

ANNUAL REPORT ON THE POTENTIAL DONOR AUDIT

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

PUBLISHED OCTOBER 2020

1 INTRODUCTION

This report presents Potential Donor Audit (PDA) information on the financial year 1 April 2019 to 31 March 2020.

The dataset used to compile this report includes all audited patient deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 8 July 2020. 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Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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

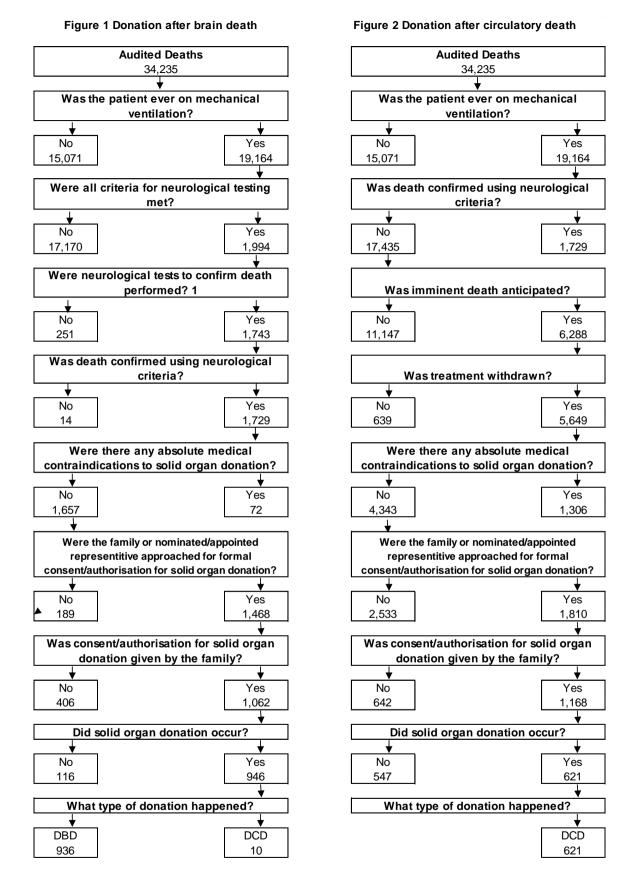
Deemed consent applies in Wales if a person has not registered an organ donation decision to either opt-in or opt-out or appoint a representative, is aged 18 or over, has lived for longer than 12 months and is ordinarily resident and also died in Wales, and had the capacity to understand the notion of 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 2019 to 31 March 2020, there were a total of 34,235 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.



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	1994	6288	8282
Referred to NHS Blood and Transplant	1975	5718	7693
Referral rate %	99.0%	90.9%	92.9%
Neurological death tested	1743		1743
Testing rate %	87.4%		87.4%
Family approached	1468	1810	3278
Family approached and SN-OD present	1413	1615	3028
% of approaches where SN-OD present	96.3%	89.2%	92.4%
Consent/authorisation given	1062	1168	2230
Consent/authorisation rate %	72.3%	64.5%	68.0%
- Opt-in decision registered on the ODR	539	587	1088
- Opt-in decision registered on the ODR %	92.9%	89.9%	91.3%
- Opt-in decision expressed by any method	588	652	1240
- Opt-in decision expressed by any method %	93.9%	90.1%	91.9%
- Deemed consent applied	17	13	30
- Deemed consent applied %	70.8%	48.1%	58.8%
- No known decision to donate	474	516	990
- No known decision to donate %	56.3%	47.5%	51.3%
Actual donors from each pathway	946	621	1567
% of consented/authorised donors that became actual donors	89.1%	53.2%	70.3%

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 4 hours

4 NEUROLOGICAL DEATH TESTING RATE

Table 2 Reasons given for neurological dead	th tests not being perfo	ormed
	N	%
Patient haemodynamically unstable	73	29.1
Clinical reason/Clinicians decision	61	24.3
Biochemical/endocrine abnormality	25	10.0
Family declined donation	18	7.2
Inability to test all reflexes	18	7.2
Other	15	6.0
Family pressure not to test	12	4.8
Treatment withdrawn	7	2.8
SN-OD advised that donor not suitable	7	2.8
Continuing effects of sedatives	6	2.4
Medical contraindication to donation	4	1.6
Unknown	4	1.6
Patient had previously expressed a wish not to donate	1	0.4
Total	251	100.0

The neurological death testing rate was 87% 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, brainstem reflexes returned, neonates - less than 2 months post term were not possible to test meaning these reasons were excluded. Neurological death tests were not performed in 251 patients (13%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

73 (29%) patients were haemodynamically unstable and were therefore not tested. Other reasons given for not performing neurological death tests were: 61 (24%) patients had a clinical reason or it was the clinician's decision, and 25 (10%) of patients had a biochemical/endocrine abnormality.

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 91%.

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 referre	ed			
	DBD		DCD	
	N	%	N	%
Not identified as a potential donor/organ donation not considered	7	36.8	284	49.8
Other	4	21.1	67	11.8
Medical contraindications	3	15.8	119	20.9
Family declined donation after neurological testing	2	10.5		
Thought to be medically unsuitable	2	10.5	71	12.5
Family declined donation prior to neurological testing	1	5.3	-	-
Coroner/Procurator Fiscal Reason	-	-	1	0.2
Family declined donation following decision to withdraw treatment	-	-	11	1.9
Reluctance to approach family	-	-	3	0.5
Thought to be outside age criteria	-	-	4	0.7
Pressure on ICU beds	-	-	3	0.5
Clinician assessed that patient was unlikely to become asystolic within 4 hours	-	-	5	0.9
Patient had previously expressed a wish not to donate	-	-	2	0.4
Total	19	100.0	570	100.0

Of the patients who met the referral criteria and were not referred, the reason given for 37% of DBD and 50% of DCD was that the patients were not identified as potential donors

and so organ donation was not considered. For 21% of DBD and 12% of DCD not referred other was given as the reason for not referring the patient. For 16% of DBD and 21% of DCD patients not referred medical contradictions were the reason for not referring.

6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 89% of DBD and 42% of DCD cases. 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 22% of DBD cases, the reason stated was other. For 14% of DBD cases Coroner/Procurator Fiscal refused permission was the reason given.

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For eligible DCD donors not approached, the main reasons stated were the patient's general medical condition (43%), other reason (24%) or other medical reason (13%).

Table 4 Reasons given why family not formally approached					
	DBD		D	DCD	
	N	%	N	%	
Patient's general medical condition	60	31.7	1,079	42.6	
Other	41	21.7	611	24.1	
Coroner / Procurator Fiscal refused permission	26	13.8	43	1.7	
Other medical reason	24	12.7	320	12.6	
Family stated that they would not support donation before they were formally approached	11	5.8	41	1.6	
Patient had previously expressed a wish not to donate	10	5.3	23	0.9	
Family untraceable	9	4.8	23	0.9	
Family considered too upset to approach	4	2.1	13	0.5	
Not identified as a potential donor / organ donation not considered	3	1.6	320	12.6	
Patient outside age criteria	1	0.5	49	1.9	
Resource failure	-	-	1	0.0	
Pressure on ICU beds	-	-	10	0.4	
Total	189	100.0	2,533	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 65% and the 95% confidence limits for this percentage are 62% - 67%. The overall consent/authorisation rate was 68% and the 95% confidence limits for this percentage are 66% - 70%.

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 93% compared to 60% 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 90% compared with 50%. Overall, these rates were 91% compared with 55%.

In total during the financial year, 110 families overruled their loved one's known opt-in decision (recorded via the ODR, verbally or in writing) to be an organ donor.

Of the 1413 occasions, when a SN-OD was present for the formal organ donation discussion with the family, the DBD consent/authorisation rate was 74% compared with 44% on the 55 occasions when the SN-OD was not present. Similarly, for DCD the rate was 69% of 1615 compared with 24% of the 195 occasions when the SN-OD was not present. The overall rate was 71% (N=3028) compared with 29% (N=250).

Table 5 Reasons given why family did not give	e consen	t			
	DBD		D	DCD	
	N	%	N	%	
Patient previously expressed a wish not to donate	114	28.1	148	23.1	
Family were not sure whether the patient would have agreed to donation	57	14.0	89	13.9	
Family did not want surgery to the body	44	10.8	60	9.3	
Family felt it was against their religious/cultural beliefs	42	10.3	17	2.6	
Other	30	7.4	57	8.9	
Family felt the patient had suffered enough	26	6.4	71	11.1	
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	24	5.9	13	2.0	
Family felt the length of time for donation process was too long	20	4.9	114	17.8	
Family were divided over the decision	17	4.2	23	3.6	
Family did not believe in donation	15	3.7	15	2.3	
Strong refusal - probing not appropriate	11	2.7	17	2.6	
Family wanted to stay with the patient after death	3	0.7	7	1.1	
Family had difficulty understanding/accepting neurological testing	3	0.7			
Family concerned that other people may disapprove/be offended	-	-	1	0.2	
Family concerned that organs may not be transplanted	-	-	7	1.1	
Families concerned about organ allocation	-	-	1	0.2	
Family concerned donation may delay the funeral	-	-	2	0.3	
Total	406	100.0	642	100.0	

The reasons why the family did not give consent/authorisation 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 (28% 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 did not want surgery to the body or felt it was against their religious/cultural beliefs. 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 March 2020 (79%) and lowest in August 2019 (64%), whereas the DCD consent/authorisation rate was highest in July 2019 (73%) and lowest in April 2019 (61%). The differences in the monthly consent/authorisation rates from 1 April 2019 to 31 March 2020 are not statistically significant for either DBD or DCD, p=0.4 and p=0.6 respectively.

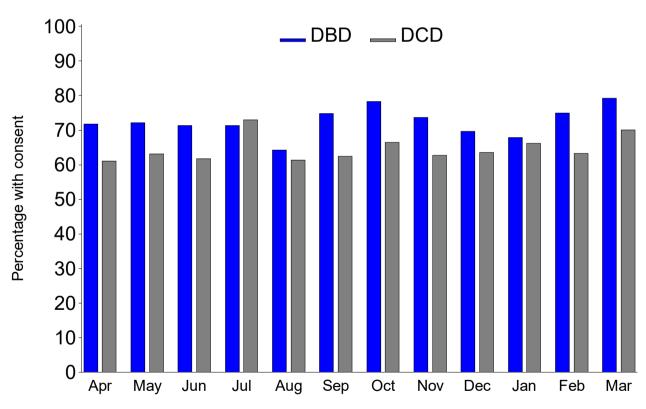


Figure 3 Month-to-month variation in consent/authorisation rate

9 EFFECT OF DEMOGRAPHIC VARIABLES ON THE CONSENT/AUTHORISATION RATE

The consent/authorisation rate for the 776 male eligible DBD was 74% and the consent/authorisation rate for the 692 female eligible DBD was 71%. The difference is not

statistically significant, p=0.2. For the 1129 male eligible DCD the consent/authorisation rate was 66% and for the 680 female eligible DCD was 61%. This difference is statistically significant, p=0.03.

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 1,468 eligible DBD and 1,809 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest consent/authorisation rate for eligible DBD occurred in the 35-49 age group (76%) and for eligible DCD in the 18-24 age group (84%). The lowest consent/authorisation rate for eligible DBD was in the 0-17 age group (68%). The lowest consent/authorisation rate for eligible DCD was in the 0-17 age group (46%). The differences in consent/authorisation rate across the six age groups for DBD are not statistically significant (p=0.6) and for DCD are statistically significant (p=0.001).

When comparing only between adult and paediatric (<18 years), the differences in consent/authorisation rate for DBD are not statistically significant (p=0.5) and for DCD are statistically significant (p<0.001).

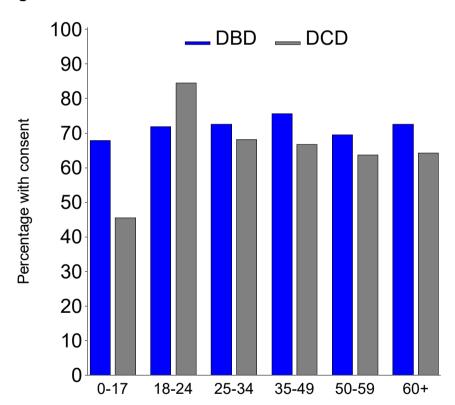


Figure 4 Age variation in consent/authorisation rate

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 20 DBD and 48 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 78% for eligible white donors compared to 41% for eligible BAME donors. The 95% confidence limits for these DBD consent/authorisation rates are 76% - 80% and 34% - 47%, respectively.

For eligible DCD, the consent/authorisation rates were 67% for eligible white DCD and 43% for eligible BAME DCD donors. The 95% confidence limits for these DCD consent/authorisation rates are 64% - 69% and 35% - 52%, respectively.

The overall consent/authorisation rates were 72% for eligible white donors and 42% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 70% - 73% for eligible white donors and 37% - 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.

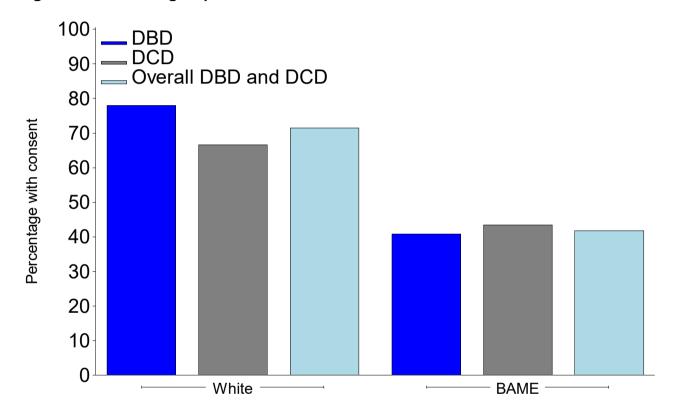


Figure 5 Ethnic group variation in consent/authorisation rate

10 SOLID ORGAN DONATION

Of the eligible donors whose families were approached for formal organ donation discussion and consent/authorisation was ascertained, 89% of the eligible DBD and 53% 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 11% were declined due to coroner/procurator fiscal refusal and 10% due to positive virology.

Similarly, 29% 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 44% cases.

	DBD		DCD	
	N	%	N	%
Organs deemed medically unsuitable by recipient centres	44	37.9	158	28.9
Other	13	11.2	48	8.8
Coroner/ Procurator Fiscal refusal	12	10.3	17	3.1
Positive virology	11	9.5	11	2.0
Organs deemed medically unsuitable on surgical inspection	10	8.6	8	1.5
Family changed mind	9	7.8	17	3.1
General instability	9	7.8	32	5.9
Cardiac arrest	8	6.9	11	2.0
Prolonged time to asystole	-	-	238	43.6
Logistic reasons	-	-	4	0.7
Family placed conditions on donation	-	-	2	0.4

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 continued to increase and the testing rate has risen from 85% to 87%. Both DBD and DCD referral rates have also improved over the same time period, from 96% to 99% and from 83% to 91%, respectively and the associated number of missed referrals has dropped from 63 to just 19, in DBD, and from 1099 to 570, in DCD. Furthermore, there has been a steady increase in the percentage of family approaches where a SNOD was present, increasing from 91% to 96% for DBD and from 78% to 89% for DCD. The DBD consent/authorisation rate has increased from 69% to 72% over the past five years. The DCD consent/authorisation rate has risen over the past five years from 57% to a record high of 65%.

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

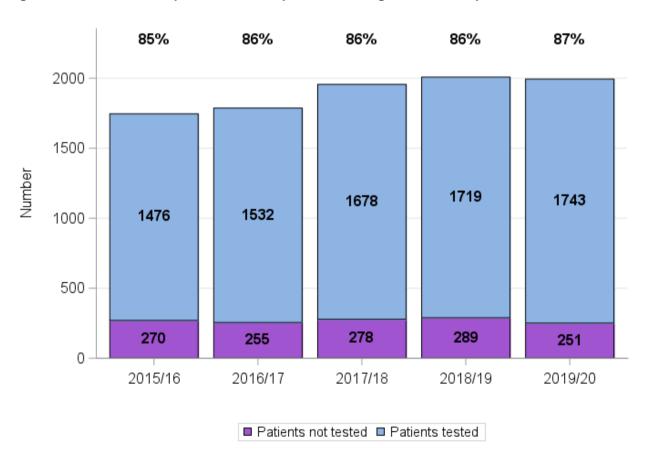
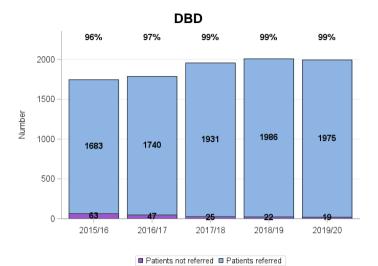
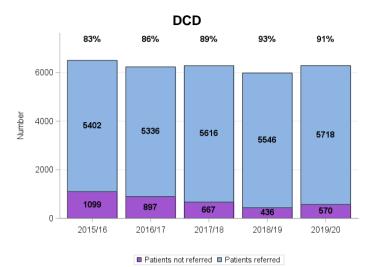


Figure 7 Number of patients meeting referral criteria, 1 April 2014 – 31 March 2019





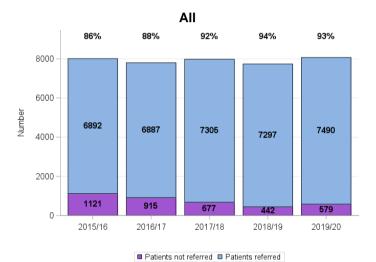
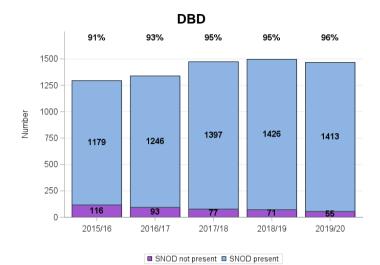
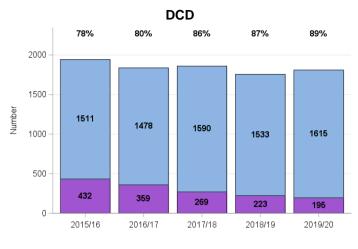
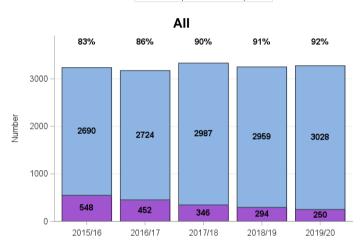


Figure 8 Number of families approached by SNOD presence, 1 April 2015 – 31 March 2020



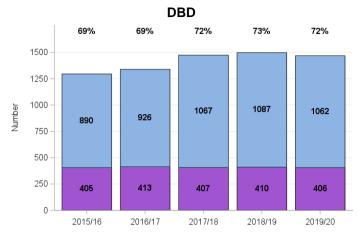


■ SNOD not present ■ SNOD present

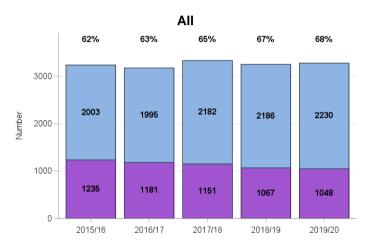


■ SNOD not present ■ SNOD present

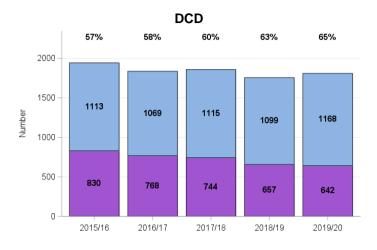
Figure 9 Number of families approached by consent/authorisation ascertained, 1 April 2015 – 31 March 2020







■ Consent/authorisation not ascertained ■ Consent/authorisation ascertained



■ Consent/authorisation not ascertained ■ Consent/authorisation ascertained

12 SUMMARY

In the year 1 April 2019 to 31 March 2020, there were 34,235 deaths audited for the PDA. Of these deaths, 1,994 and 6,288 patients met the referral criteria for DBD and/or DCD, respectively and 99% and 91% were referred to NHS Blood and Transplant. Of the 1,994 patients for whom neurological death was suspected, 87% were tested

Of the families approached, 72% and 65% consented to/authorised DBD and DCD donation. Of these, 89% and 53%, respectively, became actual solid organ donors. 110 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. There was a statistically significant different difference in the consent/authorisation rate between male and female patients for DCD. The difference in the consent/authorisation rate across the different age groups was statistically significant for DCD, but not DCD. For DCD paediatric patients (0-17 years) have a much lower consent/authorisation rate than the adult groups.

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 2015/16, the testing rate for neurological death as well as referral, SNOD present and consent/authorisation rates have all improved. Notably, DBD and DCD referral rates are very high, 99% and 91% respectively. In addition, the DBD consent/authorisation rate has increased to 72%, over the five year period, and the DCD consent/authorisation rate has also increased to a record high of 65%.

Roddy Jaques NHS Blood and Transplant

October 2020

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

A patient who meets all four criteria for neurological death testing excluding Potential DBD donor

Nurse - Organ Donation (SNOD)

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). A patient with suspected neurological death

medical contraindications to solid organ donation

DBD referral criteria A patient with suspected neurological death discussed with the Specialist

Discussed with Specialist Nurse - Organ

Donation

Neurological death tested

Eligible DBD donor

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.

Neurological death tests were performed

Consent/authorisation ascertained Family supported expressed or deemed consent/authorisation,

nominated/appointed representative gave consent, or where applicable

A patient confirmed dead by neurological death tests, with no absolute

family gave consent/authorisation

Neurological death confirmed patients who became actual DBD as reported

through the PDA

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

Percentage of patients for whom neurological death was suspected who Referral rate

were discussed with the SNOD

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 Percentage of formal organ donation discussions with families or

nominated/appointed representatives where a SNOD was present where

consent/authorisation was ascertained

Actual donors: DBD

Actual donors: DCD

Approach rate

Consent/authorisation rate where SNOD was present

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

Discussed with Specialist Nurse - Organ

Donation

Potential DCD donor

the SNOD A patient who had treatment withdrawn and death was anticipated within

Patients for whom imminent death was anticipated who were discussed with

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

A patient in whom imminent death is anticipated (as defined above)

donation

Family approached for formal organ

Consent/authorisation ascertained

Consent/authorisation rate where SNOD

donation discussion

was present

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

Family supported expressed or deemed consent/authorisation,

nominated/appointed representative gave consent, or where applicable

family gave consent/authorisation

DCD patients who became actual DCD as reported through the PDA Actual DCD

Percentage of patients for whom imminent death was anticipated who were Referral rate

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

Percentage of formal organ donation discussions with families or

nominated/appointed representatives where a SNOD was present where

consent/authorisation was ascertained