



Blood and Transplant

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

**SUMMARY REPORT FOR THE 12 MONTH PERIOD
1 APRIL 2020 – 31 MARCH 2021**

PUBLISHED SEPTEMBER 2021

Key messages

- In the year 1 April 2020 to 31 March 2021, there were 982 paediatric deaths audited for the PDA. Of these deaths, 92 and 206 patients met the referral criteria for DBD and/or DCD, respectively and 98% and 86% were referred to a SNOD.
- Of the 92 patients for whom neurological death was suspected, 67% were tested and there were 59 and 165 eligible DBD and DCD, respectively.
- Of the families approached, consent/authorisation was ascertained for 57% eligible DBD donors and 52% of eligible DCD donors. Of these, 92% and 82% respectively, became actual solid organ donors. No families overruled their loved one's known wish to be an organ donor.
- The testing rate has fallen to 67% in the most recent year after staying consistent for the previous 4 years. The DBD referral rate has improved over the past 5 years, rising to 98%. The DBD SNOD presence rate has fallen in the past year but remains an improvement over the past 5 years. The DBD consent rate has fallen in the past year to a 5-year low. The DCD referral, SNOD presence and consent rates have all continued to improve over the past 5 years.
- At 31 March 2021, there were a total of 206 paediatric patients on the transplant list. In the year 1 April 2020 to 31 March 2021, 226 paediatric patients received a transplant. The number of paediatric patients on the transplant list at 31 March 2021 increased by 12 patients compared with 29 February 2020. There were 8 fewer paediatric patients transplanted during 2020/21 when compared with 2019/20.

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2020 to 31 March 2021 and summaries of the following are provided:

- POTENTIAL DONOR AUDIT
- TRANSPLANT LIST
- TRANSPLANT ACTIVITY

The PDA dataset used to compile this report includes all audited paediatric deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 10 May 2021. 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, with no absolute medical contraindications to solid organ donation.

Absolute medical contraindications to organ donation are listed here:
https://nhsbtddb.blob.core.windows.net/umbraco-assets-corp/6455/contraindications_to_organ_donation.pdf

SNOD Specialist Nurse in Organ Donation, including Specialist Requesters

The consent/authorisation rate is the percentage of eligible donor donation decision conversations where consent/authorisation 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 2020 to 31 March 2021, there were a total of 982 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

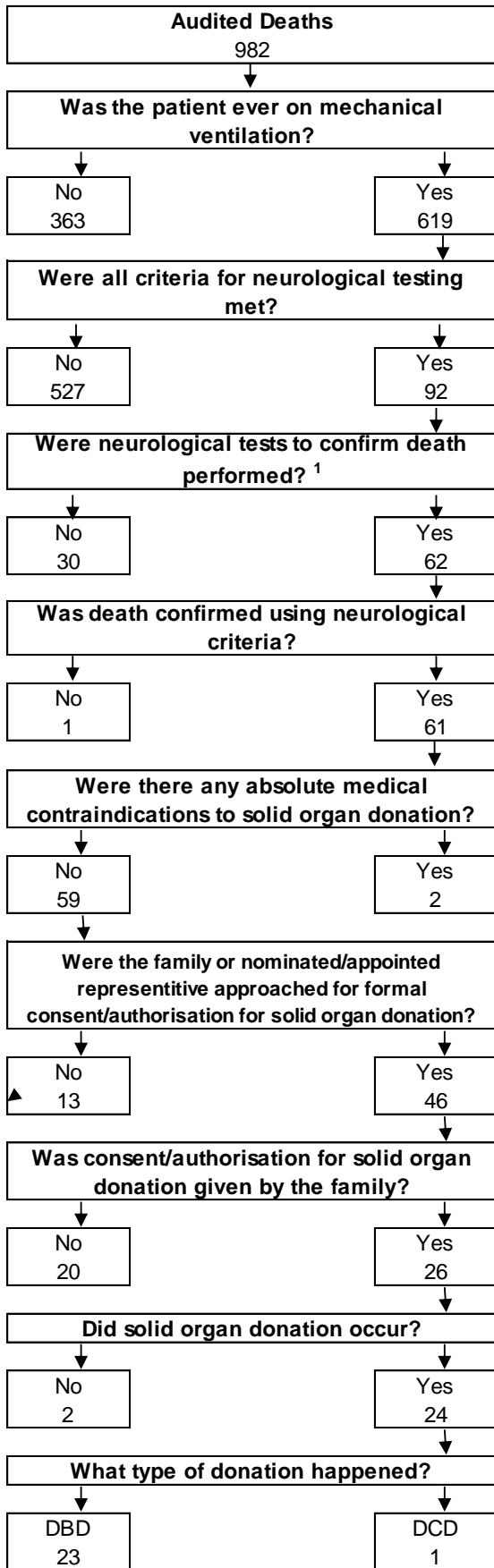
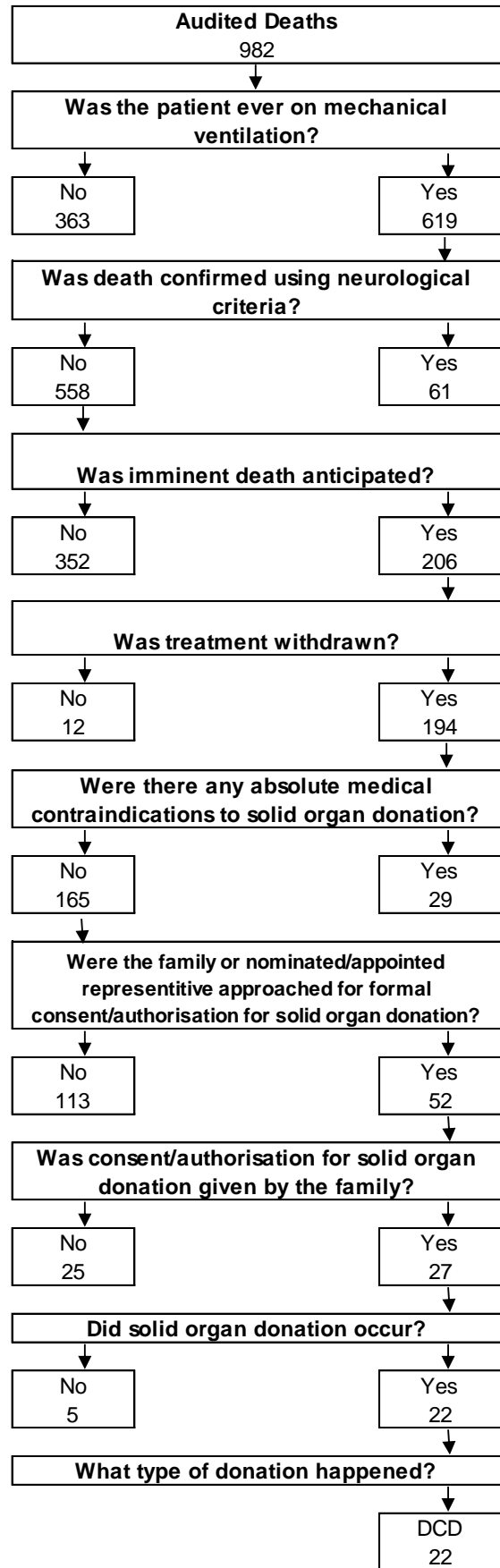


Figure 2 Donation after circulatory death



¹ Patients for whom tests were not performed due to; cardiac arrest despite resuscitation occurred, brainstem reflexes returned, or neonates - less than 2 months post term 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	92	206	269
Referred to NHS Blood and Transplant	90	177	238
<i>Referral rate %</i>	<i>97.8</i>	<i>85.9</i>	<i>88.5</i>
Neurological death tested	62		62
<i>Testing rate %</i>	<i>67.4</i>		<i>67.4</i>
Eligible donors ²	59	165	224
Family approached	46	52	98
Family approached and SNOD present	40	40	80
<i>% of approaches where SNOD present</i>	<i>87</i>	<i>76.9</i>	<i>81.6</i>
Consent/authorisation given	26	27	53
<i>Consent/authorisation rate %</i>	<i>56.5</i>	<i>51.9</i>	<i>54.1</i>
- Expressed opt in	4	6	10
- <i>Expressed opt in %</i>	<i>100</i>	<i>100</i>	<i>100</i>
- Other*	22	21	43
- <i>Other* %</i>	<i>53.7</i>	<i>47.7</i>	<i>50.6</i>
Actual donors from each pathway	24	22	46
<i>% of consented/authorised donors that became actual donors</i>	<i>92.3</i>	<i>81.5</i>	<i>86.8</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 2 months post term 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 a time frame to allow donation to occur			
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			
* Includes all patients who have not expressed a donation decision and those, aged 16 or 17 in Scotland, where deemed criteria are not met.			

4 NEUROLOGICAL DEATH TESTING RATE

The neurological death testing rate was 67%, this 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 criteria - invasive ventilation, Glasgow Coma Scale 3 not explained by sedation, no respiratory effort, fixed pupils, no cough or gag reflex. 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 30 patients (33%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

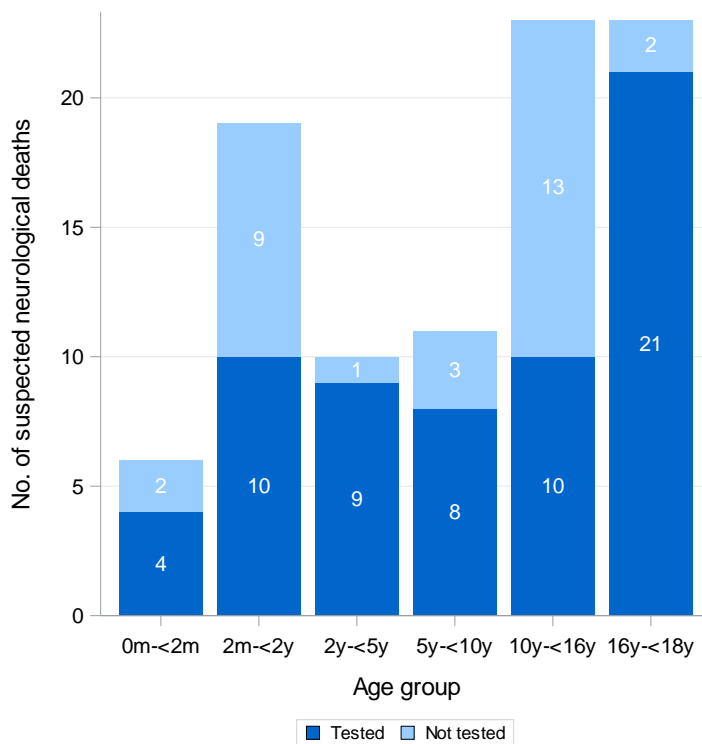
Family pressure not to test and 'other' were each stated as the reason for not testing for 5 (17%) patients. The family declining donation, the continuing effects of sedatives and clinical reason or the clinician's decision were each given as the reason for not testing 4 (13%) patients.

Table 2 Reasons given for neurological death tests not being performed		
	N	%
Family pressure not to test	5	16.7
Other	5	16.7
Family declined donation	4	13.3
Continuing effects of sedatives	4	13.3
Clinical reason/Clinician's decision	4	13.3
Patient haemodynamically unstable	2	6.7
Inability to test all reflexes	2	6.7
Treatment withdrawn	1	3.3
Biochemical/endocrine abnormality	1	3.3
SN-OD advised that donor not suitable	1	3.3
Medical contraindication to donation	1	3.3
Total	30	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 92 neurological deaths suspected in paediatric patients in the UK from 1 April 2020 – 31 March 2021 and a total of 62 deaths where neurological tests were performed (67%). **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 91%.

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, should be referred to a Specialist Nurse Organ Donation (SNOD). The DBD referral rate was 98% and the DCD referral rate was 86%.

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**.

For the 2 (100%) DBD patients who met referral criteria but were not referred, the reason given for non-referral was the family declined donation prior to neurological testing. For patients who met the DCD referral criteria but were not referred, 13 (45%) patients were thought to be medically unsuitable. The reason given for not referring 9 (31%) patients meeting the DCD referral criteria was that the patients were not identified as potential donors and so organ donation was not considered.

Reasons given why patient not referred	DBD		DCD	
	N	%	N	%
Family declined donation prior to neurological testing	2	100.0	-	-
Not identified as potential donor/organ donation not considered	-	-	9	31.0
Coroner / Procurator Fiscal reason	-	-	1	3.4
Family declined donation following decision to remove treatment	-	-	2	6.9
Medical contraindications	-	-	2	6.9
Thought to be medically unsuitable	-	-	13	44.8
Other	-	-	2	6.9
Total	2	100.0	29	100.0

6 APPROACH RATE

Families of eligible donors were asked to make or support a patient's organ donation decision in 78% of DBD and 32% of DCD cases. 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. Prior to September 2020 it was not possible to identify such cases and consequently, the DCD approach rate, for 2020/21 underestimates the actual approach rate, as families of these patients are never approached for the formal organ donation discussion. The reason for not approaching is grouped with '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 9 (69%) cases, was the Coroner/Procurator Fiscal refused permission. In 2 (15%) cases the reason for not approaching the family was other reason.

For eligible DCD donors not approached 56 (50%) were deemed unsuitable by DCD assessment prior to approach.

Other reason was given for 40 (35%) of DCD donors not approached. The majority of these cases were also deemed unsuitable by DCD assessment prior to approach but these data were not capture separately prior to September 2020.

Table 4 Reasons given why family were not asked to make or support patient's organ donation decision					
	DBD		DCD		
	N	%	N	%	
Coroner/Proc Fiscal refused permission	9	69.2	7	6.2	
Other	2	15.4	40	35.4	
Family stated they would not consent/authorise prior to donation decision conversation	1	7.7	5	4.4	
Not identified as a potential donor	1	7.7	5	4.4	
Deemed unsuitable by DCD assessment prior to approach	-	-	56	49.6	
Total	13	100.0	113	100.0	

7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose families asked to make or support a patient's organ donation decision. 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 57% and the 95% confidence limits for this percentage are 42% - 71%. The DCD consent/authorisation rate was 52% and the 95% confidence limits for this percentage are 38% - 66%. The overall consent/authorisation rate was 54% and the 95% confidence limits for this percentage are 44% - 64%.

Two 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. Both of these children were older than 16 years old. Consent/authorisation was ascertained for both donors registered on the ODR. No families overruled their loved one's known wish to be an organ donor.

The consent/authorisation rate was 53% when the patient had not expressed a opt in decision.

For the 6 DBD families who were asked to make or support a patient's organ donation decision, where the SN-OD was not present, consent/authorisation was not ascertained in any of the approaches. For DCD patients, consent/authorisation was ascertained for 2 of the 12 eligible DCD patients when the SN-OD was not present. The overall consent/authorisation rate was 64% when the SN-OD was present compared to 11% when the SN-OD was not present.

The reasons why the family did not support organ donation are shown in **Table 5**. The main reasons given that families of eligible DBD patients did not support organ donation were that the family did not want surgery to the body, 7 (35%) and other, 4 (20%). The main reasons that families of eligible DCD patients did not support organ donation were

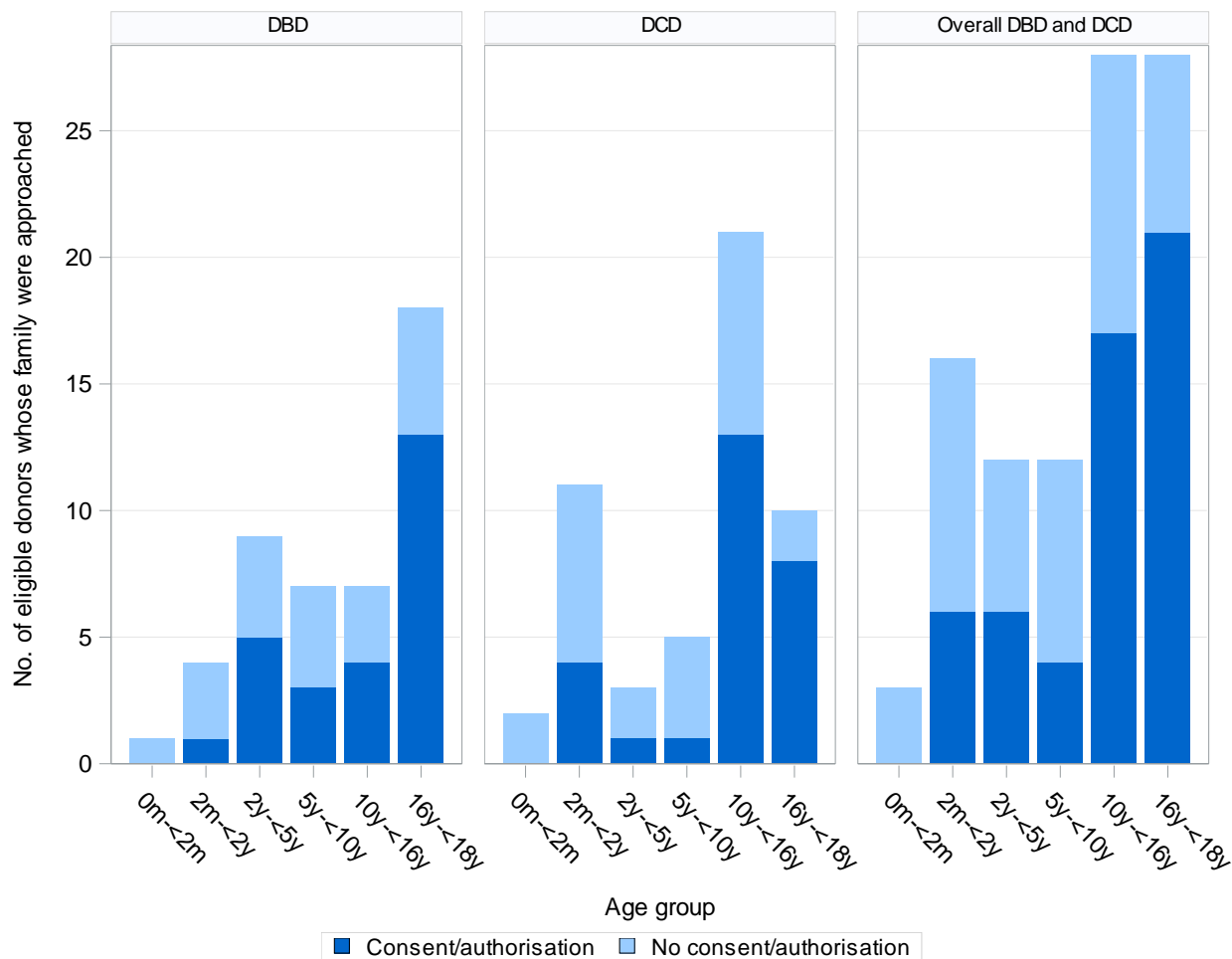
other, 5 (20%), the family felt it was against their religious/cultural beliefs, 5 (20%), and the family felt the length of time for the donation process was too long, 5 (20%).

Table 5 Reasons why the family did not support organ donation					
	DBD		DCD		
	N	%	N	%	
Family did not want surgery to the body	7	35.0	5	20.0	
Other	4	20.0	5	20.0	
Family felt it was against their religious/cultural beliefs	2	10.0	2	8.0	
Family felt the length of time for the donation process was too long	2	10.0	5	20.0	
Family felt that the body should be buried whole (unrelated to religious/cultural reasons)	2	10.0	-	-	
Patient had registered a decision to Opt Out	1	5.0	-	-	
Family felt patient had suffered enough	1	5.0	4	16.0	
Family had difficulty understanding/accepting neurological testing	1	5.0	-	-	
Patient had previously expressed a wish not to donate	-	-	2	8.0	
Family divided over the decision	-	-	1	4.0	
Family wanted to stay with the patient after death	-	-	1	4.0	
Total	20	100.0	25	100.0	

7.1 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

The consent/authorisation rates for the six age groups (for the 46 eligible DBD and 52 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 (75%). The lowest consent/authorisation rate was in the 0 months - <2 months group (0%).

Figure 4 Number of families approached by age group

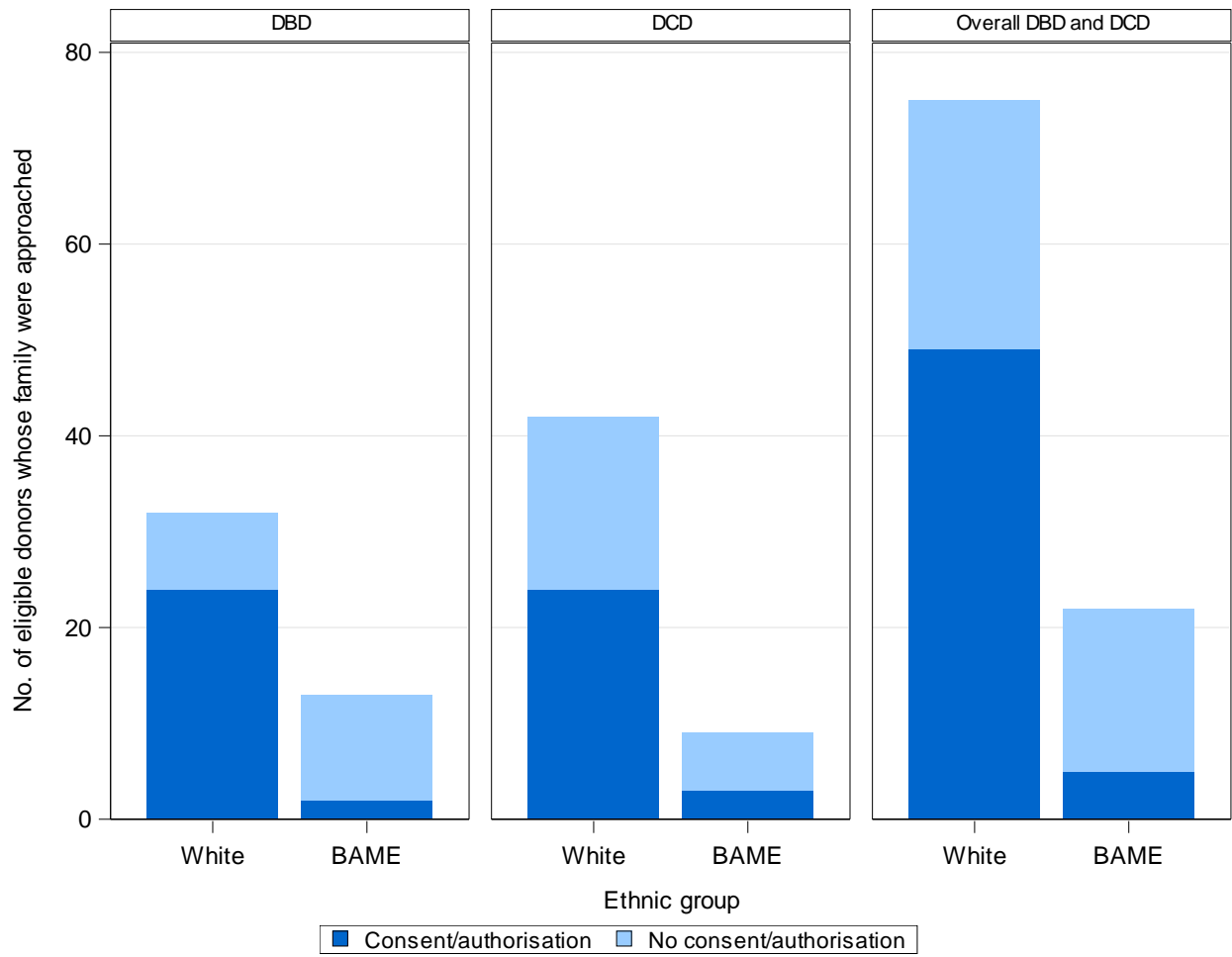


Consent/authorisation rates for patients from the white ethnic community are compared with patients from Black, Asian, Mixed Race and Minority Ethnic (BAME) communities and are shown in **Figure 5**. There were a total of 22 approaches to families of BAME patients, 13 DBD and 9 DCD. Note that there was an additional DBD family and an additional DCD family approached where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 75% for eligible white donors and 15% for eligible BAME donors. For eligible DCD, the consent/authorisation rates were 57% for eligible white DCD and 33% for eligible BAME DCD.

The overall consent/authorisation rates were 65% for eligible white donors and 23% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 54% - 76% for eligible white donors and 5% - 40% for eligible BAME donors.

Figure 5 Number of approaches by patient ethnicity



8 SOLID ORGAN DONATION

Of the eligible donors whose families consented to/authorised donation, 92% of the eligible DBD and 82% 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 reasons given for the two consented/authorised eligible DBD patients not proceeding to become solid organ donors were that the organs were deemed medically unsuitable by recipient centres and positive virology. The main reasons given for consented/authorised eligible DCD not proceeding was that the organs were deemed medically unsuitable by recipient centres, 2 (40%) and next of kin withdrew consent / authorisation, 2 (40%).

Table 6	Reasons why consented/authorised eligible donors did not proceed to donate			
		DBD		DCD
	N	%	N	%
Clinical - Organs deemed medically unsuitable by recipient centres	1	50.0	2	40.0
Clinical - Positive virology	1	50.0	-	-
Clinical - Patient's general medical condition			1	20.0
Consent / Auth - NOK withdraw consent / authorisation	-	-	2	40.0
Total	2	100.0	5	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.

The testing rate has dropped in the most recent year to 67% after remaining consistent at around 73% over the previous 4 years. DBD and DCD referral rates have continued to improve to 98% and 86% respectively. The actual number of missed referrals has decreased for DBD, from 12 in 2016/17 to just 2 in 2020/21. The actual number of missed referrals for DCD has decreased to 29 in 2020/21, compared to 52 in 2016/17. Compared to 2019/20 there has been a slight decrease in the percentage of DBD family approaches where a SNOD was present, from 94% to 87%, however this is still an increase on the 2016/17 rate. For DCD the SNOD presence rate has continued to increase from 68% to 77% over 5 years. The actual number of missed opportunities to have a SNOD present for the family approach has increased in the past year for DBD but is still a decrease over the past 5 years from 12 in 2016/17 to 6 in 2020/21. The true number of missed opportunities for a SNOD to be present for DCD donation has continued to decrease to 12 in 2020/21. There has been a decrease in the DBD consent/authorisation rate from 68% in 2019/20 to 57% in 2020/21, however the DCD consent/authorisation rate has increased to 52%, the highest in the past 5 years.

Figure 6 Number of patients with suspected neurological death, 1 April 2016 – 31 March 2021

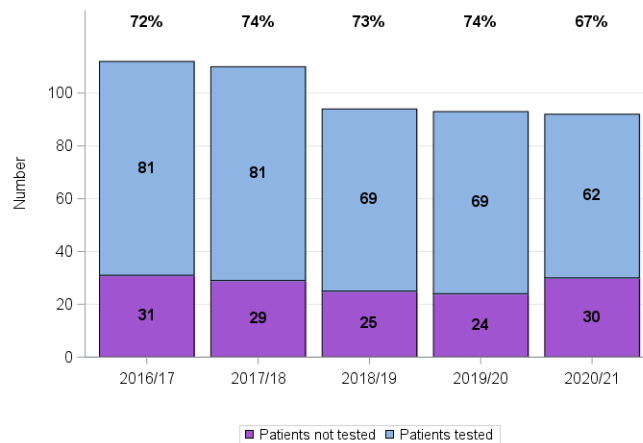


Figure 7 Number of patients meeting referral criteria, 1 April 2016 – 31 March 2021

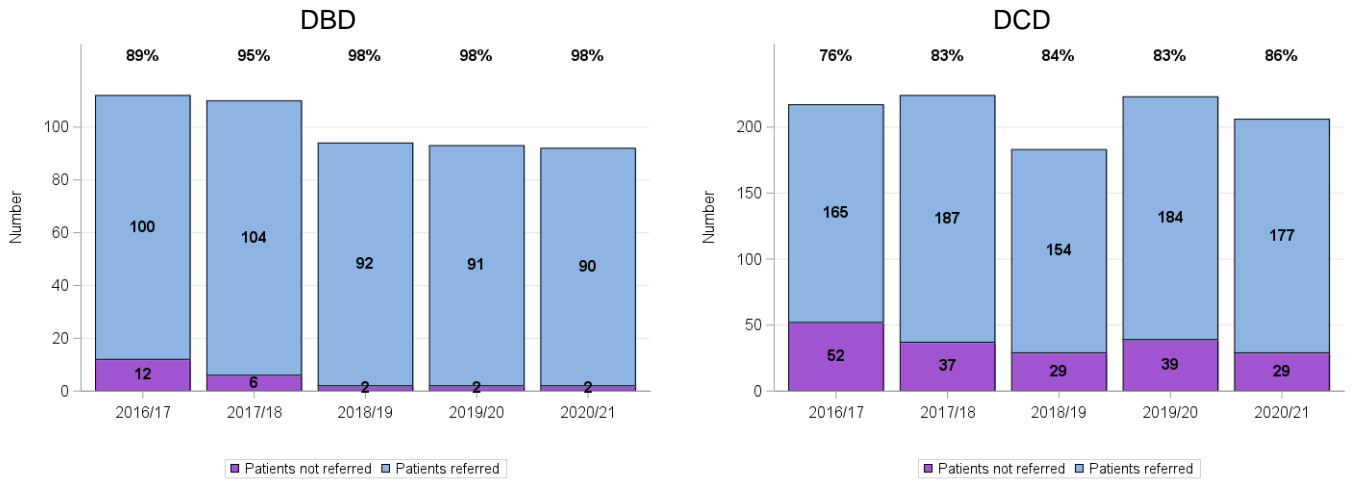


Figure 8 Number of families approached by SNOD presence, 1 April 2016 – 31 March 2021

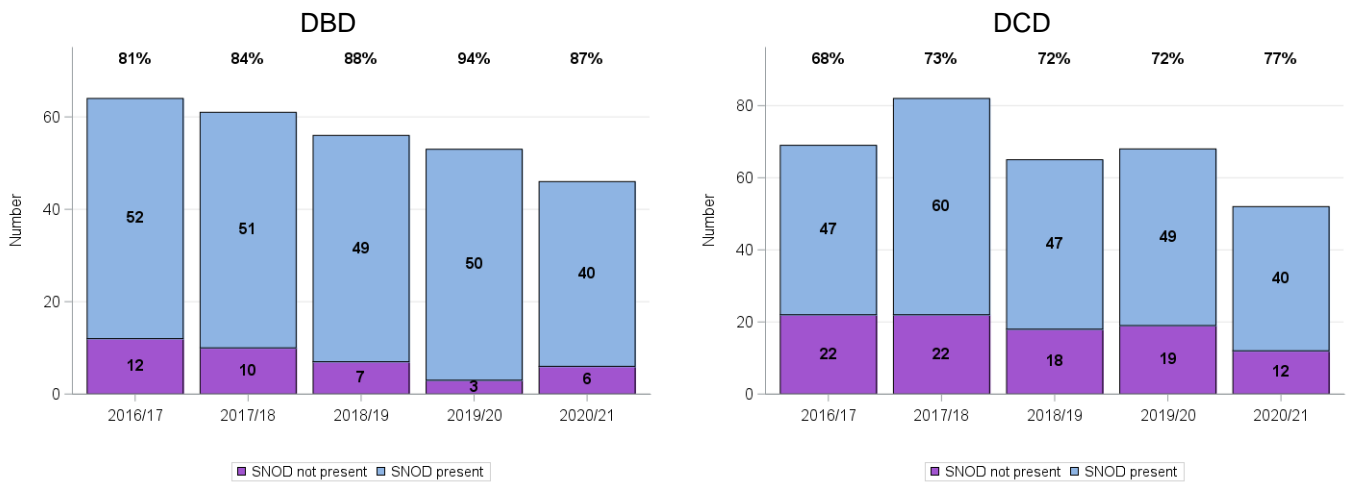
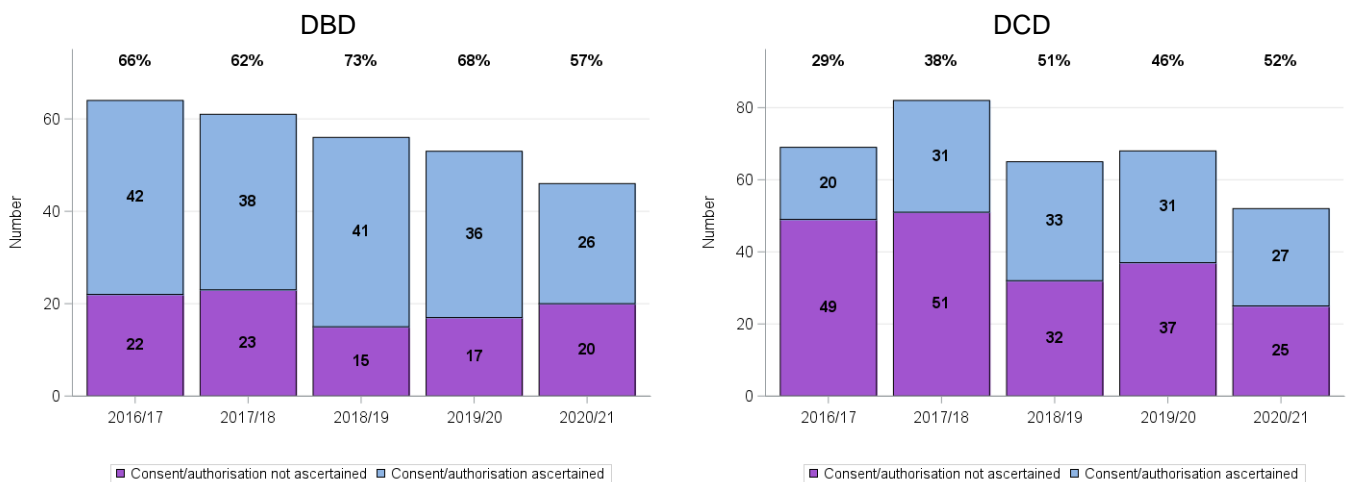


Figure 9 Number of families approached by consent/authorisation ascertained, 1 April 2016 – 31 March 2021



10 TRANSPLANT LIST

Table 7 shows the number of paediatric patients on the active transplant list as at 31 March 2021. For the previous year, waiting list figures at 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 206 patients waiting for a transplant, 112 (54%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant was higher than as at 29 February 2020, with 194 waiting.

Table 7 Active paediatric transplant list in the UK, as at 31 March 2021 (29 February 2020)		
	Active transplant list	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Heart	44	(36)
Lung	8	(2)
Heart/Lung	3	(-)
Total cardiothoracic	55	(38)
Renal paediatric patients (<18 years at time of registration)		
Kidney	112	(108)
Kidney/pancreas	-	(1)
Total renal	112	(109)
Liver paediatric patients (<17 years at time of registration)		
Liver	30	(35)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	6	(10)
Multi-organ paediatric patients (<18 years at time of registration)		
	3	(2)
Total	206	(194)

11 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2020 to 31 March 2021 are presented in **Table 8**. In the 12-month period, there were a total of 226 transplants performed. Of these, 158 were deceased donor transplants and 68 were from living donors.

Table 8 Paediatric transplants in the UK, 1 April 2020 – 31 March 2021 (2019/2020)		
	Transplant numbers	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Deceased heart	27	(23)
Lung only – DBD	2	(4)
Lung only - DCD	0	(0)
Total cardiothoracic	29	(27)
Renal paediatric patients (<18 years at time of registration)		
Kidney - DBD	35	(36)
Kidney - DCD	11	(6)
Kidney – living donor	50	(73)
Total kidney	96	(115)
Liver paediatric patients (<17 years at time of registration)		
Liver - DBD	74	(76)
Liver - DCD	3	(1)
Liver – living or domino donor	18	(12)
Total liver	95	(89)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	2	(1)
Multi-organ paediatric patients (<18 years at time of registration)		
	4	(2)
Total	226	(234)

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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