

**ANNUAL REPORT ON DECEASED DONATION
AND TRANSPLANTATION IN PAEDIATRIC
PATIENTS**

**SUMMARY REPORT FOR THE 12 MONTH PERIOD
1 APRIL 2021 – 31 MARCH 2022**

PUBLISHED OCTOBER 2022

Key messages

- In the year 1 April 2021 to 31 March 2022, there were 1,141 paediatric deaths audited for the PDA. Of these deaths, 75 and 201 patients met the referral criteria for DBD and/or DCD, respectively and 97% and 89% were referred to a SNOD.
- Of the 75 patients for whom neurological death was suspected, 61% were tested and there were 44 and 158 eligible DBD and DCD, respectively. Of the eligible DCD, 71 were considered medically suitable eligible DCD donors.
- Of the families approached, consent/authorisation was ascertained for 66% eligible DBD donors and 44% of eligible DCD donors. Of these, 100% and 63% 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 fallen to 61% in the most recent year.
 - The DBD referral rate has remained consistent, with a rate of 97% in 2021/22.
 - The DBD SNOD presence rate has increased to 94% in 2021/22 from 87% in 2020/21.
 - The DBD consent rate has risen to 66% in 2021/22 from a five year low of 57% in 2020/21.
 - The DCD referral rate has risen to a five year high of 89% in the most recent year.
 - The DCD SNOD presence rate was 74% in 2021/22, a decrease compared to 77% in 2020/21.
 - The DCD consent rate was 44%, a decrease on the previous year's rate of 52%, but still an improvement on 38% in 2017/18.
- At 31 March 2022, there were a total of 194 paediatric patients on the transplant list, 12 less than 31 March 2021. During 2021/22, 277 paediatric patients received a transplant, an increase of 52 transplants when compared with the previous year.

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2021 to 31 March 2022 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 8 July 2022. 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://nhsbtdeb.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 2021 to 31 March 2022, there were a total of 1,141 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

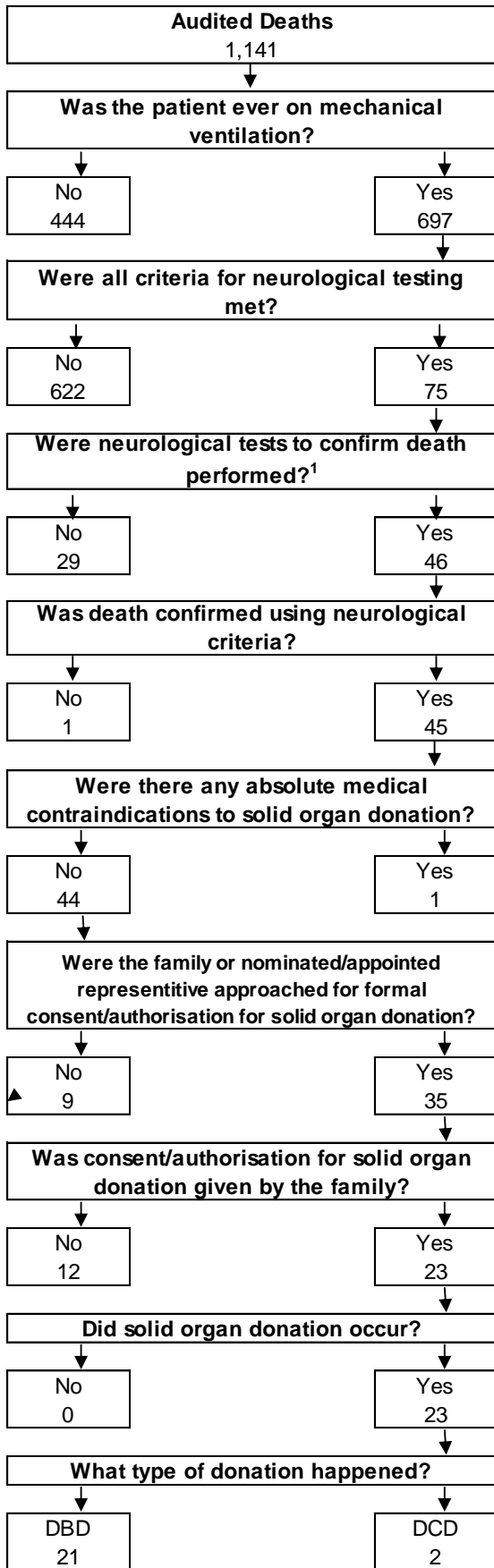
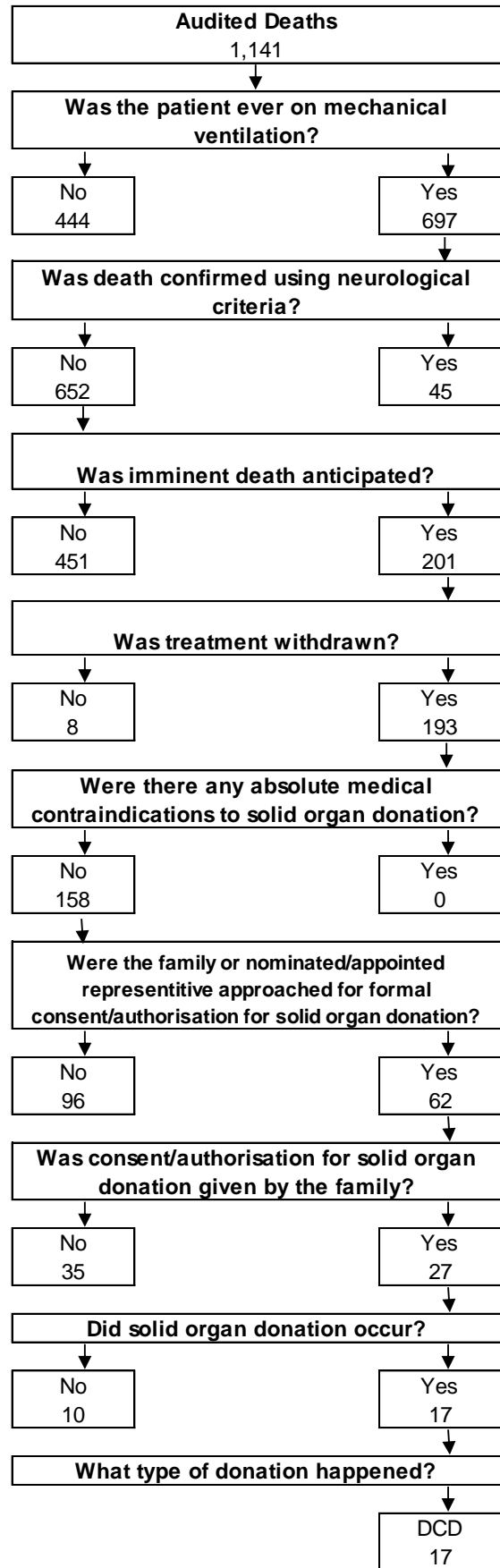


Figure 2 Donation after circulatory death



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	75	201	247
Referred to NHS Blood and Transplant	73	179	223
<i>Referral rate %</i>	<i>97.3</i>	<i>89.1</i>	<i>90.3</i>
Neurological death tested	46	-	46
<i>Testing rate %</i>	<i>61.3</i>	<i>-</i>	<i>61.3</i>
Eligible donors ²	44	158	202
Family approached	35	62	97
Family approached and SN-OD present	33	46	79
<i>% of approaches where SN-OD present</i>	<i>94.3</i>	<i>74.2</i>	<i>81.4</i>
Consent/authorisation given	23	27	50
<i>Consent/authorisation rate %</i>	<i>65.7</i>	<i>43.5</i>	<i>51.5</i>
- Expressed opt in	3	5	8
<i>- Expressed opt in %</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
- Other*	19	22	41
<i>- Other* %</i>	<i>65.5</i>	<i>42.3</i>	<i>50.6</i>
Actual donors from each pathway	23	17	40
<i>% of consented/authorised donors that became actual donors</i>	<i>100.0</i>	<i>63.0</i>	<i>80.0</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 61%, 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 29 patients (39%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

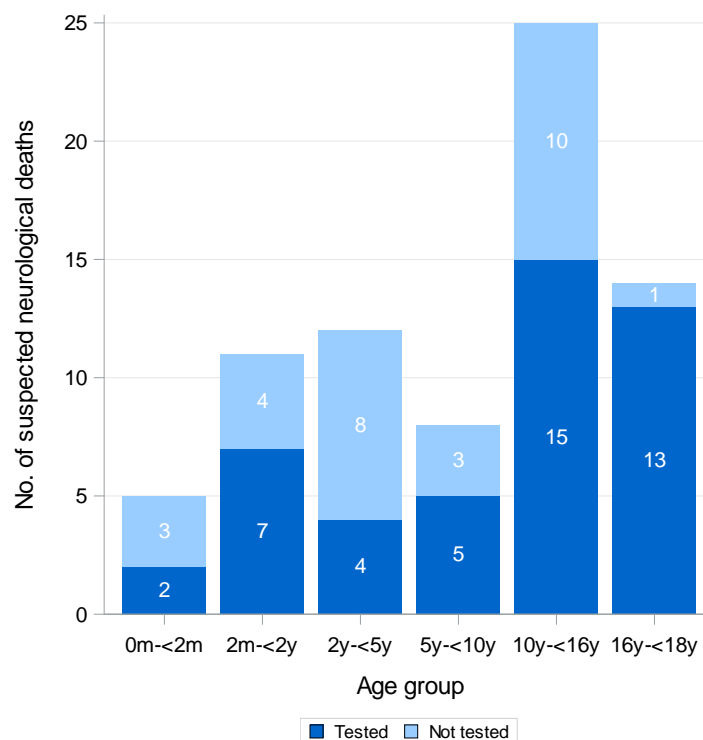
The most common reason for not testing was that the patient was haemodynamically unstable. This was given as the reason for not testing 9 (31%) patients. Family pressure not to test and family declining donation were each given as the reason for not testing 4 (14%) patients.

Table 2 Reasons given for neurological death tests not being performed		
	N	%
Patient haemodynamically unstable	9	31.0
Family declined donation	4	13.8
Family pressure not to test	4	13.8
Biochemical/endocrine abnormality	3	10.3
Clinical reason/Clinician's decision	3	10.3
Other	3	10.3
Treatment withdrawn	1	3.4
Continuing effects of sedatives	1	3.4
SN-OD advised that donor not suitable	1	3.4
Total	29	100.0

4.1 NEUROLOGICAL DEATH TESTING RATE BY PATIENT AGE

Age is represented by a categorical variable with intervals <2 months, 2 months - <2 years, 2-<5 years, 5-<10 years, 10-<16 years and 16-<18 years. There were a total of 75 neurological deaths suspected in paediatric patients in the UK from 1 April 2021 – 31 March 2022 and a total of 46 deaths where neurological tests were performed (61%). **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 93%.

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 97% and the DCD referral rate was 89%.

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 DBD patients who met referral criteria but were not referred, the reason given for non-referral for one patient was the family declined donation prior to neurological testing. For the other patient the reason for non-referral was the family declined donation after neurological testing. For patients who met the DCD referral criteria but were not referred, 13 (59%) were referred for reasons in the “Other” category. For 4 (18%) DCD patients the reason given for non-referral was patient thought to be medically unsuitable, and for 3 (14%) DCD patients the reason for non-referral was not identified as potential donor/organ donation not considered.

Table 3	Reasons given why patient not referred			
		DBD		DCD
	N	%	N	%
Family declined donation prior to neurological testing	1	50.0	1	4.5
Family declined donation after neurological testing	1	50.0	-	-
Not identified as potential donor/organ donation not considered	-	-	3	13.6
Coroner / Procurator Fiscal reason	-	-	1	4.5
Thought to be medically unsuitable	-	-	4	18.2
Other	-	-	13	59.1
Total	2	100.0	22	100.0

6 APPROACH RATE

Families of eligible donors were asked to make or support a patient’s organ donation decision in 80% of DBD and 39% of DCD cases. This rate is considerably lower for DCD donor families than DBD, as the DCD assessment process identifies many eligible DCD donors which are unsuitable for organ donation prior to the approach. In 2021/22, 81 eligible DCD donors were excluded by this process. Families of the remaining 71 medically suitable eligible DCD donors were asked to make or support a patient’s organ donation decisions in 85% of cases. The information in **Table 4** shows the reasons given why the families of eligible DBD and medically suitable eligible DCD donors were not approached.

The main reason given for not approaching families of eligible DBD donors, in 4 (44%) cases, was the Coroner/Procurator Fiscal refused permission. In 2 (22%) cases the reason for not approaching the family was other reason.

For medically suitable eligible DCD donors not approached, 5 (46%) were because the Coroner/Procurator Fiscal refused permission and 3 case the family previously stated they

would not support organ donation and in a further 3 cases, the patient was not identified as a potential donor.

Table 4 Reasons given why family were not asked to make or support patient's organ donation decision

	Eligible DBD		Medically suitable eligible DCD	
	N	%	N	%
Coroner/Proc Fiscal refused permission	4	44.4	5	45.5
Other	2	22.2	-	-
Family stated they would not consent/authorise prior to donation decision conversation	1	11.1	3	27.3
Pressure on ICU beds	1	11.1	-	-
Not identified as a potential donor	1	11.1	3	27.3
Total	9	100.0	11	100.0

7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose families were 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 66% and the 95% confidence limits for this percentage are 50% - 81%. The DCD consent/authorisation rate was 44% and the 95% confidence limits for this percentage are 31% - 56%. The overall consent/authorisation rate was 52% and the 95% confidence limits for this percentage are 42% - 61%.

Eight 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 younger than 16 years old. Consent/authorisation was ascertained for all donors registered on the ODR. No families overruled their loved one's known wish to be an organ donor.

The consent/authorisation rate was 51% where patients have not expressed a donation decision and where deemed criteria are not met.

For the 2 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 one of the 16 eligible DCD patients when the SN-OD was not present. The overall consent/authorisation rate was 62% when the SN-OD was present compared to 6% 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, 3 (25%), patient had previously expressed a decision not to donate, 2 (17%) and other, 2 (17%). The main reasons that families of eligible DCD patients did not support organ donation were the family felt the

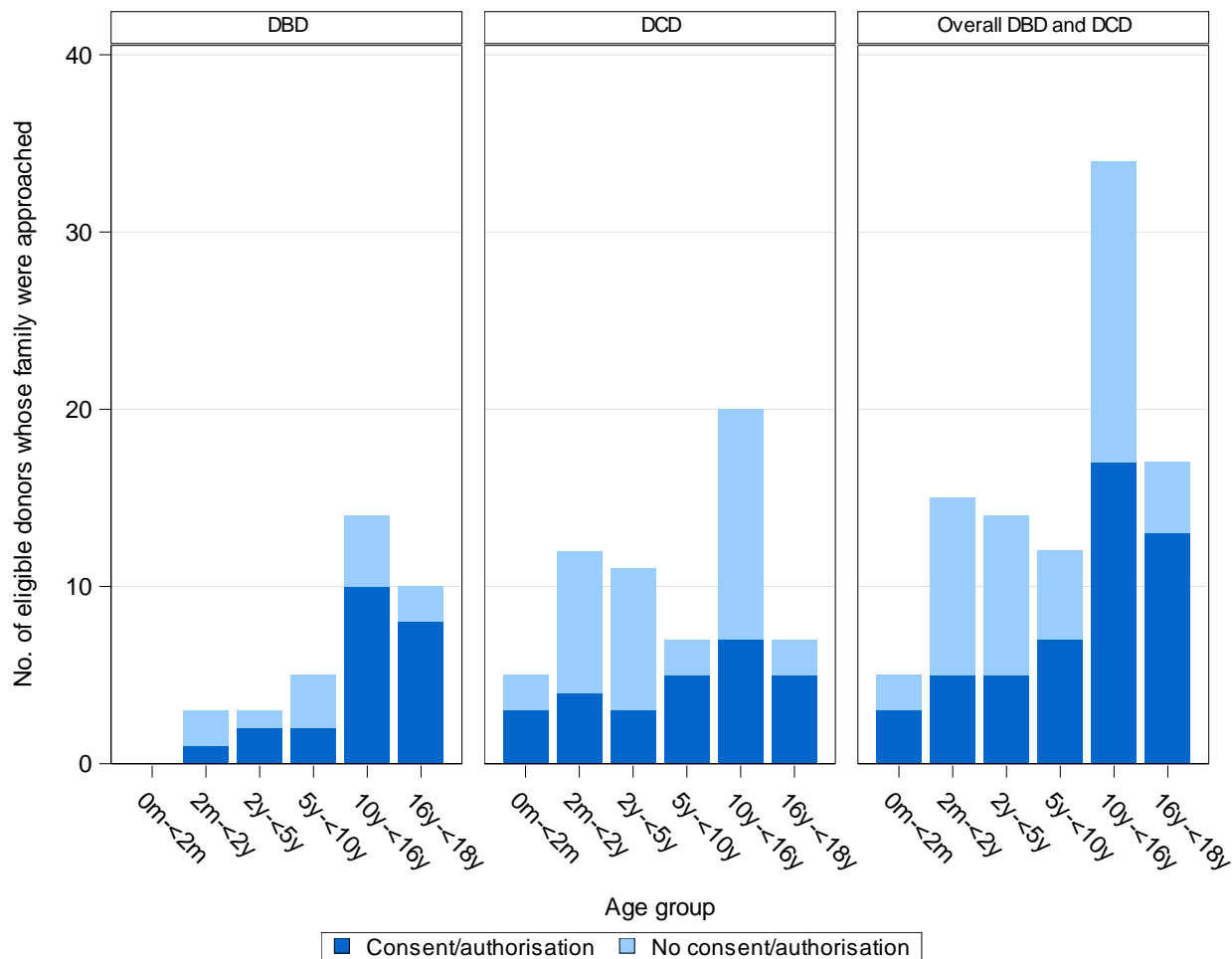
patient had suffered enough, 9 (26%), the family did not want surgery to the body, 8 (23%) and other, 6 (17%).

Table 5 Reasons why the family did not support organ donation				
	DBD		DCD	
	N	%	N	%
Family did not want surgery to the body	3	25.0	8	22.9
Patient had previously expressed a wish not to donate	2	16.7	1	2.9
Other	2	16.7	6	17.1
Family did not believe in donation	1	8.3	3	8.6
Family felt it was against their religious/cultural beliefs	1	8.3	-	-
Family felt patient had suffered enough	1	8.3	9	25.7
Family felt the length of time for the donation process was too long	1	8.3	2	5.7
Family felt that the body should be buried whole (unrelated to religious/cultural reasons)	1	8.3	-	-
Family wanted to stay with the patient after death	-	-	1	2.9
Family concerned donation may delay the funeral	-	-	1	2.9
Strong refusal - probing not appropriate	-	-	4	11.4
Total	12	100.0	35	100.0

7.1 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

The consent/authorisation rates for the six age groups (for the 35 eligible DBD and 62 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 (76%). The lowest consent/authorisation rate was in the 2 months - <2 years group (33%).

Figure 4 Number of families approached by age group



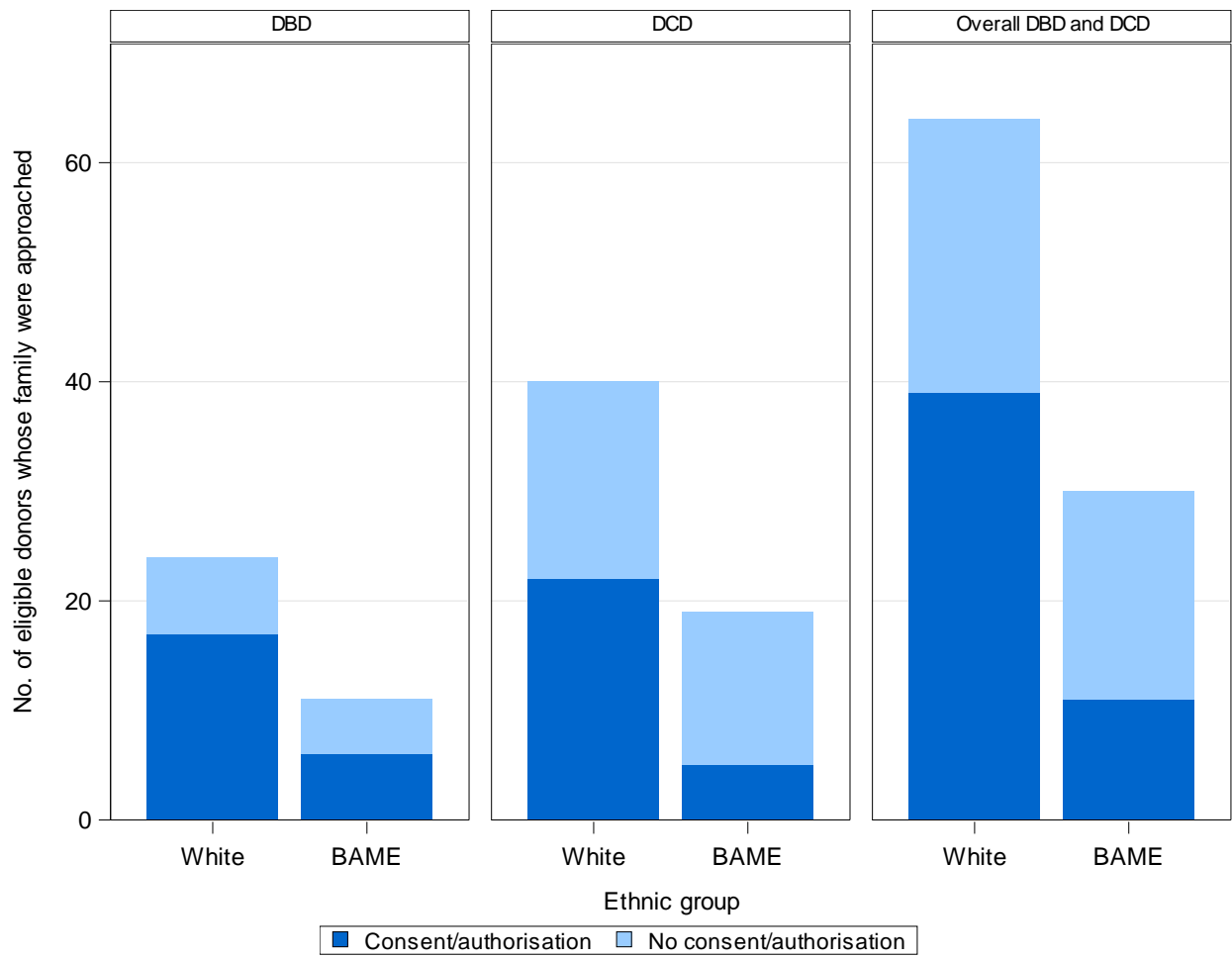
Consent/authorisation rates for patients from the white ethnic community are compared with patients from Black, Asian, Mixed Race and Minority Ethnic (BAME) communities and are shown in **Figure 5**. There were a total of 30 approaches to families of BAME patients, 11 DBD and 19 DCD. Note that there were an additional 3 DCD family approaches where the ethnicity was not known or not reported.

For eligible DBD, the consent/authorisation rates were 71% for eligible white donors and 55% for eligible BAME donors. For eligible DCD, the consent/authorisation rates were 55% for eligible white DCD and 26% for eligible BAME DCD.

The overall consent/authorisation rates were 61% for eligible white donors and 37% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 49% - 73% for eligible white donors and 19% - 54% for eligible BAME donors.

Additional information on trends in organ donation and transplantation by ethnicity can be found in the Annual report on ethnicity differences in Organ Donation and Transplantation here: <https://www.odt.nhs.uk/statistics-and-reports/>.

Figure 5 Number of approaches by patient ethnicity



8 SOLID ORGAN DONATION

Of the eligible donors whose families consented to/authorised donation, 100% 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 reasons given for consented/authorised eligible DCD not proceeding was that the organs were deemed medically unsuitable by recipient centres, 4 (40%) and prolonged time to asystole (PTA) post withdrawal of life-sustaining treatment (WLST), 4 (40%).

Table 6	Reasons why consented/authorised eligible donors did not proceed to donate			
	DBD		DCD	
	N	%	N	%
Clinical - PTA post WLST	-	-	4	40.0
Clinical - Organs deemed medically unsuitable by recipient centres	-	-	4	40.0
Consent / Auth - Coroner/Procurator fiscal refusal	-	-	1	10.0
Consent / Auth - NOK withdraw consent / authorisation	-	-	1	10.0
Total	-	-	10	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 61%. The number of patients tested dropped to the lowest in 5 years, while the number not tested has remained static. The DBD referral rate has remained stable at 97%. The DCD referral rate has continued to improve to 89%, the highest rate in the past 5 years. The actual number of missed referrals has decreased for DBD, from 6 in 2017/18 to just 2 in 2021/22. The actual number of missed referrals for DCD has decreased to 22 in 2021/22, compared to 37 in 2017/18. Compared to 2020/21 there has been an increase in the percentage of DBD family approaches where a SNOD was present, from 87% to 94%. For DCD, the SNOD presence rate has decreased slightly from 77% to 74%. This is still an increase compared to 2017/18. The actual number of DBD missed opportunities to have a SNOD present for the family approach has decreased to the lowest level in the past 5 years. The true number of missed opportunities for a SNOD to be present for DCD donation has decreased from 22 in 2017/18 to 16 in 2021/22. There has been an increase in the DBD consent/authorisation rate from 57% in 2020/21 to 66% in 2021/22. The DCD consent/authorisation rate has decreased from 52% in 2020/21 to 44%, though this is still an increase from 38% in 2017/18.

Figure 6 Number of patients with suspected neurological death, 1 April 2017 – 31 March 2022

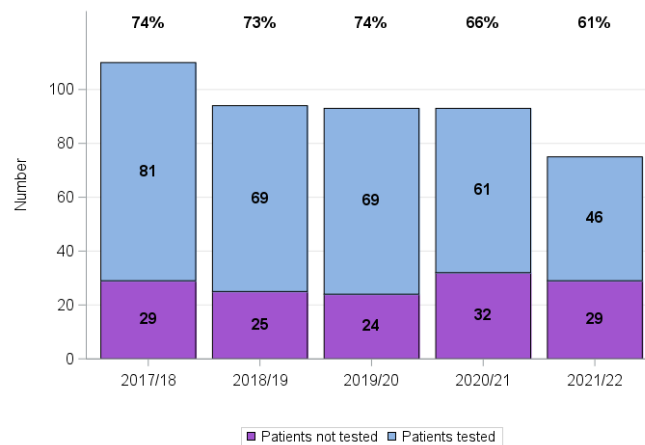


Figure 7 Number of patients meeting referral criteria, 1 April 2017 – 31 March 2022

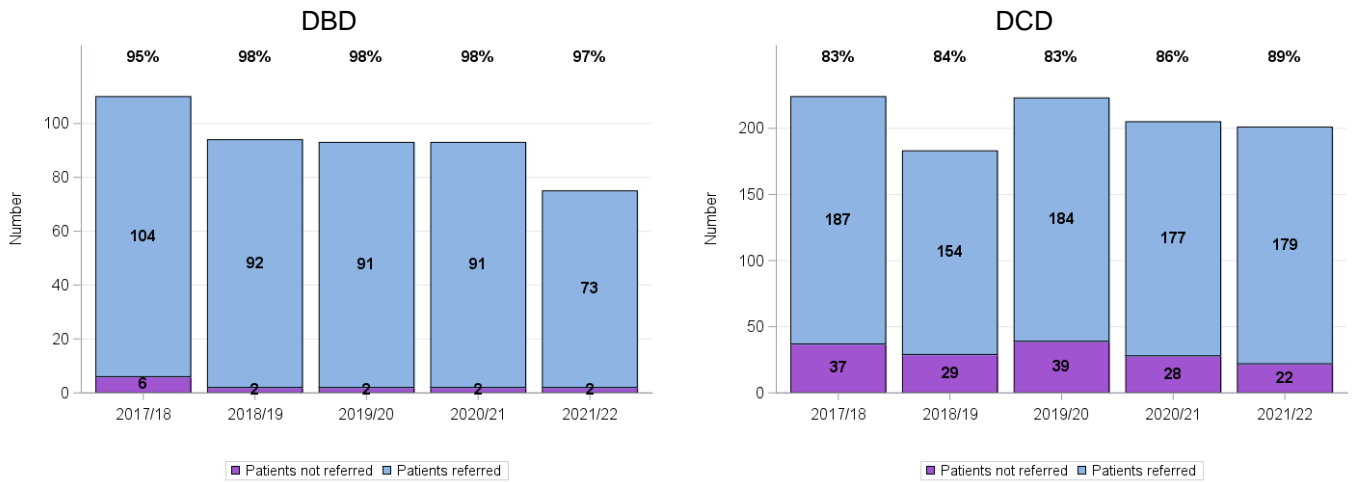


Figure 8 Number of families approached by SNOD presence, 1 April 2017 – 31 March 2022

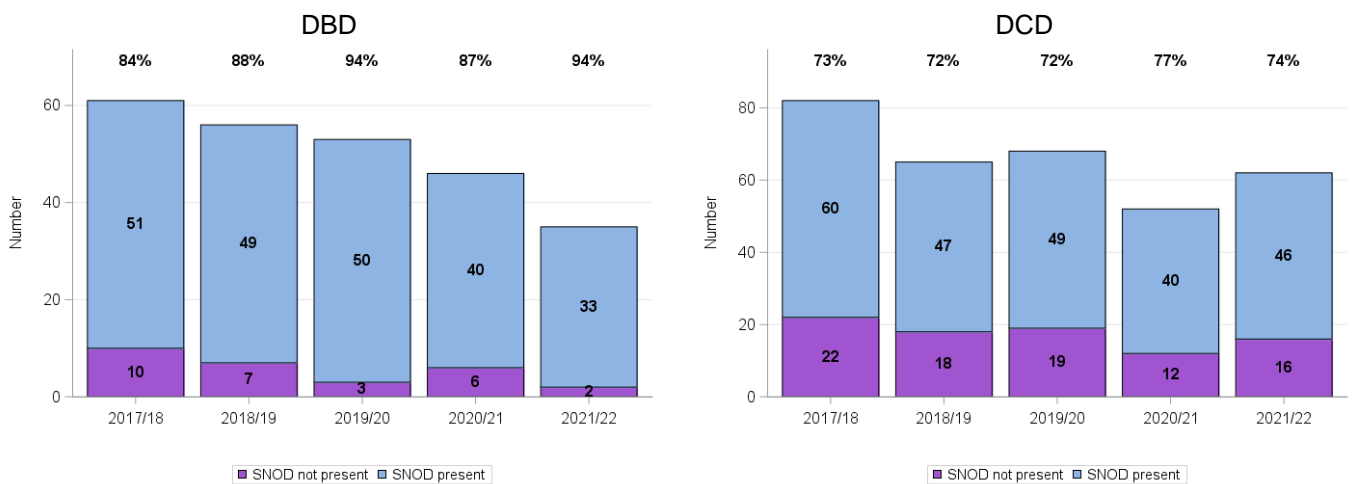
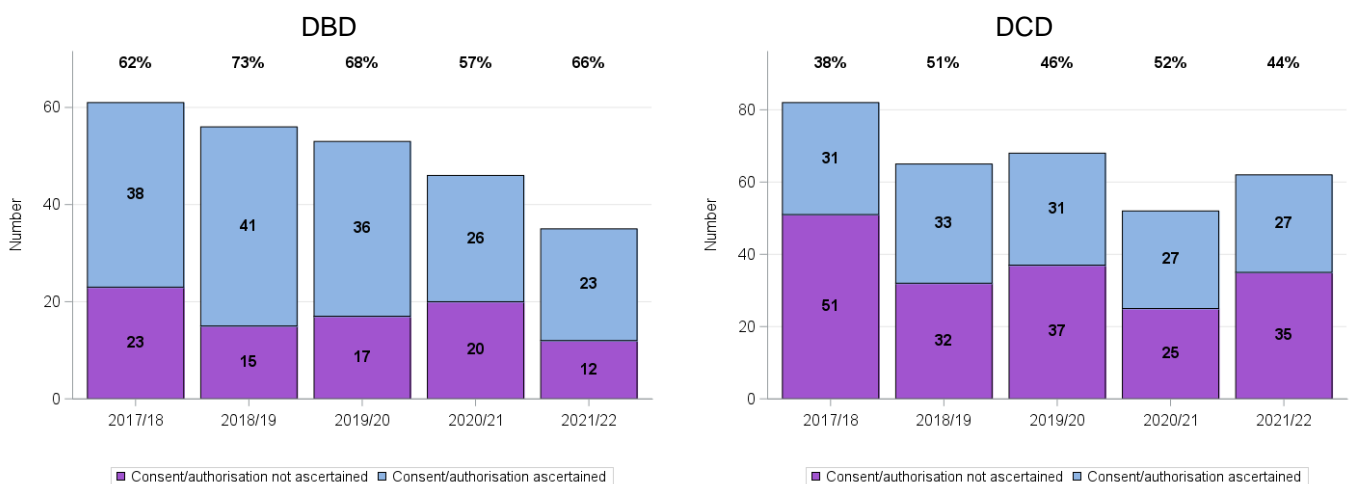


Figure 9 Number of families approached by consent/authorisation ascertained, 1 April 2017 – 31 March 2022



10 TRANSPLANT LIST

Table 7 shows the number of paediatric patients on the active transplant list as at 31 March 2022 and 31 March 2021.

In total there were 194 patients waiting for a transplant, 101 (52%) of which were waiting for a kidney transplant. The number of patients waiting for a transplant is lower than as at 31 March 2021, with 206 waiting.

Table 7 Active paediatric transplant list in the UK, as at 31 March 2022 (31 March 2021)		
	Active transplant list	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Heart	44	(44)
Lung	9	(8)
Heart/Lung	1	(3)
Total cardiothoracic	54	(55)
Renal paediatric patients (<18 years at time of registration)		
Kidney	101	(112)
Kidney/pancreas	-	(-)
Total renal	101	(112)
Liver paediatric patients (<17 years at time of registration)		
Liver	30	(30)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	4	(6)
Multi-organ paediatric patients (<18 years at time of registration)		
	5	(3)
Total	194	(206)

11 TRANSPLANT ACTIVITY

The number of paediatric transplants performed in the UK, from 1 April 2021 to 31 March 2021 are presented in **Table 8**. In the 12-month period, there were a total of 277 transplants performed. Of these, 166 were deceased donor transplants and 111 were from living donors.

Table 8 Paediatric transplants in the UK, 1 April 2021 – 31 March 2022 (2020/2021)		
	Transplant numbers	
Cardiothoracic paediatric patients (< 16 years at time of registration)		
Deceased heart	27	(26)
Lung only – DBD	2	(2)
Lung only - DCD	0	(0)
Total cardiothoracic	29	(28)
Renal paediatric patients (<18 years at time of registration)		
Kidney - DBD	37	(35)
Kidney - DCD	15	(11)
Kidney – living donor	97	(50)
Total kidney	149	(96)
Liver paediatric patients (<17 years at time of registration)		
Liver - DBD	74	(74)
Liver - DCD	2	(3)
Liver – living or domino donor	14	(18)
Total liver	90	(95)
Intestinal paediatric patients (<18 years at time of registration)		
Intestinal	3	(2)
Multi-organ paediatric patients (<18 years at time of registration)		
	6	(4)
Total	277	(225)

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' (i.e., 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