



**Blood and Transplant**

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

**SUMMARY REPORT FOR THE 12 MONTH PERIOD  
1 APRIL 2019 – 31 MARCH 2020**

**PUBLISHED SEPTEMBER 2020**

## Key messages

- In the year 1 April 2019 to 31 March 2020, there were 1,125 paediatric deaths audited for the PDA. Of these deaths, 93 and 223 patients met the referral criteria for DBD and/or DCD, respectively and 98% and 83% were referred to a SN-OD.
- Of the 93 patients for whom neurological death was suspected, 74% were tested and there were 65 and 180 eligible DBD and DCD, respectively.
- Of the families approached, consent/authorisation was ascertained for 68% eligible DBD donors and 46% of eligible DCD donors. Of these, 89% and 58% 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 around 73% and there have been improvements in referral and SNOD presence for both DBD and, more notably, DCD donation.
- At 29 February 2020, there were a total of 198 paediatric patients on the transplant list. In the year 1 April 2019 to 31 March 2020, 230 paediatric patients received a transplant. The number of paediatric patients on the transplant list at 29 February 2020 increased by 18 patients compared with the end of 2018/19. There were 40 fewer paediatric patients transplanted during 2019/20 when compared with 2018/19.

## 1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2019 to 31 March 2020 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 July 2020. 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](https://nhsbtdeb.blob.core.windows.net/umbraco-assetscorp/4376/contraindications_to_organ_donation.pdf)

**SNOD** Specialist Nurse in Organ Donation, including Specialist Requesters

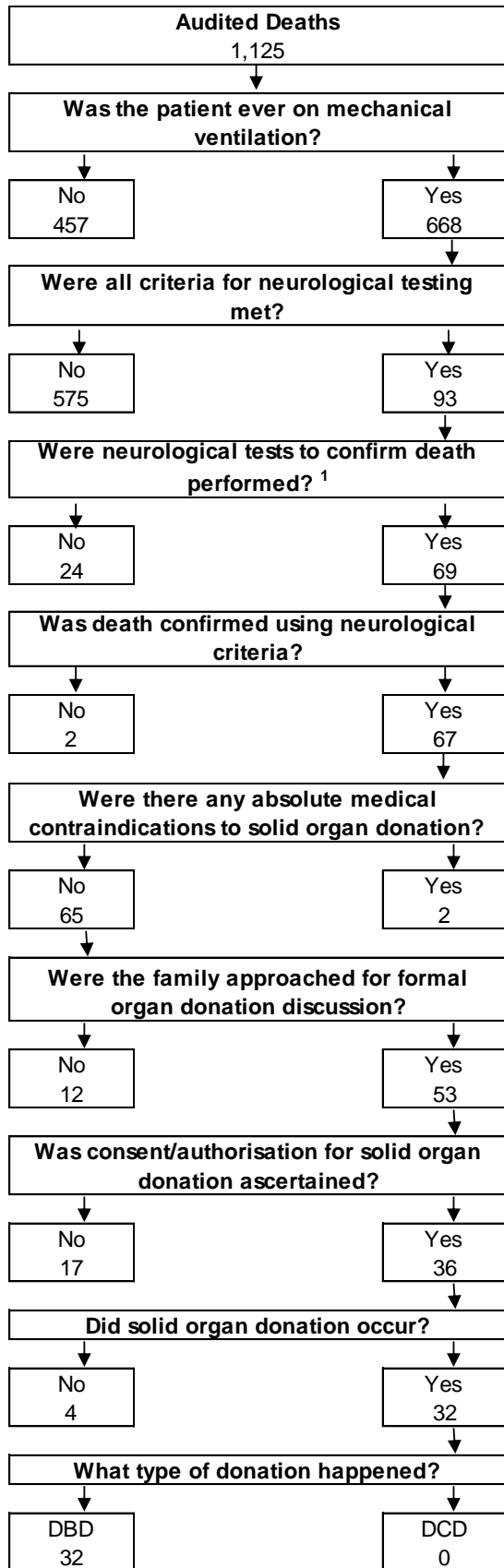
**Consent/authorisation rate** is the percentage of eligible donor families approached for organ donation discussion where consent/authorisation for donation was ascertained.

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

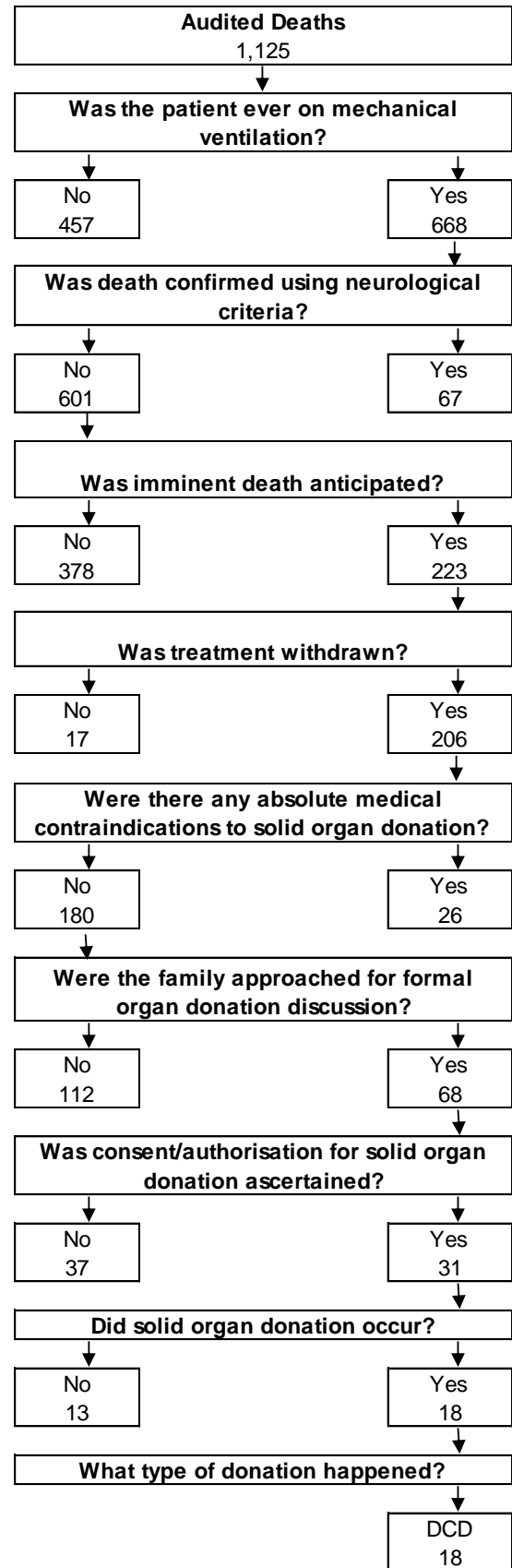
## 3 BREAKDOWN OF AUDITED PAEDIATRIC DEATHS

In the 12-month period from 1 April 2019 to 31 March 2020, there were a total of 1,125 audited paediatric patient deaths in the UK. A detailed breakdown for both the DBD and DCD data 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**



<sup>1</sup> 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**

	<b>DBD</b>	<b>DCD</b>	<b>All</b>
Patients meeting organ donation referral criteria <sup>1</sup>	93	223	290
Referred to SN-OD	91	184	250
<i>Referral rate %</i>	<i>97.8</i>	<i>82.5</i>	<i>86.2</i>
Neurological death tested	69		69
<i>Testing rate %</i>	<i>74.2</i>		<i>74.2</i>
Eligible donors <sup>2</sup>	65	180	245
Family approached	53	68	121
Family approached and SN-OD present	50	49	99
<i>% of approaches where SN-OD present</i>	<i>94.3</i>	<i>72.1</i>	<i>81.8</i>
Consent/authorisation given	36	31	67
<i>Consent/authorisation rate %</i>	<i>67.9</i>	<i>45.6</i>	<i>55.4</i>
Actual donors from each pathway	32	18	50
<i>% of consented/authorised donors that became actual donors</i>	<i>88.9</i>	<i>58.1</i>	<i>74.6</i>

<sup>1</sup> 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

<sup>2</sup> 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 24 patients (26%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 5 (21%) patients not tested, the reasons stated were biochemical/endocrine abnormality, clinical reason/clinician's decision and other reasons. Family pressure not to test, 2 (8%), haemodynamic instability, 2 (8%), and donor unsuitability, 2 (8%), were other reasons given.

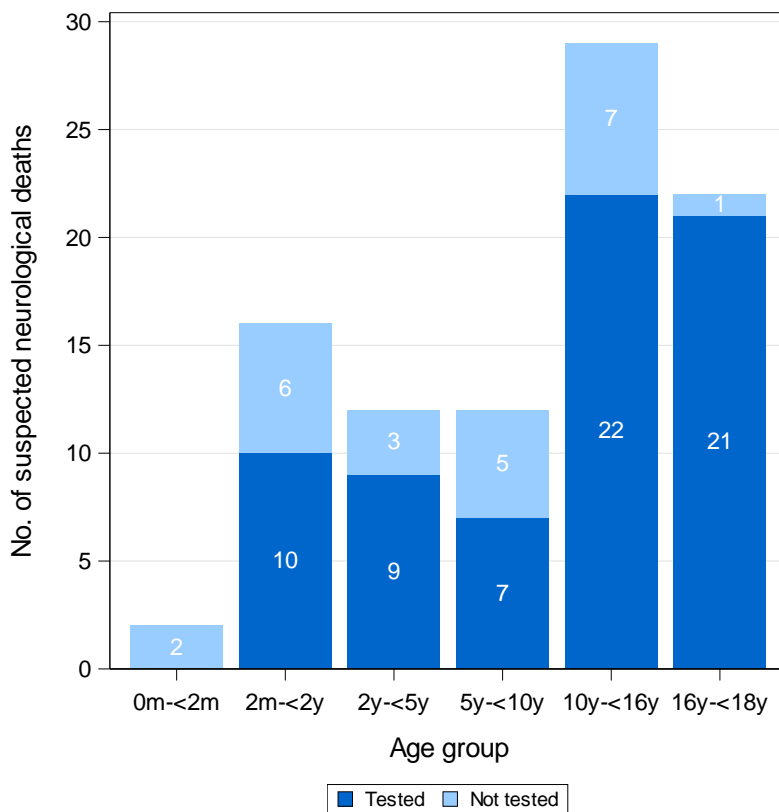
	<b>N</b>	<b>%</b>
Biochemical/endocrine abnormality	5	20.8
Clinical reason/Clinicians decision	5	20.8
Other	5	20.8
Family pressure not to test	2	8.3
Patient haemodynamically unstable	2	8.3
SN-OD advised that donor not suitable	2	8.3
Family declined donation	1	4.2
Treatment withdrawn	1	4.2
Unknown	1	4.2
<b>Total</b>	<b>24</b>	<b>100.0</b>

#### 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 93 neurological deaths suspected in paediatric patients in the UK from 1 April 2019 – 31 March 2020 and a total of 69 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 of 95%.

**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 83%. **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 the family declined donation after neurological testing and the reason given for the other patient was 'Other' reason. The reason given for 16 (41%) DCD patients was the patient was not identified as a potential donor/organ donation was not considered.

	DBD		DCD	
	N	%	N	%
Family declined donation prior to neurological testing	1	50.0	-	-
Other	1	50.0	7	17.9
Not identified as a potential donor/organ donation not considered	-	-	16	41.0
Family declined donation following decision to withdraw treatment	-	-	2	5.1
Reluctance to approach family	-	-	1	2.6
Medical contraindications	-	-	6	15.4
Thought to be medically unsuitable	-	-	7	17.9
<b>Total</b>	<b>2</b>	<b>100.0</b>	<b>39</b>	<b>100.0</b>

## 6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 82% and 38% 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 7 (58%) cases, was 'Other' reason. In 3 (25%) cases the reason for not approaching the family was Coroner/Procurator Fiscal refused permission.

The main reasons stated for not approaching families of eligible DCD donors, were the patient's general medical condition 44 (39%) and 'Other' reason 26 (23%). The majority of these cases are due to the DCD assessment process which identifies patients unsuitable for donation prior to the approach. For 17 (15%) patients the Coroner/Procurator Fiscal refused permission and for 12 (11%) patients the reason stated was the patient was not identified as a potential donor / organ donation was not considered.

	DBD		DCD	
	N	%	N	%
Other	7	58.3	26	23.2
Coroner / Procurator Fiscal refused permission	3	25.0	17	15.2
Patient's general medical condition	2	16.7	44	39.3
Family stated that they would not support donation before they were formally approached	-	-	1	0.9
Family considered too upset to approach	-	-	1	0.9
Other medical reason	-	-	10	8.9
Patient outside age criteria	-	-	1	0.9
Not identified as a potential donor / organ donation not considered	-	-	12	10.7
<b>Total</b>	<b>12</b>	<b>100.0</b>	<b>112</b>	<b>100.0</b>

## 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 68% and the 95% confidence limits for this percentage are 55% - 80%. The DCD consent/authorisation rate was 46% and the 95% confidence limits for this percentage are 34% - 57%. The overall consent/authorisation rate was 55% and the 95% confidence limits for this percentage are 44% - 67%.

Four 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. One of these children was less than 16 years old. Consent/authorisation was ascertained for all four donors registered on the ODR. No families overruled their loved one's known wish to be an organ donor.

The consent/authorisation rate was 54% when a patient's ODR status was not known at the time of approach.

Of the 3 DBD families approached for formal organ donation discussion, where the SN-OD was not present, consent/authorisation was not ascertained. For DCD patients, consent/authorisation was ascertained for 3 of the 19 eligible DCD patients when the SN-OD was not present. The overall the consent/authorisation rate was 65%, when the SN-OD was present compared to 14% 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 were that the family felt the patient had suffered enough, 5 (29%) and the family did not want surgery to the body, 5 (29%). The main reasons that families of eligible DCD patients did not support organ donation was 'Other' reason, 10 (27%) and the family felt the patient had suffered enough 9 (24%).



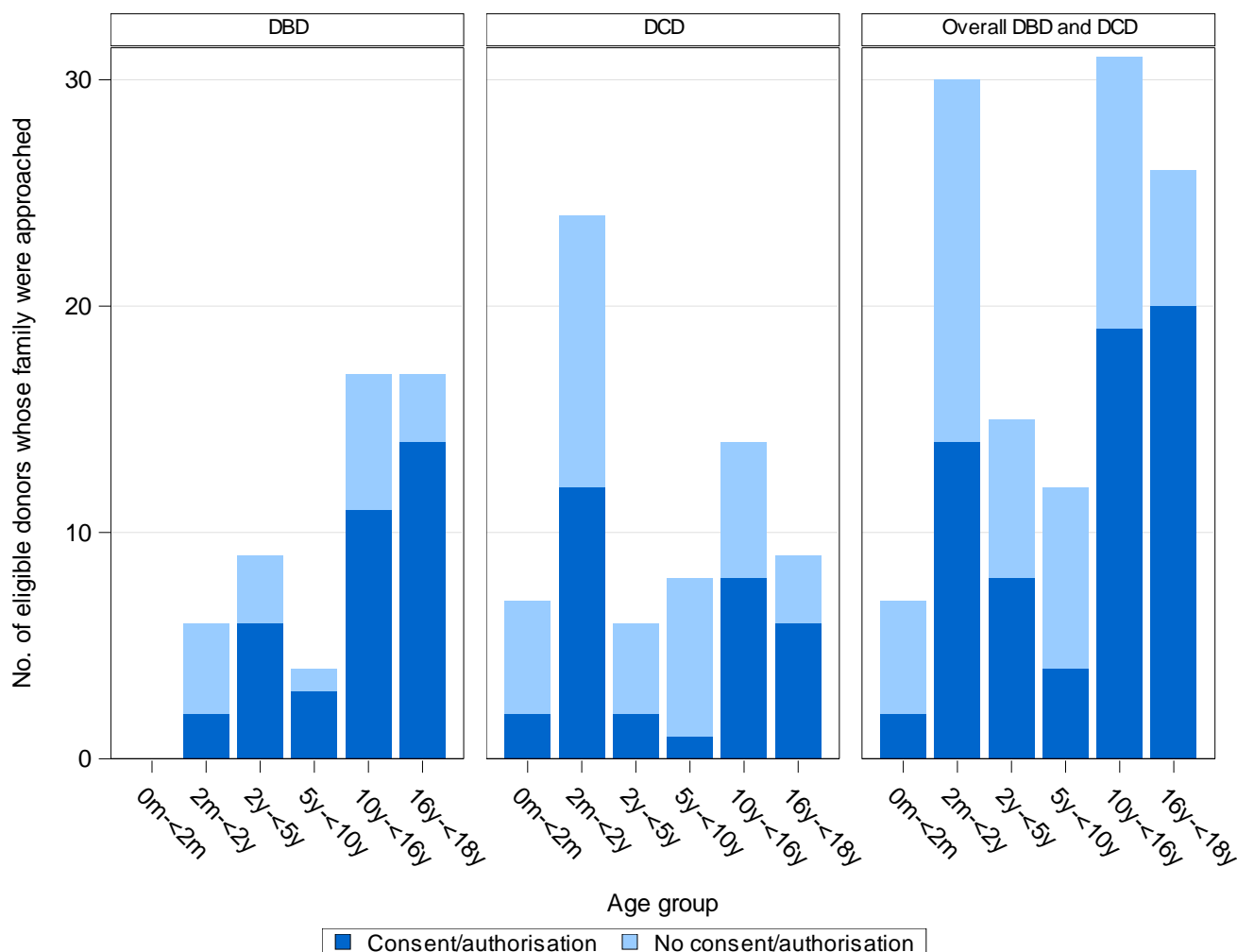
**Table 5**      **Reasons given why family did not support organ donation**

	DBD		DCD	
	N	%	N	%
Family felt the patient had suffered enough	5	29.4	9	24.3
Family did not want surgery to the body	5	29.4	3	8.1
Family felt it was against their religious/cultural beliefs	2	11.8	1	2.7
Family did not believe in donation	1	5.9	-	-
Family wanted to stay with the patient after death	1	5.9	1	2.7
Family had difficulty understanding/accepting neurological testing	1	5.9	-	-
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	1	5.9	1	2.7
Other	1	5.9	10	27.0
Patient previously expressed a wish not to donate	-	-	1	2.7
Family were divided over the decision	-	-	1	2.7
Family felt the length of time for donation process was too long	-	-	5	13.5
Family concerned that organs may not be transplanted	-	-	1	2.7
Family concerned donation may delay the funeral	-	-	1	2.7
Strong refusal - probing not appropriate	-	-	3	8.1
<b>Total</b>	<b>17</b>	<b>100.0</b>	<b>37</b>	<b>100.0</b>

## 7.1 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

The consent/authorisation rates for the six age groups (for the 53 eligible DBD and 68 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 (77%). The lowest consent/authorisation rate was in the 2 months - <2 years age group (29%).

**Figure 4** Number of families approached by age group

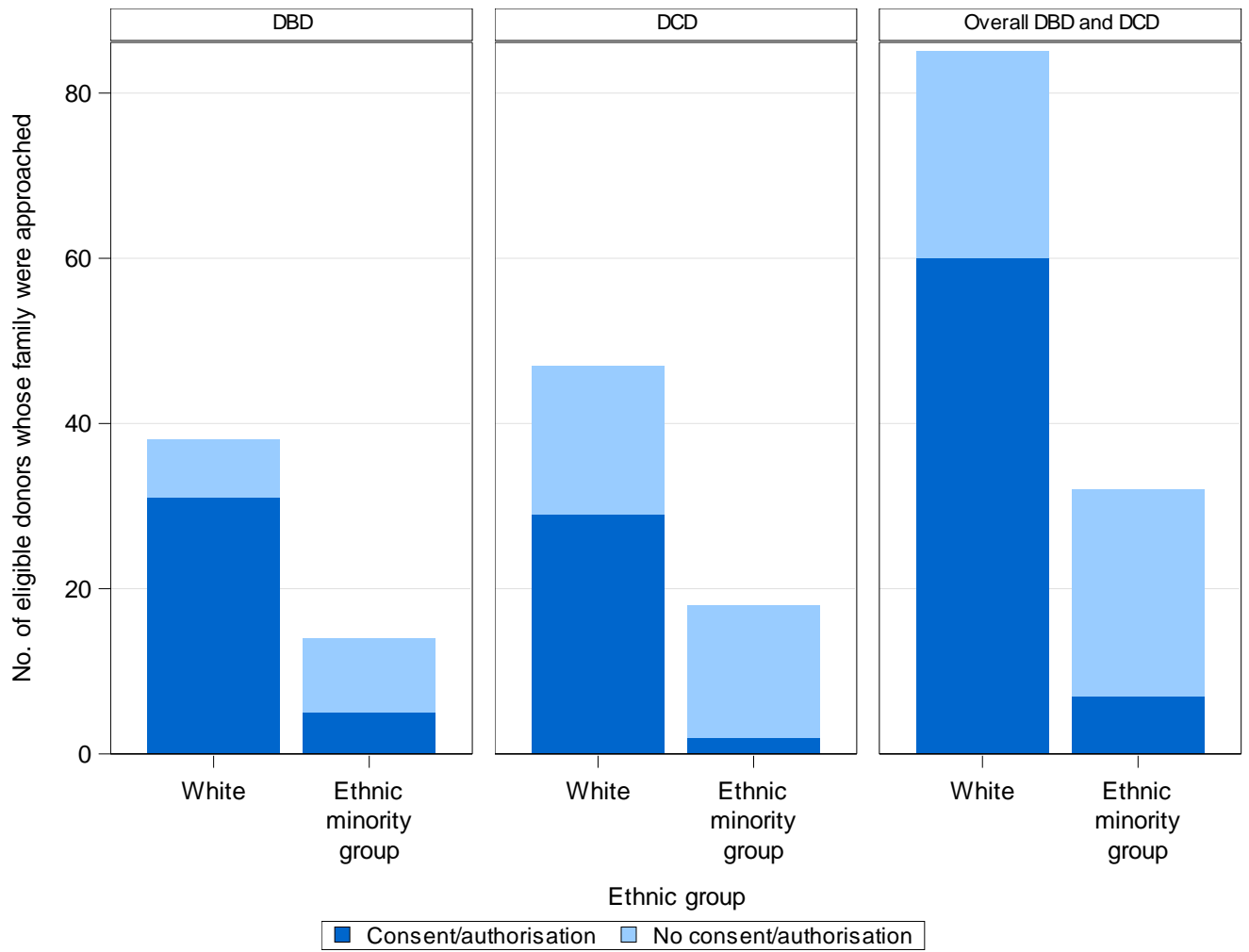


Consent/authorisation rates for patients from the white ethnic community are compared with patients from the Black, Asian and Minority Ethnic (BAME) community and are shown in **Figure 5**. There were a total of 32 approaches to families of BAME patients, 14 DBD and 18 DCD. Note that there was an additional DBD and 3 DCD families approached where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 82% for eligible white donors and 36% for eligible BAME donors. For eligible DCD, the consent/authorisation rates were 62% for eligible white DCD and 11% for eligible BAME DCD.

The overall consent/authorisation rates were 71% for eligible white donors and 22% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 61% - 80% for eligible white donors and 8% - 36% 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, 89% of the eligible DBD and 58% 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 that the organs were deemed medically unsuitable by recipient centres, 6 (46%). The reasons given for consented/authorised eligible DBD not proceeding were due to the family changed their mind, 1 (25%), Coroner/Procurator Fiscal refusal, 1 (25%), the organs were deemed medically unsuitable by recipient centres, 1 (25%) and cardiac arrest, 1 (25%).

	<b>DBD</b>		<b>DCD</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
Family changed mind	1	25.0	1	7.7
Coroner/ Procurator Fiscal refusal	1	25.0	1	7.7
Organs deemed medically unsuitable by recipient centres	1	25.0	6	46.2
Cardiac arrest	1	25.0	1	7.7
Prolonged time to asystole	-	-	3	23.1
Other	-	-	1	7.7
<b>Total</b>	<b>4</b>	<b>100.0</b>	<b>13</b>	<b>100.0</b>

## 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 around 73%. DBD and DCD referral rates have continued to improve to 98% and 83% respectively. The actual number of missed referrals has continued to decrease for DBD, to just 2 in 2019/20. The actual number of missed referrals for DCD has slightly increased to 39 in 2019/20, compared to 29 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% over 5 years. The actual number of missed opportunities to have a SNOD present for the family approach has continued to decline in DBD but remained static in DCD donation. In 2019/20 there have been slight decreases in both the DBD and DCD consent/authorisation rates, with a DBD consent/authorisation rate of 68% and a DCD consent/authorisation rate of 46%.

Figure 6 Number of patients with suspected neurological death, 1 April 2015 – 31 March 2020

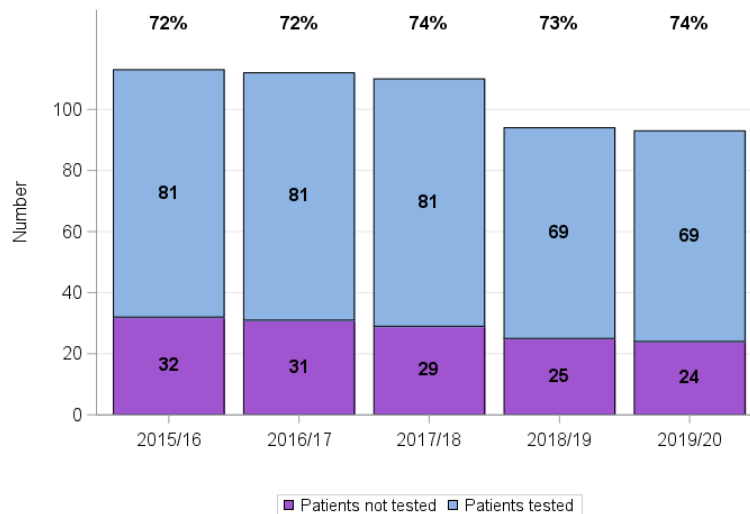
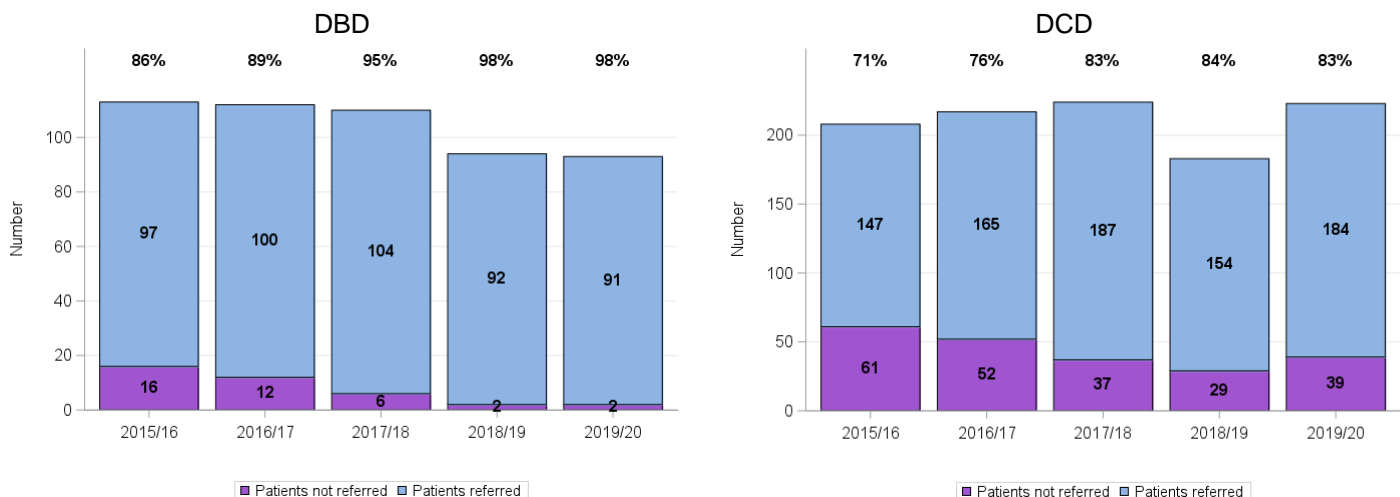
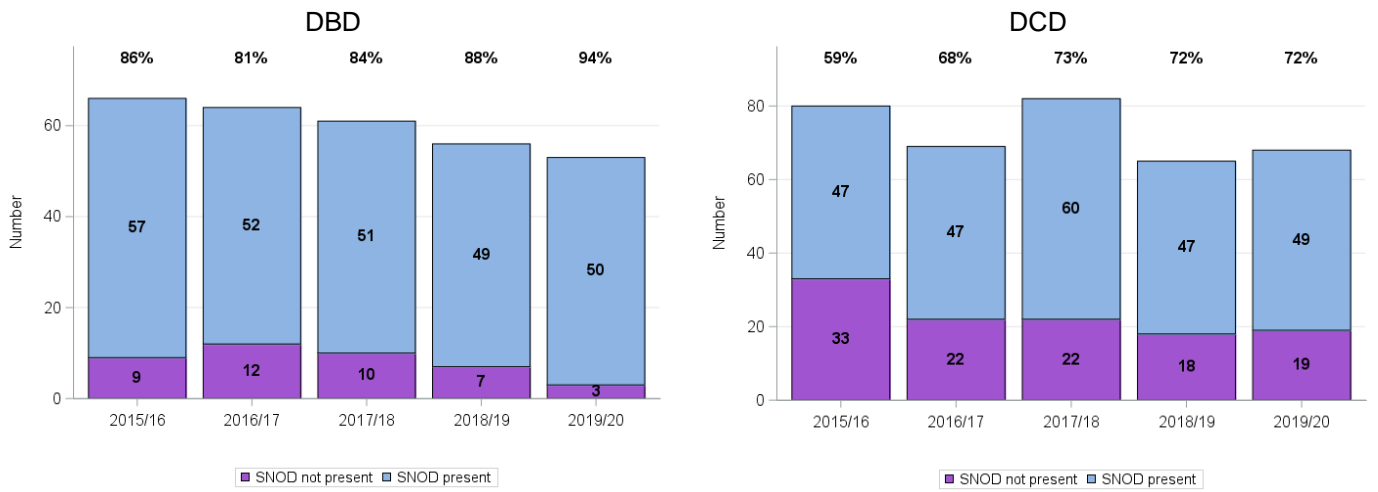


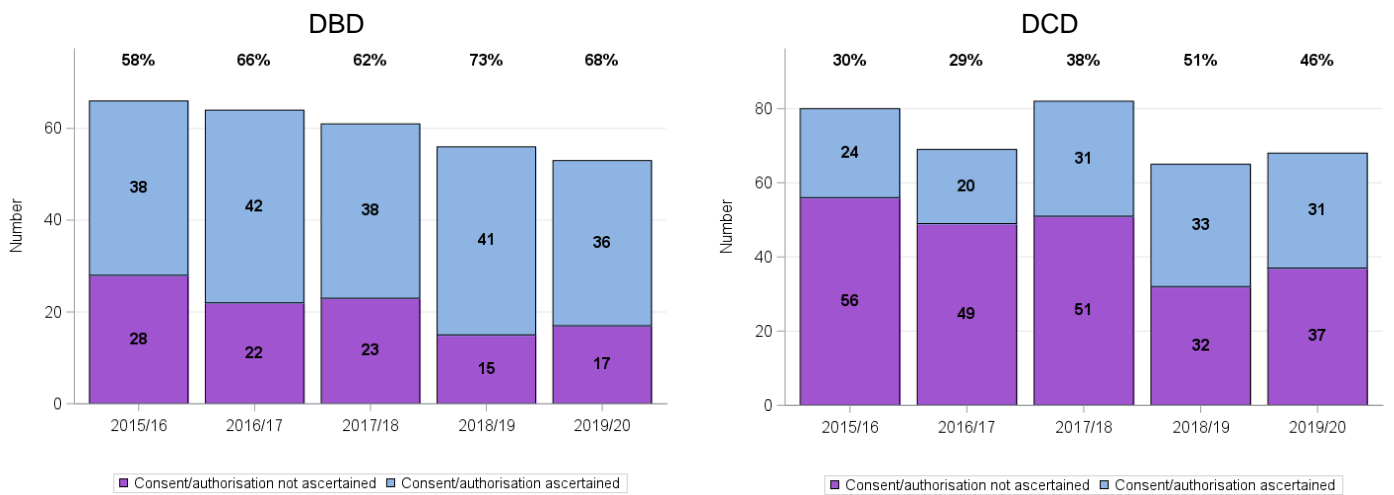
Figure 7 Number of patients meeting referral criteria, 1 April 2015 – 31 March 2020



**Figure 8** Number of families approached by SNOD presence, 1 April 2015 – 31 March 2020



**Figure 9** Number of families approached by consent/authorisation ascertained, 1 April 2015 – 31 March 2020



## 10 TRANSPLANT LIST

**Table 7** shows the number of paediatric patients in the active transplant list as at 29 February 2020. Waiting list figures at the 31 March 2020 do not accurately reflect the need for an organ transplant due to the COVID-19 pandemic. Different practices have been established across the UK and across organ groups with regards to waiting list management. Due to this, a snapshot of the waiting list at 29 February 2020 is used to better reflect activity near the end of 2019/20. In total there were 198 patients waiting for a transplant, 111 (56%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant was higher than as at 31 March 2019, with 180 waiting.

<b>Table 7 Active paediatric transplant list in the UK, as at 29 February 2020 (31 March 2019)</b>		
	<b>Active transplant list</b>	
<b>Cardiothoracic paediatric patients (&lt; 16 years at time of registration)</b>		
Heart	36	(35)
Lung	2	(8)
<b>Total cardiothoracic</b>	<b>38</b>	<b>(43)</b>
<b>Renal paediatric patients (&lt;18 years at time of registration)</b>		
Kidney	110	(92)
Kidney/pancreas	1	(1)
<b>Total renal</b>	<b>111</b>	<b>(93)</b>
<b>Liver paediatric patients (&lt;17 years at time of registration)</b>		
Liver	37	(36)
<b>Intestinal paediatric patients (&lt;18 years at time of registration)</b>		
Intestinal	10	(7)
<b>Multi-organ paediatric patients (&lt;18 years at time of registration)</b>		
	2	(1)
<b>Total</b>	<b>198</b>	<b>(180)</b>

## 11 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2019 to 31 March 2020 are presented in **Table 8**. In the 12-month period, there were a total of 230 transplants performed. Of these, 148 were deceased donor transplants and 82 were from living donors. Around half of all the paediatric transplants were kidney transplants.

<b>Table 8 Paediatric transplants in the UK, 1 April 2019 – 31 March 2020 (2018/2019)</b>		
	<b>Transplant numbers</b>	
<b>Cardiothoracic paediatric patients (&lt; 16 years at time of registration)</b>		
Deceased heart	23	(26)
Heart and lung	0	(2)
Lung only – DBD	3	(5)
Lung only - DCD	0	(1)
<b>Total cardiothoracic</b>	<b>26</b>	<b>(34)</b>
<b>Renal paediatric patients (&lt;18 years at time of registration)</b>		
Kidney - DBD	36	(56)
Kidney - DCD	6	(4)
Kidney – living donor	70	(79)
<b>Total kidney</b>	<b>112</b>	<b>(139)</b>
<b>Liver paediatric patients (&lt;17 years at time of registration)</b>		
Liver - DBD	76	(74)
Liver - DCD	1	(4)
Liver – living or domino donor	12	(16)
<b>Total liver</b>	<b>89</b>	<b>(94)</b>
<b>Intestinal paediatric patients (&lt;18 years at time of registration)</b>		
Intestinal	1	(1)
<b>Multi-organ paediatric patients (&lt;18 years at time of registration)</b>		
	2	(2)
<b>Total</b>	<b>230</b>	<b>(270)</b>



## Appendix I - Definitions

<b>POTENTIAL DONOR AUDIT / REFERRAL RECORD</b>	
Data excluded	Patients who did not die on a critical care unit or an emergency department and patients aged over 80 years are excluded.
<b>Donors after brain death (DBD)</b>	
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

<b>Donors after circulatory death (DCD)</b>	
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