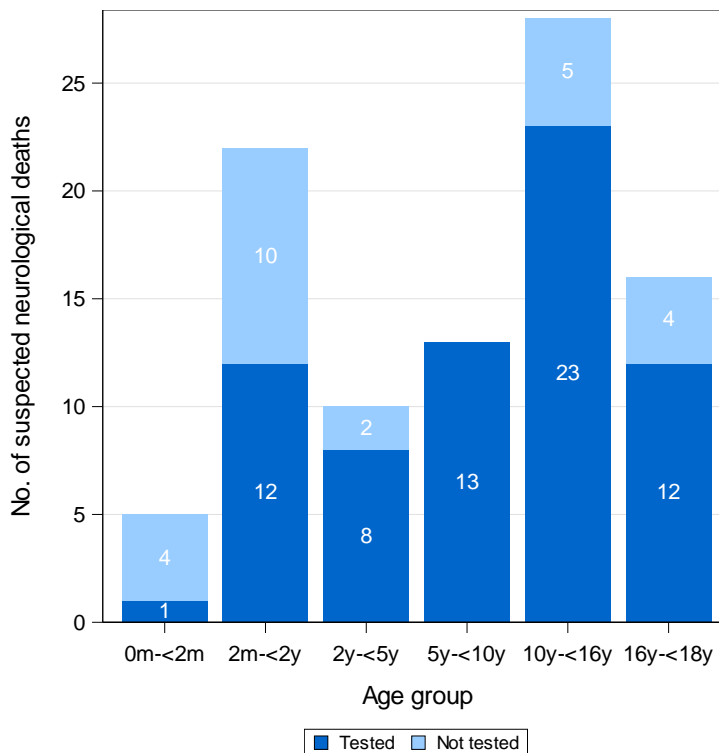
	N	%
Family pressure not to test	6	24.0
Biochemical/endocrine abnormality	4	16.0
Patient haemodynamically unstable	3	12.0
Clinical reason/Clinicians decision	3	12.0
Family declined donation	2	8.0
Continuing effects of sedatives	2	8.0
Inability to test all reflexes	2	8.0
Other	2	8.0
Treatment withdrawn	1	4.0
Total	25	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 94 neurological deaths suspected in paediatric patients in the UK from 1 April 2018 – 31 March 2019 and a total of 69 deaths where neurological tests were performed (73%).

Figure 3 shows the number of neurological death tests performed by age group. The 5 - < 10 year old age group had the highest testing rate of 100%.

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 98% 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 one patient was coroner/procurator fiscal reason and the reason given for the other patient was the family declined donation after neurological testing. The reason given for 10 (35%) DCD patients was the patient was not identified as a potential donor/organ donation was not considered.

	DBD		DCD	
	N	%	N	%
Coroner/Procurator Fiscal Reason	1	50.0	2	6.9
Family declined donation prior to neurological testing	1	50.0	1	3.4
Not identified as a potential donor/organ donation not considered	-	-	10	34.5
Family declined donation following decision to withdraw treatment	-	-	2	6.9
Thought to be medically unsuitable	-	-	5	17.2
Thought to be outside age criteria	-	-	1	3.4
Clinician assessed that patient was unlikely to become asystolic within 4 hours	-	-	1	3.4
Other	-	-	7	24.1
Total	2	100.0	29	100.0

6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 84% and 45% 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 family were not approached.

The main reason given for not approaching families of eligible DBD donors, in 8 (73%) cases, was Coroner/Procurator Fiscal refused permission.

The reason stated for not approaching families of eligible DCD donors, were patient's general medical condition 26 (33%) and 'Other' reason 17 (21%). For 12 (15%) patients the reason stated was the patient was not identified as a potential donor / organ donation was not considered. 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	8	72.7	13	16.3
Family stated that they would not support donation before they were formally approached	1	9.1	1	1.3
Patient's general medical condition	1	9.1	26	32.5
Other medical reason	1	9.1	9	11.3
Family considered too upset to approach	-	-	2	2.5
Other	-	-	17	21.3
Not identified as a potential donor / organ donation not considered	-	-	12	15.0
Total	11	100.0	80	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 73% and the 95% confidence limits for this percentage are 62% - 85%. The DCD consent/authorisation rate was 51% and the 95% confidence limits for this percentage are 39% - 63%. The overall consent/authorisation rate was 61% and the 95% confidence limits for this percentage are 49% - 73%.

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. Four 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. No families overruled their loved one's known wish to be an organ donor.

The consent/authorisation rate was 59% when a patient's ODR status was not known at the time of approach.

Of the 7 DBD families approached for formal organ donation discussion, where the SN-OD was not present, consent/authorisation was ascertained for 5 donors. For DCD patients, consent/authorisation was ascertained for 3 of the 18 eligible DCD patients when the SN-OD was not present. The overall the consent/authorisation rate was 69%, when the SN-OD was present compared to 32% when the SN-OD was not present.

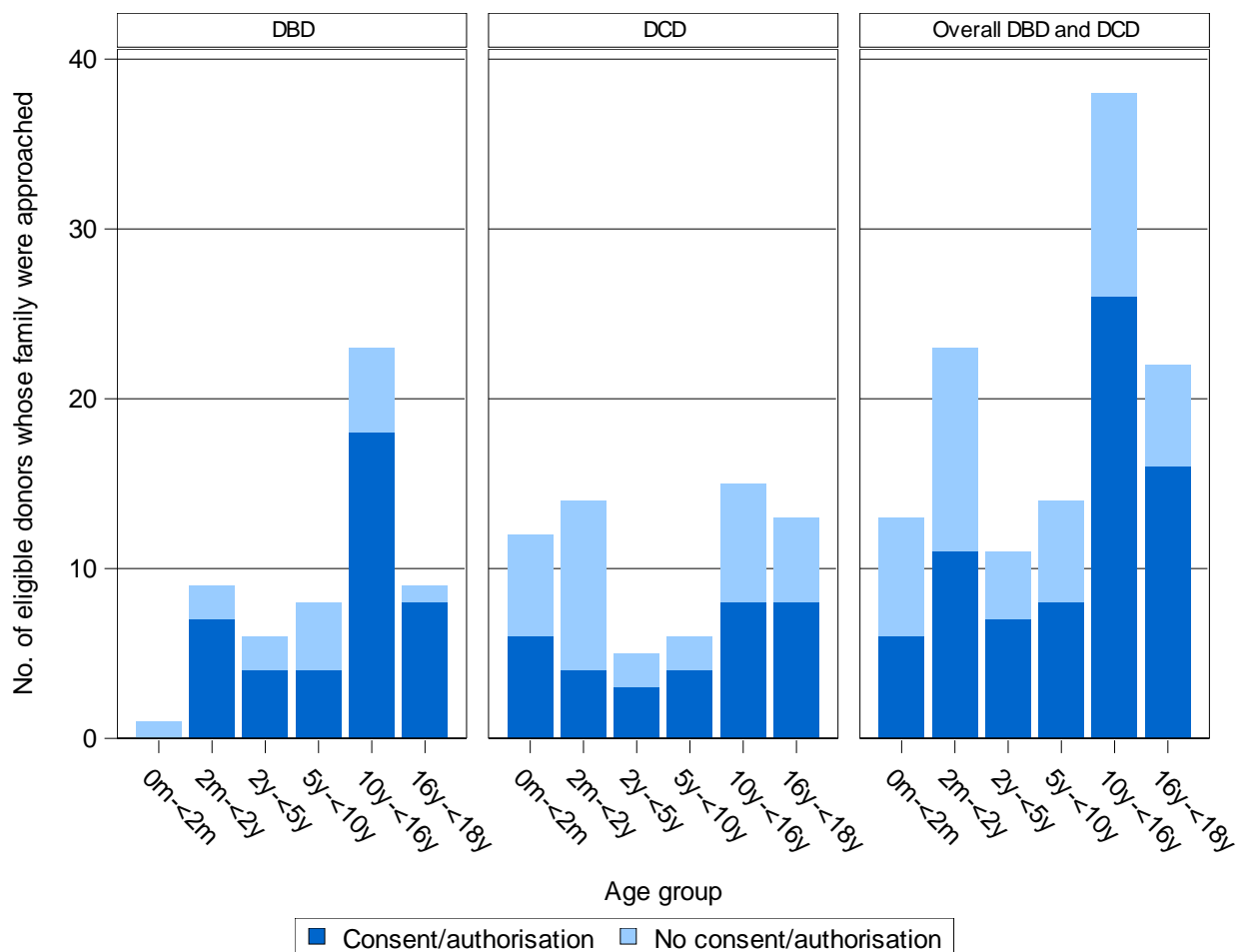
The reasons why the family did not support organ donation are shown in **Table 5**. The main reason that families of eligible DBD patients did not support organ donation was the family felt the patient had suffered enough, 4 (27%). The main reasons that families of eligible DCD patients did not support organ donation was other/unknown reason, 9 (28%) and the family felt the patient had suffered enough 6 (19%).

	DBD		DCD	
	N	%	N	%
Family felt the patient had suffered enough	4	26.7	6	18.8
Family did not want surgery to the body	3	20.0	3	9.4
Family felt it was against their religious/cultural beliefs	2	13.3	2	6.3
Family were divided over the decision	2	13.3	2	6.3
Family did not believe in donation	1	6.7	3	9.4
Family wanted to stay with the patient after death	1	6.7	2	6.3
Family concerned that other people may disapprove/be offended	1	6.7	-	-
Other	1	6.7	9	28.1
Family were not sure whether the patient would have agreed to donation	-	-	1	3.1
Family felt the length of time for donation process was too long	-	-	1	3.1
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	-	-	1	3.1
Family concerned that organs may not be transplanted	-	-	1	3.1
Strong refusal - probing not appropriate	-	-	1	3.1
Total	15	100.0	32	100.0

7.1 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

The consent/authorisation rates for the six age groups (for the 56 eligible DBD and 65 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest overall consent/authorisation rate for eligible donors occurred in the 16 - <18 year old age group (73%). The lowest consent/authorisation rate was in the 0 - <2 months age group (46%).

Figure 4 Number of families approached by age group

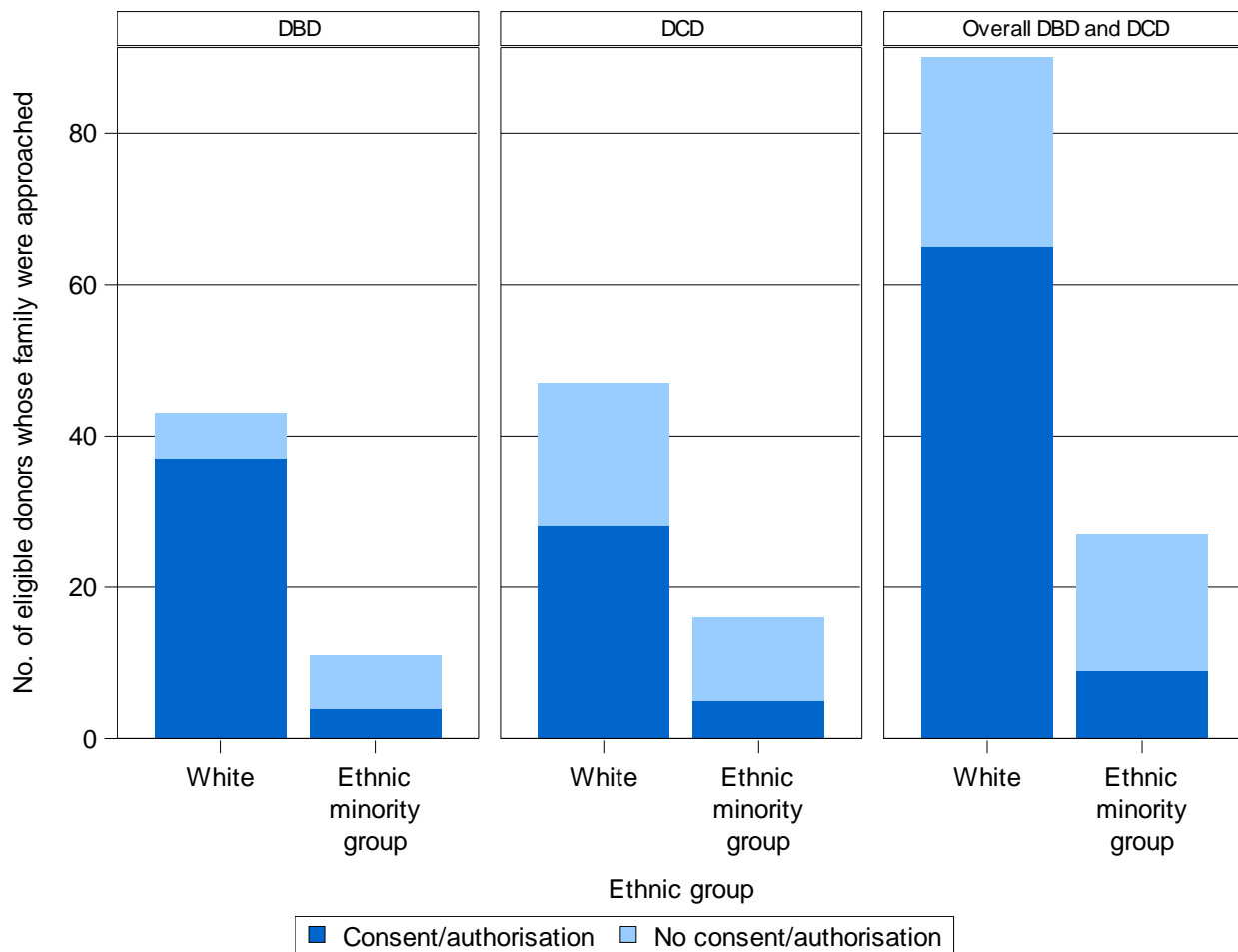


Consent/authorisation rates for patients from the white ethnic community are compared with patients from the Black, Asian and Minority Ethnic (BAME) community and are shown in **Figure 5**. Note that there were an additional 2 DBD and 2 DCD families approached where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 86% for eligible white donors and 36% for eligible BAME donors. For eligible DCD, the consent/authorisation rates were 60% for eligible white DCD and 31% for eligible BAME DCD.

The overall consent/authorisation rates were 72% for eligible white donors and 33% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 63% - 81% for eligible white donors and 16% - 51% 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, 83% of the eligible DBD and 64% 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, 6 (50%). There main reasons given for consented/authorised eligible DBD not proceeding were due to Coroner/Procurator Fiscal refusal, 2 (29%), the organs were deemed medically unsuitable on surgical inspection, 2 (29%) and general instability, 2 (29%).

	DBD		DCD	
	N	%	N	%
Coroner/ Procurator Fiscal refusal	2	28.6	-	-
Organs deemed medically unsuitable on surgical inspection	2	28.6	-	-
General instability	2	28.6	-	-
Cardiac arrest	1	14.3	-	-
Family changed mind	-	-	1	8.3
Organs deemed medically unsuitable by recipient centres	-	-	3	25.0
Prolonged time to asystole	-	-	6	50.0
Other	-	-	2	16.7
Total	7	100.0	12	100.0

9 FIVE YEAR TRENDS IN KEY NUMBERS AND RATES

Figures 6, 7, 8 and 9 illustrate the five-year trends in key numbers and rates across the UK. Note that patients who met the referral criteria for both DBD and DCD donation will appear in both DBD and DCD bar charts in Figure 7.

Over the last five years, the testing rate has remained consistent at 73%. DBD and DCD referral rates have continued to improve to 98% and 84% respectively. The actual number of missed referrals has continued to decrease in both DBD and DCD, to just 2 DBD and 29 DCD in 2018/19. There has been an increase in the percentage of family approaches where a SNOD was present, particularly in DCD where it has increased from 59% to 72%. The actual number of missed opportunities to have a SNOD present for the family approach has continued to decline in both DBD and DCD. In 2018/19 there has been increases in both the DBD and DCD consent/authorisation rates, with a DBD consent/authorisation rate of 73% and a DCD consent/authorisation rate of 51%.

Figure 6 Number of patients with suspected neurological death, 1 April 2014 – 31 March 2019

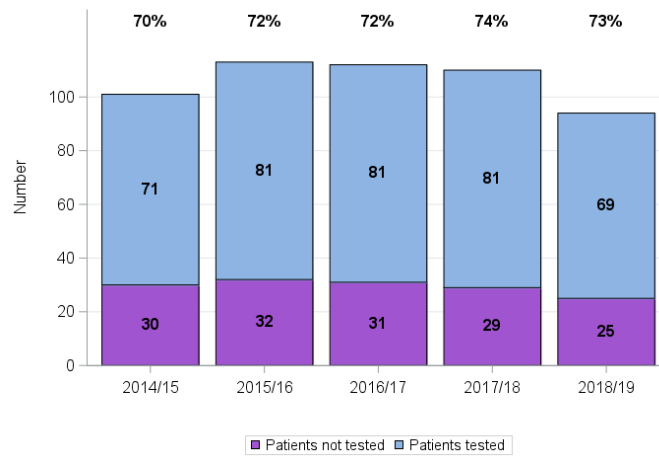


Figure 7 Number of patients meeting referral criteria, 1 April 2014 – 31 March 2019

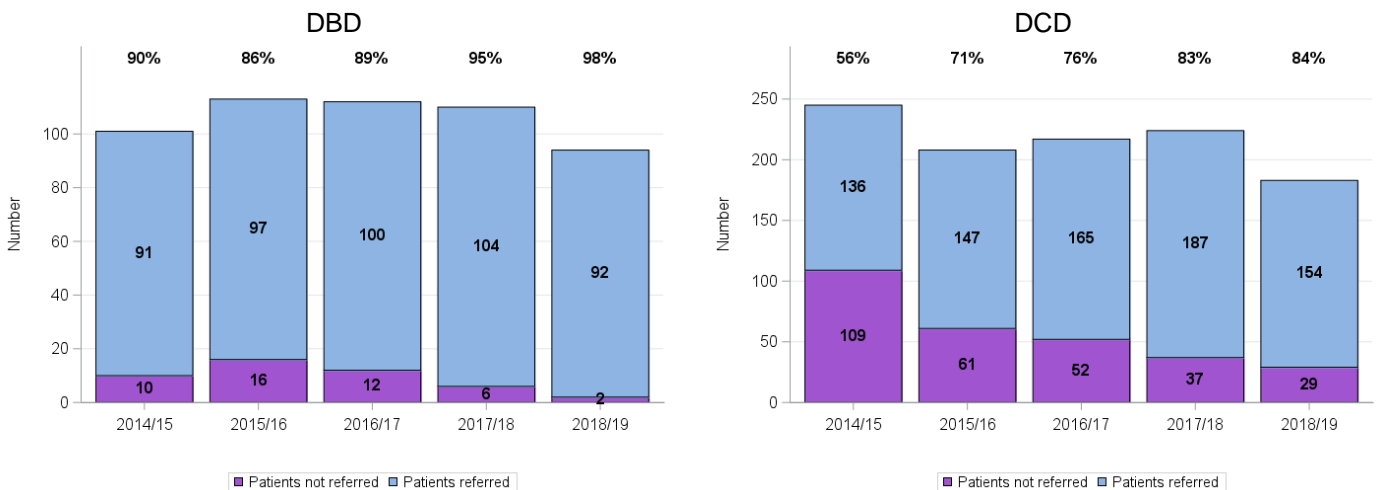


Figure 8 Number of families approached by SNOD presence, 1 April 2014 – 31 March 2019

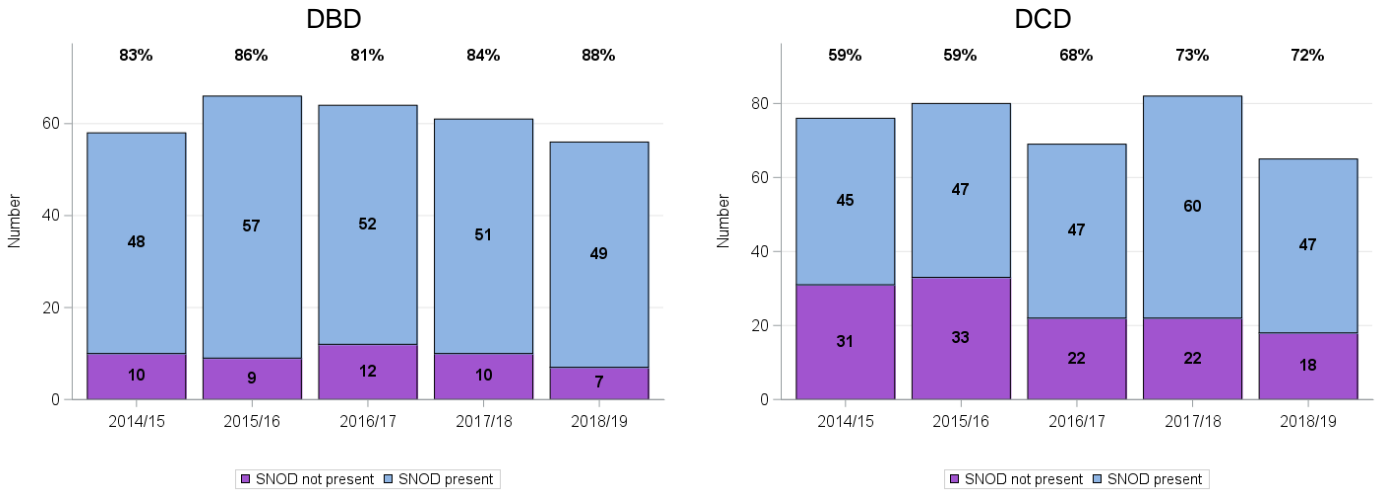
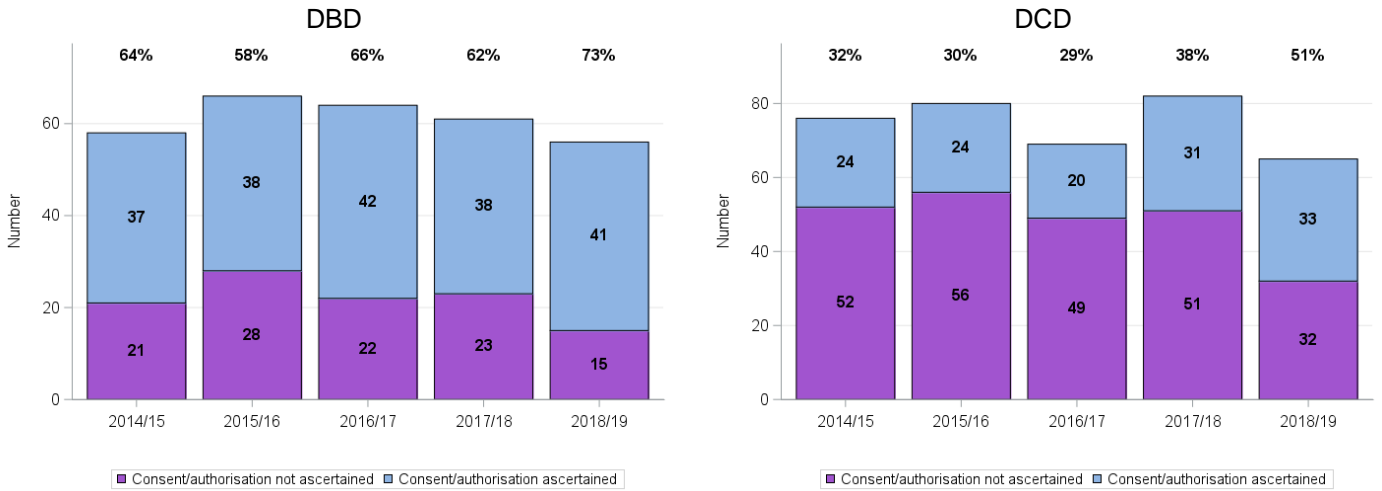


Figure 9 Number of families approached by consent/authorisation ascertained, 1 April 2014 – 31 March 2019



10 TRANSPLANT LIST

Table 7 shows the number of paediatric patients in the active transplant list as at 31 March 2019. In total there were 180 patients waiting for a transplant, 93 (52%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant was higher than as at 31 March 2018, with 130 waiting.

Table 7 Active paediatric transplant list in the UK, as at 31 March 2019 (2018)		
	Active transplant list	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Heart	35	(26)
Lung	8	(4)
Total cardiothoracic	43	(30)
Renal paediatric patients (<18 years at time of registration)		
Kidney	92	(62)
Kidney/pancreas	1	(0)
Total renal	93	(30)
Liver paediatric patients (<17 years at time of registration)		
Liver	36	(32)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	7	(4)
Multi-organ paediatric patients (<18 years at time of registration)		
	1	(2)
Total	180	(130)

11 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2018 to 31 March 2019 are presented in **Table 8**. In the 12-month period, there were a total of 270 transplants performed. Of these, 175 were deceased donor transplants and 95 were from living donors. Around half of all the paediatric transplants were kidney transplants.

Table 8 Paediatric transplants in the UK, 1 April 2018 – 31 March 2019 (2017/2018)		
	Transplant numbers	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Deceased heart	26	(36)
Heart and lung	2	(0)
Lung only – DBD	5	(5)
Lung only - DCD	1	(1)
Total cardiothoracic	34	(42)
Renal paediatric patients (<18 years at time of registration)		
Kidney - DBD	56	(57)
Kidney - DCD	4	(3)
Kidney – living donor	79	(72)
Total kidney	139	(132)
Liver paediatric patients (<17 years at time of registration)		
Liver - DBD	74	(72)
Liver - DCD	4	(7)
Liver – living or domino donor	16	(20)
Total liver	94	(99)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	1	(1)
Multi-organ paediatric patients (<18 years at time of registration)		
	2	(11)
Total	270	(285)

12 SUMMARY

In the year 1 April 2018 to 31 March 2019, there were 1,075 paediatric deaths audited for the PDA. Of these deaths, 94 and 183 patients met the referral criteria for DBD and/or DCD, respectively and 98% and 84% were referred to a SN-OD.

Of the 94 patients for whom neurological death was suspected, 73% were tested and there were 67 and 145 eligible DBD and DCD, respectively.

Of the families approached, consent/authorisation was ascertained for 73% eligible DBD donors and 51% of eligible DCD donors. Of these, 83% and 64%, respectively, became actual solid organ donors. No families overruled their loved one's known wish to be an organ donor.

Over the last five years, the testing rate has remained consistent at 73% and there have been improvements in referral, SNOD presence and consent rates for both DBD and, more notably, DCD donation.

At 31 March 2019, there were a total of 180 paediatric patients on the transplant list. In the year 1 April 2018 to 31 March 2019, 270 paediatric patients received a transplant. The number of paediatric patients on the transplant list at the end of the year increased by 50 patients compared with the end of 2017/18. There were 15 fewer paediatric patients transplanted during 2018/19 when compared with 2017/18.

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September 2019

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 2 months post term
Potential DBD donor	A patient who meets all four criteria for neurological death testing excluding those not tested due to reasons 'cardiac arrest despite resuscitation', 'brainstem reflexes returned', 'neonates – less than 2 months post term' (ie suspected neurological death, as defined above).
DBD referral criteria	A patient with suspected neurological death
Discussed with Specialist Nurse – Organ Donation	A patient with suspected neurological death discussed with the Specialist Nurse – Organ Donation (SNOD)
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 a nominated/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 , nominated/appointed representative gave consent, or where applicable 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 SNOD
Approach rate	Percentage of eligible DBD families approached for consent /authorisation for donation
Consent/authorisation rate	Percentage of families or nominated/appointed representatives approached for formal organ donation discussion where consent/authorisation was ascertained
SNOD presence rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SNOD was present
Consent/authorisation rate where SNOD was present	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SNOD was present where 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 a time frame to allow donation to occur, as determined at time of assessment
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 SNOD
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 the patient's expressed or deemed consent/authorisation decision, informed of a nominated/appointed representative, make a decision themselves on donation, or informed of a patient's opt-out decision via the Organ Donor Register
Consent/authorisation ascertained	Family supported expressed or deemed consent/authorisation , nominated/appointed representative gave consent, or where applicable 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 approached for consent /authorisation for donation
Consent / authorisation rate	Percentage of families or nominated/appointed representatives approached for formal organ donation discussion where consent/authorisation was ascertained
SNOD presence rate	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SNOD was present
Consent/authorisation rate where SNOD was present	Percentage of formal organ donation discussions with families or nominated/appointed representatives where a SNOD was present where consent/authorisation was ascertained