NHS
Blood and Transplant

ANNUAL REPORT ON THE POTENTIAL DONOR AUDIT

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

PUBLISHED AUGUST 2019

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) information on the financial year 1 April 2018 to 31 March 2019.

The dataset used to compile this report includes all audited patient deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 9 May 2019. Patients aged over 80 years and patients who died on a ward have not been audited. Paediatric ICU data are included however neonatal ICU data have been excluded from this report.

This report summarises the main findings of the PDA over the 12-month period, in particular the reasons why patients were lost along the pathway, and should be read in conjunction with the PDA section of the Organ Donation and Transplantation Activity Report, available at https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/.

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Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/6455/contraindications_to_organ_donation.pdf

SNOD Specialist Nurse in Organ Donation, including Specialist Requesters

Deemed consent applies, in Wales, if a person has not registered an organ donation decision to either opt-in or opt-out or appoint a representative, is aged 18 or over, has lived for longer than 12 months and is ordinarily resident and also died in Wales, and had the capacity to understand the notion of deemed consent for a significant period before their death.

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 DEATHS IN ICUs AND EMERGENCY DEPARTMENTS

In the 12-month period from 1 April 2018 to 31 March 2019, there were a total of 32,588 audited patient deaths in the ICUs and EDs in the UK. A detailed breakdown for both the DBD and DCD data collection flows is given in **Figure 1 and 2,** and **Table 1** summarises the key percentages.

Figure 1 Donation after brain death

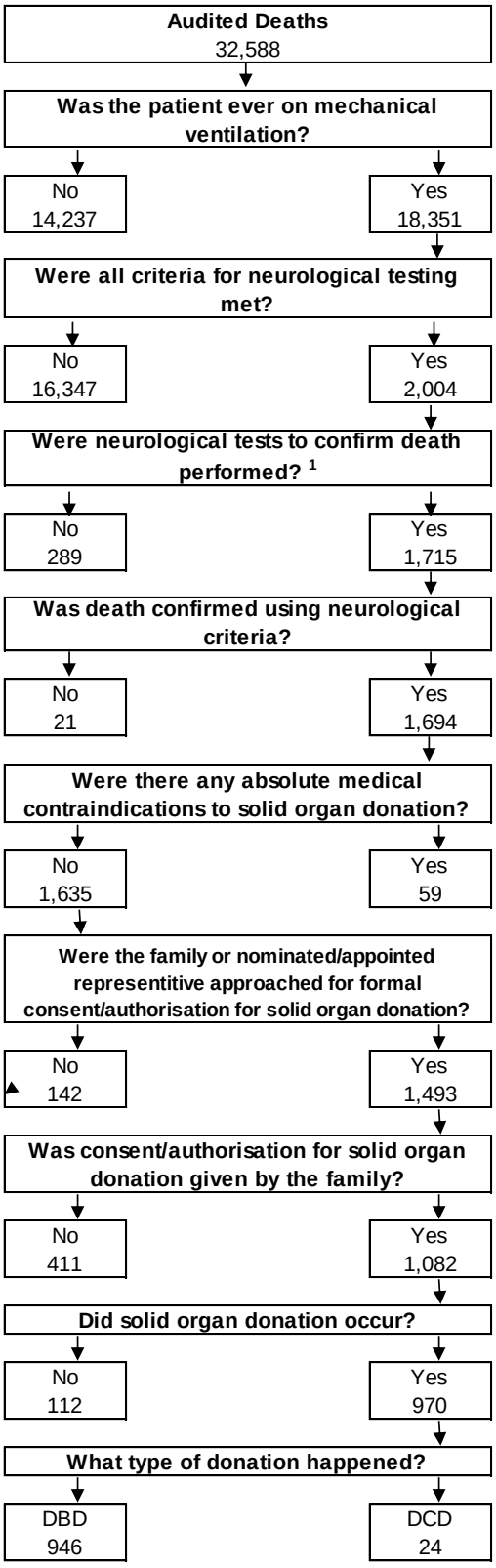
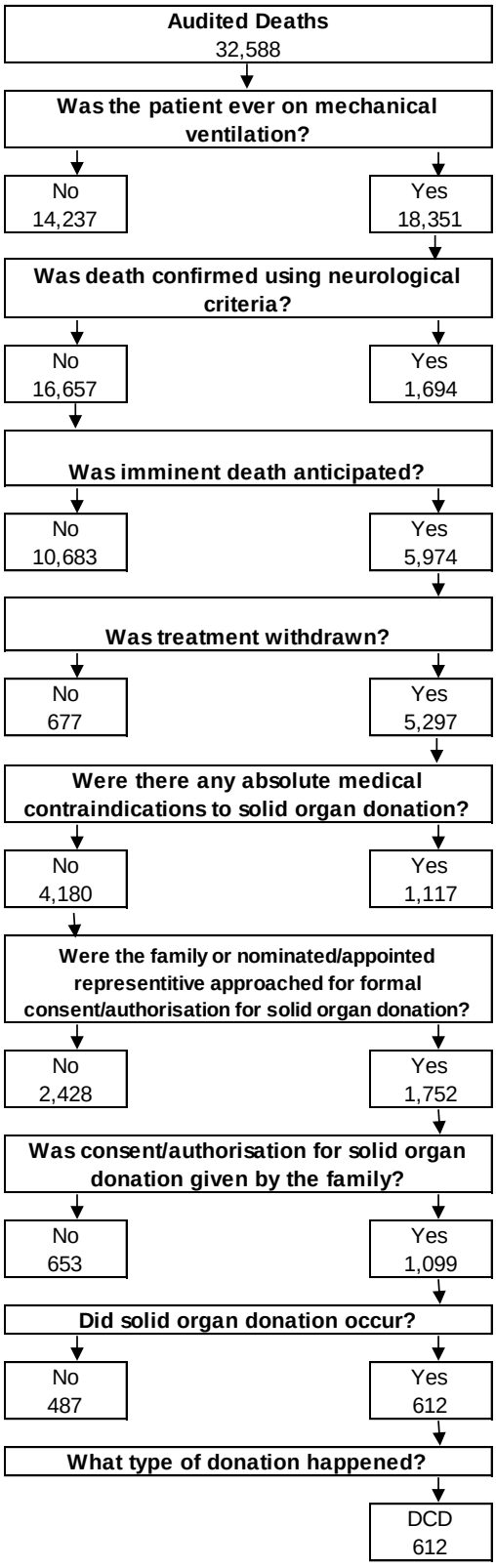


Figure 2 Donation after circulatory death



[1] Patients for whom tests were not performed due to: Cardiac arrest despite resuscitation occurred, brainstem reflexes returned, 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]	2004	5974	7728
Referred to NHS Blood and Transplant	1982	5539	7287
Referral rate %	*98.9%*	*92.7%*	*94.3%*
Neurological death tested	1715		1715
Testing rate %	*85.6%*		*85.6%*
Family approached	1493	1752	3245
Family approached and SN-OD present	1423	1527	2950
% of approaches where SN-OD present	*95.3%*	*87.2%*	*90.9%*
Consent/authorisation given	1082	1099	2181
Consent/authorisation rate %	*72.5%*	*62.7%*	*67.2%*
Actual donors from each pathway	970	612	1582
% of consented/authorised donors that became actual donors	*89.6%*	*55.7%*	*72.5%*

[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
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

4 NEUROLOGICAL DEATH TESTING RATE

Table 2 Reasons given for neurological death tests not being performed

	N	%
Patient haemodynamically unstable	80	27.7
Clinical reason/Clinicians decision	48	16.6
Family pressure not to test	35	12.1
Family declined donation	22	7.6
Biochemical/endocrine abnormality	20	6.9
Other	18	6.2
Continuing effects of sedatives	14	4.8
Inability to test all reflexes	13	4.5
Treatment withdrawn	11	3.8
Medical contraindication to donation	10	3.5
SN-OD advised that donor not suitable	7	2.4
Patient had previously expressed a wish not to donate	5	1.7
Unknown	5	1.7
Pressure on ICU beds	1	0.3
Total	**289**	**100.0**

The neurological death testing rate was 86% 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 whom tests were not performed due to; cardiac arrest occurred despite resuscitation or brainstem reflexes returned, were not possible to test meaning these reasons were excluded. Neurological death tests were not performed in 289 patients (14%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2.**

80 (28%) patients were haemodynamically unstable and were therefore not tested. Other reasons given for not performing neurological death tests were: 48 (17%) patients had a clinical reason or it was the clinician's decision, and for 35 (12%) patients there was family pressure not to test.

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 NHS Blood and Transplant. The DBD referral rate was 99% and the DCD referral rate was 93%. **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.

Table 3 Reasons given why patient not referred

	DBD		DCD	
	N	**%**	**N**	**%**
Not identified as a potential donor/organ donation not considered	11	50.0	215	49.4
Other	4	18.2	56	12.9
Family declined donation prior to neurological testing	2	9.1	2	0.5
Family declined donation following decision to withdraw treatment	2	9.1	15	3.4
Thought to be medically unsuitable	2	9.1	78	17.9
Coroner/Procurator Fiscal Reason	1	4.5	2	0.5
Reluctance to approach family	-	-	2	0.5
Medical contraindications	-	-	56	12.9
Thought to be outside age criteria	-	-	2	0.5
Pressure on ICU beds	-	-	3	0.7
Clinician assessed that patient was unlikely to become asystolic within 4 hours	-	-	4	0.9
Total	**22**	**100.0**	**435**	**100.0**

Of the patients who met the referral criteria and were not referred, the reason given for 50% of DBD and 49% of DCD was that the patients were not identified as potential donors and so organ donation was not considered. The reason given for 18% of DBD and 13% of DCD was other reason.

6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 91% and 42% of DBD and DCD cases, respectively. The DCD assessment process identifies a large number of eligible DCD donors which are unsuitable for organ donation prior to the approach. Consequently, the DCD approach rate is currently underestimated, as families of these patients are never approached for the formal organ donation discussion and the reason for not approaching is recorded as 'Patient's general medical condition', 'Other medical reason' or 'Other'. The information in **Table 4** shows the reasons given why the families were not approached.

For eligible DBD donors not approached, the reason stated in 32% of cases was the patient's general medical condition. In a further 20% of DBD cases, the reason stated was that the Coroner/Procurator Fiscal refused permission.

For eligible DCD donors not approached, the main reasons stated were the patient's general medical condition (44%), other reason (25%) or other medical reason (13%). The majority of these cases are a result of the DCD assessment process which identifies patients unsuitable for donation prior to the approach.

Table 4 Reasons given why family not formally approached

	DBD		DCD	
	N	**%**	**N**	**%**
Patient's general medical condition	45	31.7	1,074	44.2
Coroner / Procurator Fiscal refused permission	28	19.7	39	1.6
Other	25	17.6	608	25.0
Other medical reason	17	12.0	316	13.0
Family stated that they would not support donation before they were formally approached	9	6.3	39	1.6
Family untraceable	6	4.2	31	1.3
Family considered too upset to approach	5	3.5	15	0.6
Patient had previously expressed a wish not to donate	4	2.8	19	0.8
Not identified as a potential donor / organ donation not considered	3	2.1	264	10.9
Resource failure	-	-	1	0.0
Pressure on ICU beds	-	-	9	0.4
Patient outside age criteria	-	-	13	0.5
Total	**142**	**100.0**	**2,428**	**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 72% and the 95% confidence limits for this percentage are 70% - 75%. The DCD consent/authorisation rate

was 63% and the 95% confidence limits for this percentage are 60% - 65%. The overall consent/authorisation rate was 67% and the 95% confidence limits for this percentage are 65% - 69%.

When a patient was known to have registered an opt-in decision on the Organ Donor Register (ODR) at the time of approach, the DBD consent/authorisation rate was 95% compared to 61% when a patient had not registered an opt-in decision or the patient's ODR status was not known at the time of approach. For DCD, the rates were 92% compared with 49%. Overall, these rates were 93% compared with 55%.

In total during the financial year, 79 families overruled their loved one's known opt-in decision (recorded via the ODR, verbally or in writing) to be an organ donor.

When a SN-OD was present for the formal organ donation discussion with the family, the DBD consent/authorisation rate was 73% compared with 53% when the SN-OD was not present. Similarly, for DCD the rate was 69% compared with 22% when the SN-OD was not present. The overall rate was 71% compared with 30%.

Table 5 Reasons why family did not support organ donation

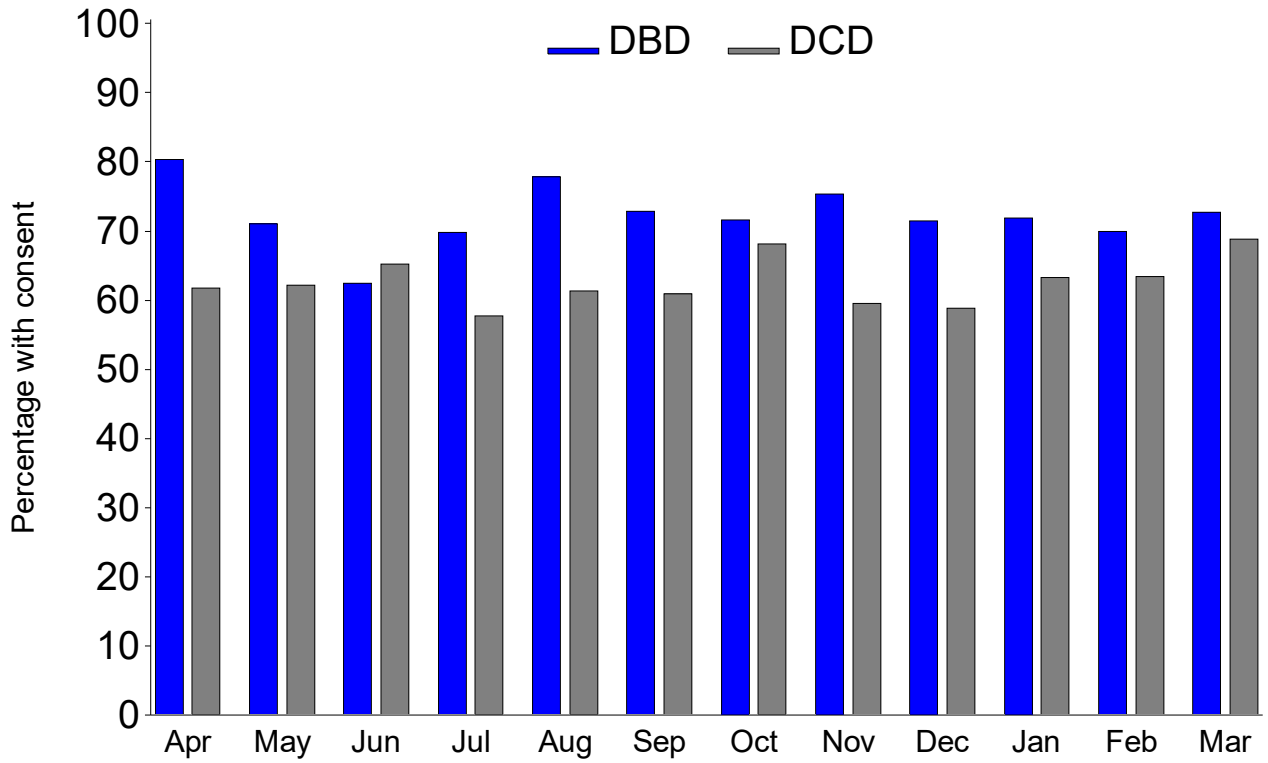
	DBD		DCD	
	N	**%**	**N**	**%**
Patient previously expressed a wish not to donate	82	20.0	147	22.5
Family were not sure whether the patient would have agreed to donation	78	19.0	123	18.8
Family felt it was against their religious/cultural beliefs	44	10.7	21	3.2
Family did not want surgery to the body	42	10.2	51	7.8
Family felt the patient had suffered enough	30	7.3	50	7.7
Family were divided over the decision	25	6.1	31	4.7
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	24	5.8	19	2.9
Family did not believe in donation	22	5.4	25	3.8
Family felt the length of time for donation process was too long	22	5.4	88	13.5
Other	18	4.4	55	8.4
Strong refusal - probing not appropriate	7	1.7	22	3.4
Family wanted to stay with the patient after death	5	1.2	11	1.7
Families concerned about organ allocation	4	1.0	-	-
Family concerned that other people may disapprove/be offended	3	0.7	1	0.2
Family concerned that organs may not be transplanted	3	0.7	8	1.2
Family had difficulty understanding/accepting neurological testing	1	0.2	-	-
Family concerned donation may delay the funeral	1	0.2	-	-
Patients treatment may be or has been limited to facilitate organ donation	-	-	1	0.2
Total	**411**	**100.0**	**653**	**100.0**

The reasons why the family did not support organ donation are shown in **Table 5.** The main reason that families of eligible DBD and DCD patients gave for no consent/authorisation was patient previously expressed a wish not to donate (20% and 23% respectively). Other common reasons why the family did not support organ donation for DBD patients were that the families were not sure whether the patient would have agreed to organ donation, they felt it was against their religious/cultural beliefs or did not want surgery to the body. Amongst DCD patients, families were not sure whether the patient would have agreed to organ donation or felt that the length of time for donation as too long.

8 MONTHLY VARIATION IN THE CONSENT/AUTHORISATION RATE

Monthly consent/authorisation rates are shown in **Figure 3.** From this figure it is apparent that over the financial year there is no clear monthly pattern. The DBD consent/authorisation rate was highest in April 2018 (80%) and lowest in June 2018 (63%), whereas the DCD consent/authorisation rate was highest in March 2019 (69%) and lowest in July 2018 (58%). The differences in the monthly consent/authorisation rates from 1 April 2018 to 31 March 2019 are not statistically significant for either DBD or DCD, p=0.3 and p=0.7, respectively.

Figure 3 Month-to-month variation in consent/authorisation rate



9 EFFECT OF DEMOGRAPHIC VARIABLES ON THE CONSENT/AUTHORISATION RATE

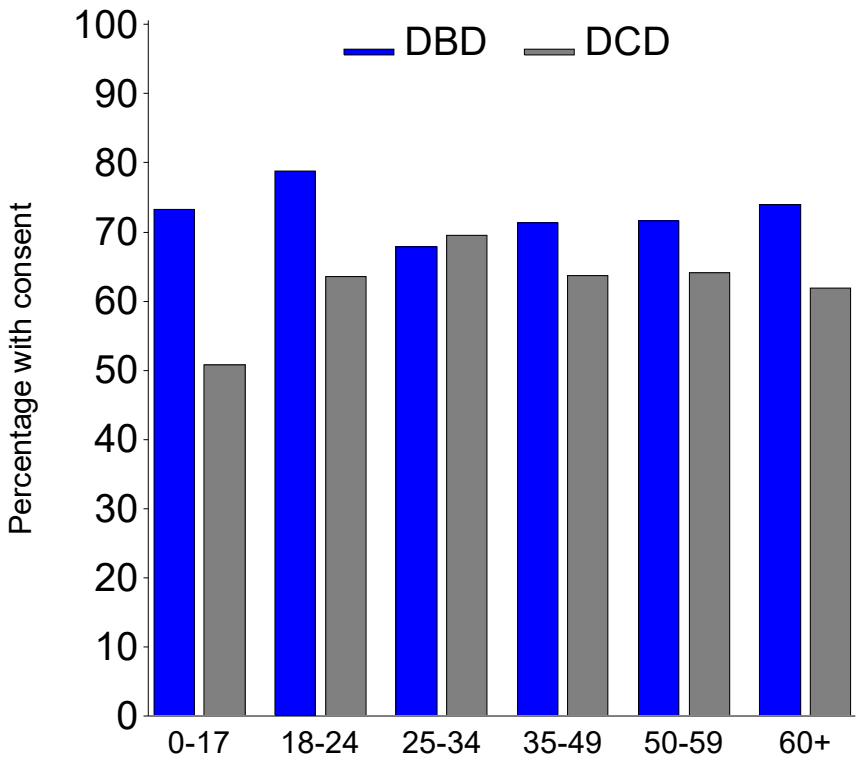
The consent/authorisation rate for the 772 male eligible DBD was 72% and the consent/authorisation rate for the 721 female eligible DBD was 74%. The difference is not statistically significant, p=0.4. For the 1098 male eligible DCD the consent/authorisation rate

was 63% and for the 654 female eligible DCD was 62%. This difference is not statistically significant, p=0.7.

Age is represented by a categorical variable with intervals 0-17, 18-24, 25-34, 35-49, 50-59 and 60+ years. The consent/authorisation rates for the six age groups (for the 1,493 eligible DBD and 1,752 eligible DCD whose families were approached) are illustrated in **Figure 4.** The highest consent/authorisation rate for eligible DBD occurred in the 18-24 age group (79%) and for eligible DCD in the 25-34 age group (70%). The lowest consent/authorisation rate for eligible DBD was in the 25-34 age group (68%). The lowest consent/authorisation rate for eligible DCD was in the 0-17 age group (51%). The differences in consent/authorisation rate across the six age groups for DBD and DCD are not statistically significant, p=0.5 and p=0.3 respectively.

When comparing only between adult and paediatric (<18 years), the differences in consent/authorisation rate for DBD are not statistically significant (p=0.9) and for DCD are statistically significant (p=0.04).

Figure 4 Age variation in consent/authorisation rate



Consent/authorisation rates for patients from the white ethnic community are compared with those of patients from the Black, Asian and Minority Ethnic (BAME) community and are shown in **Figure 5.** Note that there were an additional 31 DBD and 43 DCD families approached where the ethnicity was not known or not reported which have been excluded from the ethnicity figures below.

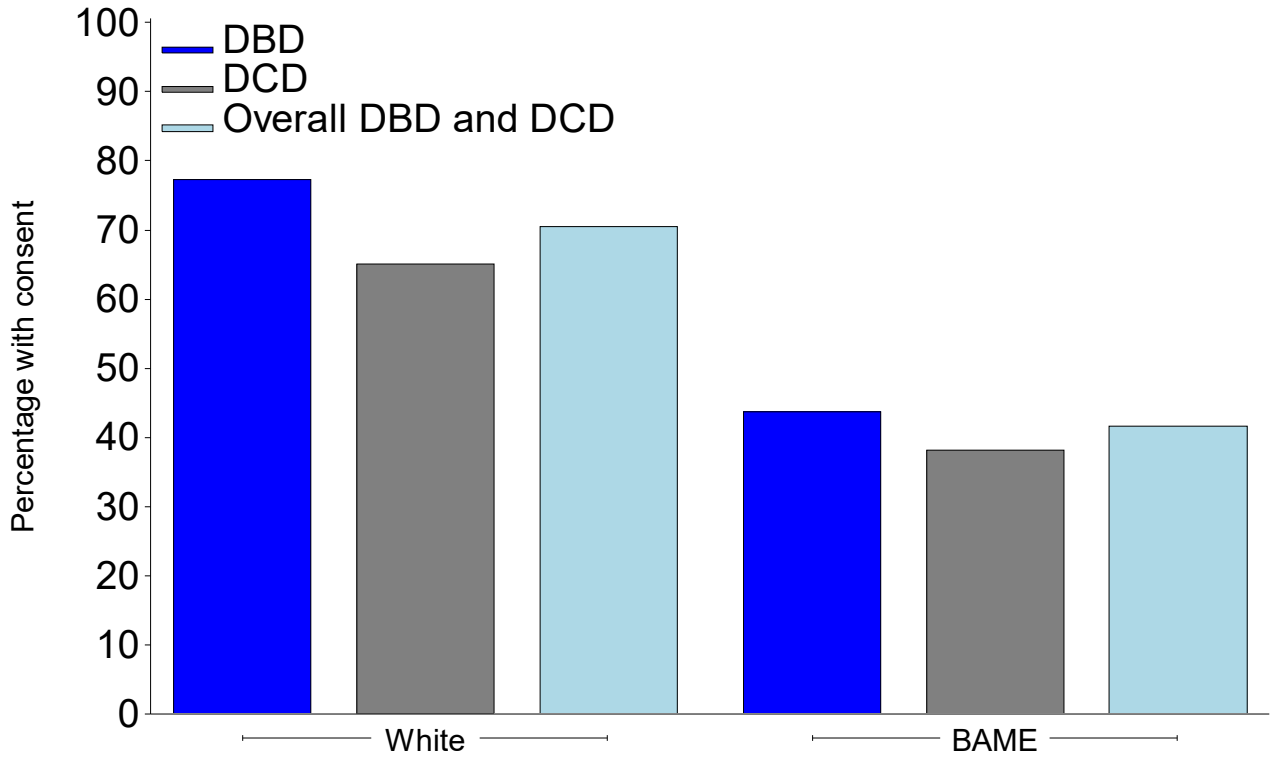
For eligible DBD, the consent/authorisation rates were 77% for eligible white donors compared to 44% for eligible BAME donors. The 95% confidence limits for these DBD consent/authorisation rates are 75% - 80% and 37% - 50%, respectively.

For eligible DCD, the consent/authorisation rates were 65% for eligible white DCD and 38% for eligible BAME DCD donors. The 95% confidence limits for these DCD consent/authorisation rates are 63% - 67% and 30% - 47%, respectively.

The overall consent/authorisation rates were 70% for eligible white donors and 42% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 69% - 72% for eligible white donors and 36% - 47% for eligible BAME donors.

The difference between consent/authorisation rates for white and BAME eligible DBD donors is statistically significant, p<.0001. The difference between consent/authorisation rates for white and BAME eligible DCD donors is statistically significant, p<.0001. The ethnicity effect remains highly significant after allowing for age, sex and month of death.

Figure 5 Ethnic group variation in consent/authorisation rate



10 SOLID ORGAN DONATION

Of the eligible donors whose families were approached for formal organ donation discussion and consent/authorisation was ascertained, 90% of the eligible DBD and 56% 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.

For consented/authorised eligible DBD the main reason given for solid organ donation not proceeding was that the organs were deemed to be medically unsuitable by recipient centres

in 38% of cases. A further 14% were declined due to coroner/procurator fiscal refusal and 13% due to positive virology.

Similarly, 28% of non-proceeding DCD donors were due to recipient centres deeming the organs to be medically unsuitable. The main reason given for consented/authorised eligible DCD not proceeding to become a solid organ donor was the prolonged time to asystole, with 45% cases.

Table 6 Reasons why solid organ donation did not happen following consent

	DBD		DCD	
	N	**%**	**N**	**%**
Organs deemed medically unsuitable by recipient centres	42	37.5	136	27.9
Coroner/ Procurator Fiscal refusal	16	14.3	23	4.7
Positive virology	14	12.5	7	1.4
Other	10	8.9	33	6.8
General instability	9	8.0	32	6.6
Family changed mind	8	7.1	18	3.7
Cardiac arrest	8	7.1	5	1.0
Organs deemed medically unsuitable on surgical inspection	5	4.5	10	2.1
Prolonged time to asystole	-	-	219	45.0
Logistic reasons	-	-	3	0.6
Family placed conditions on donation	-	-	1	0.2
Total	**112**	**100.0**	**487**	**100.0**

11 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** but only once in the deceased donor chart.

Over the last five years, the number of neurological death tested patients has increased, whilst the testing rate has remained consistent at 86%. DBD and DCD referral rates have continued to improve to 99% and 93% respectively. The actual number of missed referrals has continued to decrease in both DBD and DCD, to just 22 DBD in 2018/19. Since 2014/15 there has been a steady increase in the percentage of family approaches where a SNOD was present, increasing from 87% to 95% for DBD and from 72% to 87% for DCD. The actual number of missed opportunities to have a SNOD present for the family approach has continued to decline in both DBD and DCD. There has also been a steady increase in both the DBD and DCD consent/authorisation rates over the last five years, and in 2018/19 record consent/authorisation rates were observed in both DBD and DCD donation, 72% and 63% respectively.

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

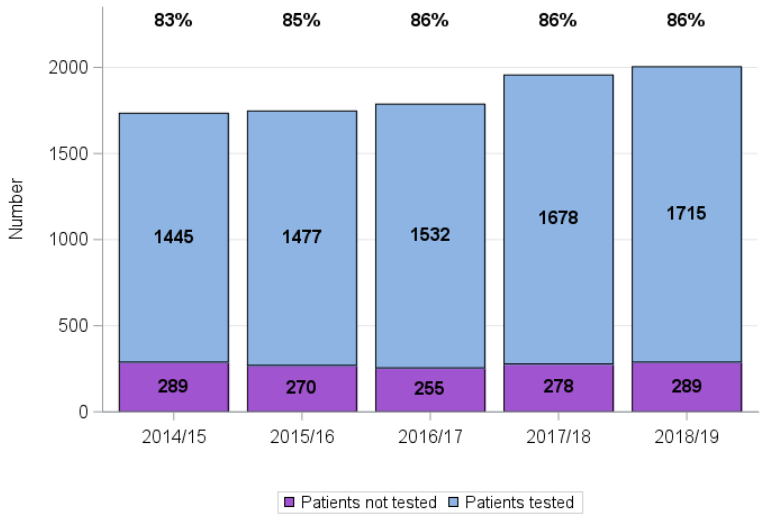
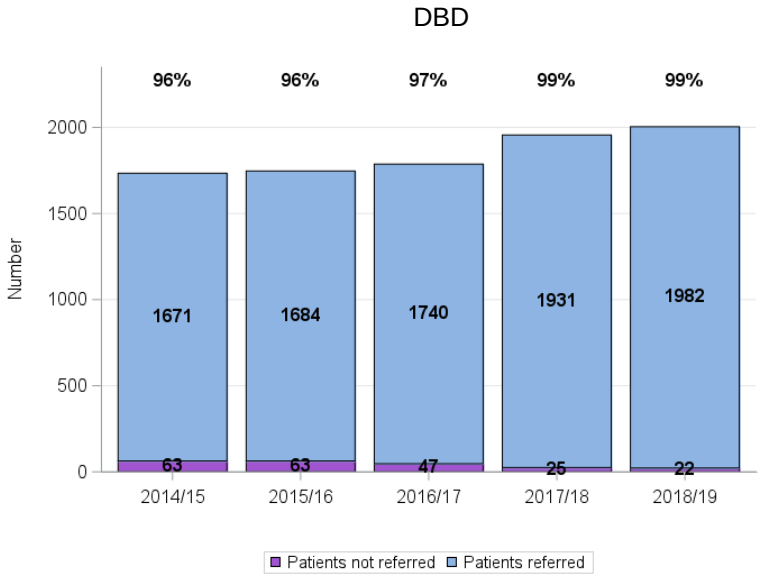
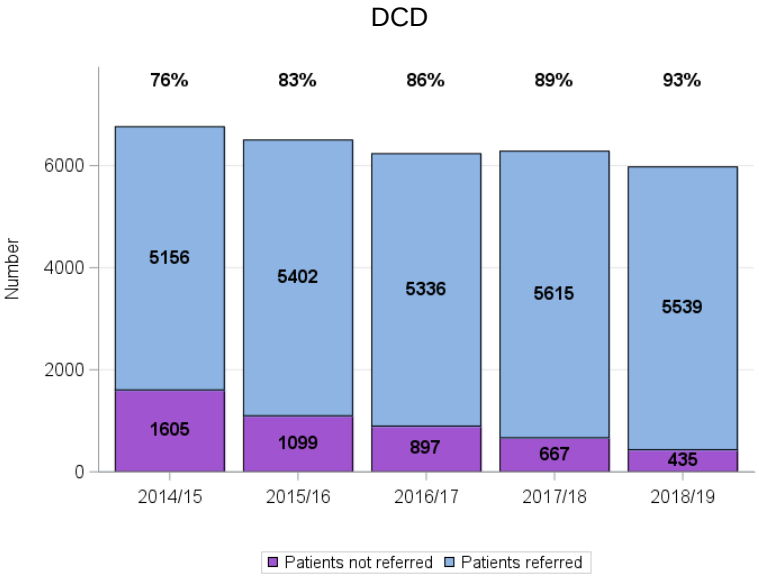


Figure 7 Number of patients meeting referral criteria, 1 April 2014 – 31 March 2019





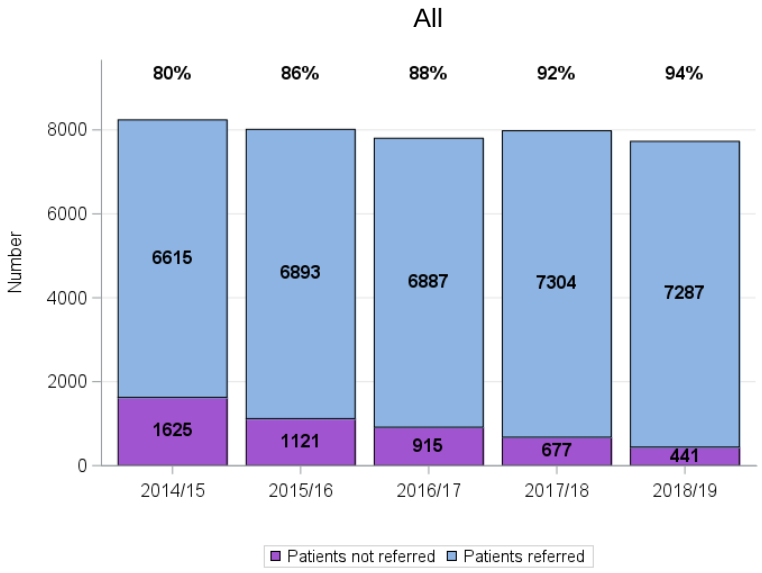
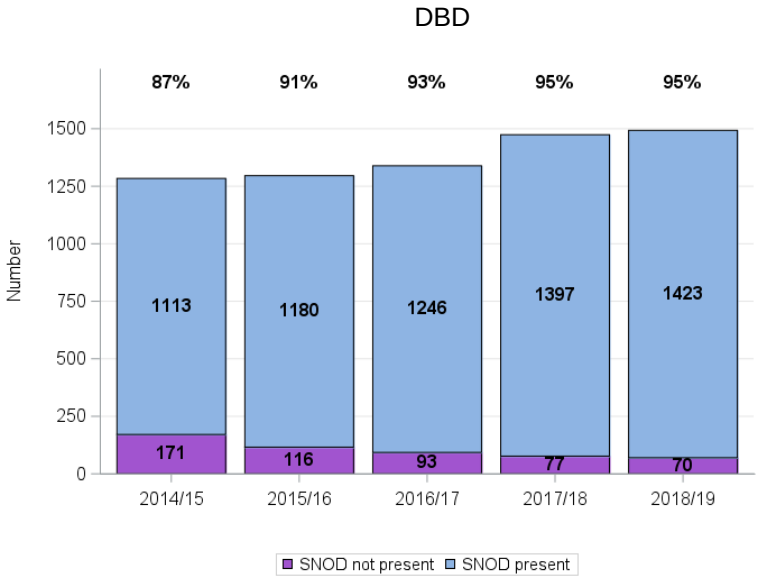
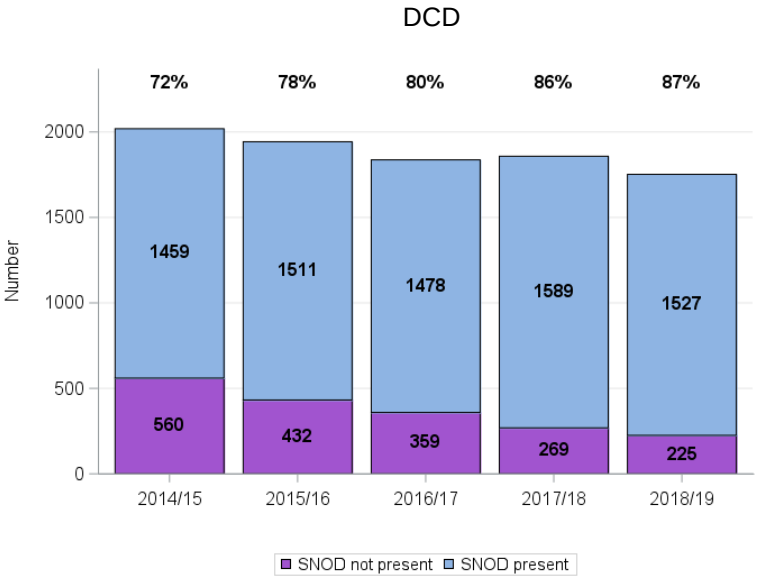


Figure 8 Number of families approached by SNOD presence, 1 April 2014 – 31 March 2019





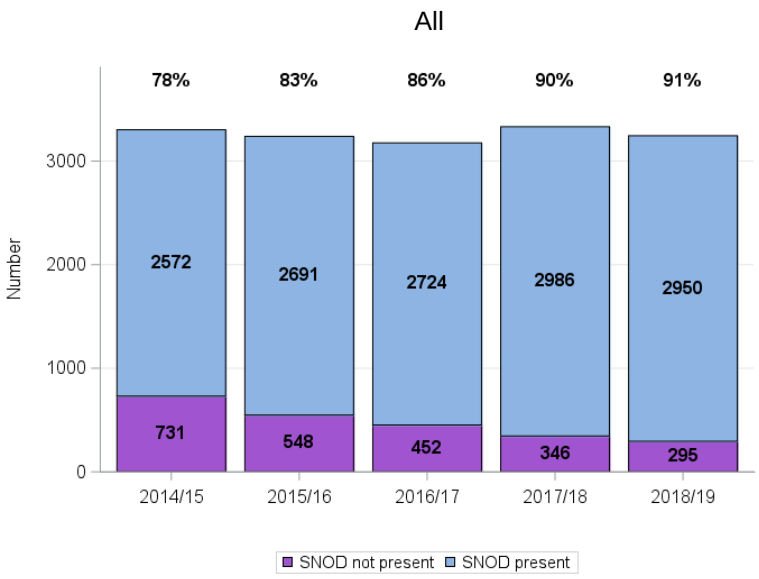
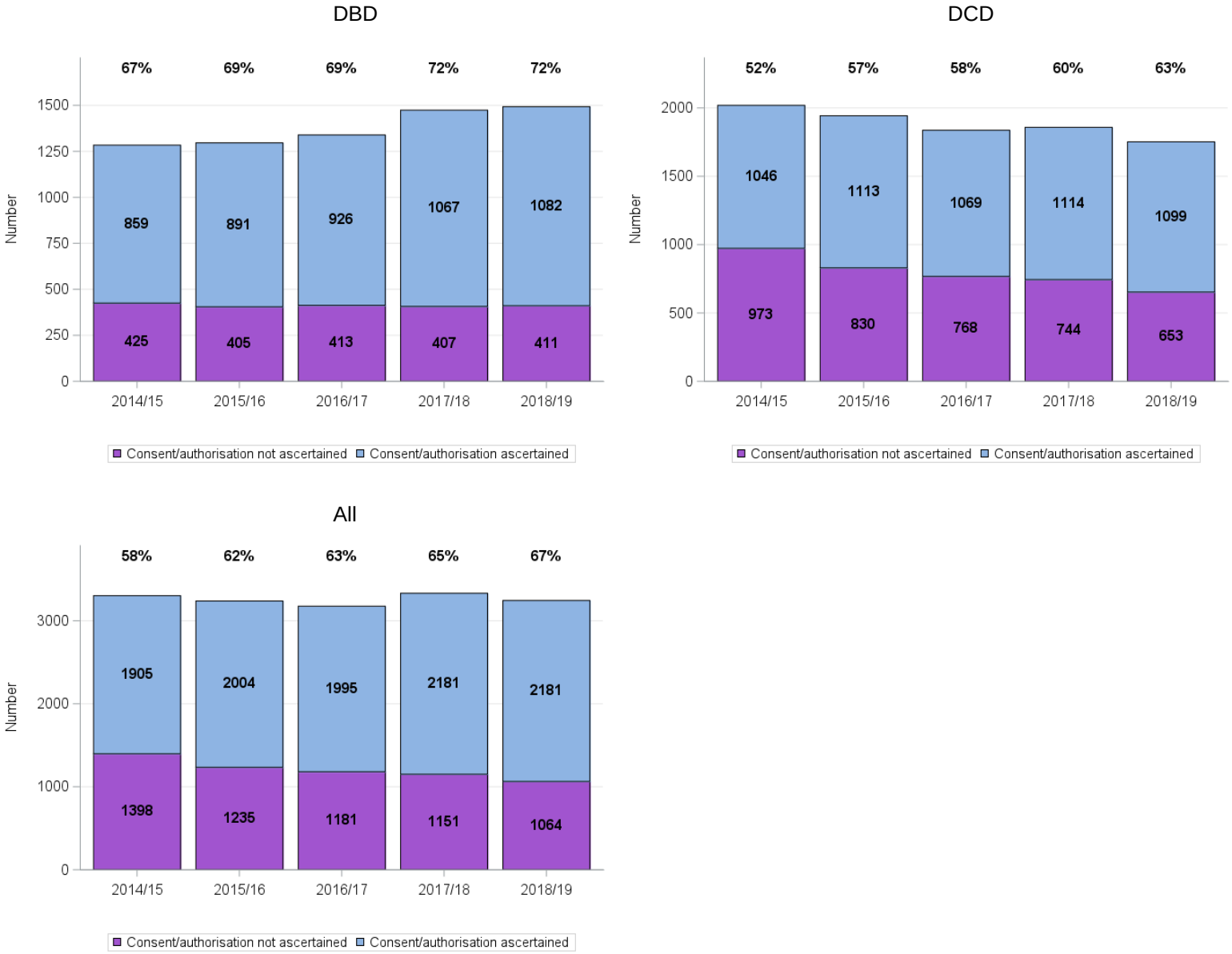


Figure 9 **Number of families approached by consent/authorisation ascertained, 1 April 2014 – 31 March 2019**



12 SUMMARY

In the year 1 April 2018 to 31 March 2019, there were 32,588 deaths audited for the PDA. Of these deaths, 2,004 and 5,974 patients met the referral criteria for DBD and/or DCD, respectively and 99% and 93% were referred to NHS Blood and Transplant. Of the 2,004 patients for whom neurological death was suspected, 86% were tested

Of the families approached, 72% and 63% consented to/authorised DBD and DCD donation. Of these, 90% and 56%, respectively, became actual solid organ donors. 79 families overruled their loved one's known decision to be an organ donor.

There was no statistically significant difference in the consent/authorisation rates for male and female patients for DBD or DCD. The difference in the consent/authorisation rate across the different age groups was not statistically significant for DBD or DCD patients. However, the difference in consent/authorisation rate when comparing only between adult and paediatric (<18 years) DCD patients was significant, with paediatric patients having a lower consent/authorisation rate than adult patients.

There was a statistically significant difference in both the DBD and DCD consent/authorisation rate between white and BAME patients and this effect remains after adjusting for patient age, sex and month of patient death.

Since 2014/15, the testing rate for neurological death has remained consistent at 86%, however referral, SNOD presence and consent/authorisation rates have steadily improved for both DBD and DCD donation. Numbers of missed referrals and opportunities to involve a SNOD in the family approach have continued to decline.

Chloe Brown and Sue Madden
NHS Blood and Transplant **August 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