# POTENTIAL DONOR AUDIT
# SUMMARY REPORT FOR THE 12 MONTH PERIOD
# 1 APRIL 2017 - 31 MARCH 2018

## 1 INTRODUCTION

This report presents Potential Donor Audit (PDA) information on the financial year 1 April 2017 to 31 March 2018.

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 2018. 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**Eligible donors after circulatory death** (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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/4376/contraindications_to_organ_donation.pdf

**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 2017 to 31 March 2018, there were a total of 35,568 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**

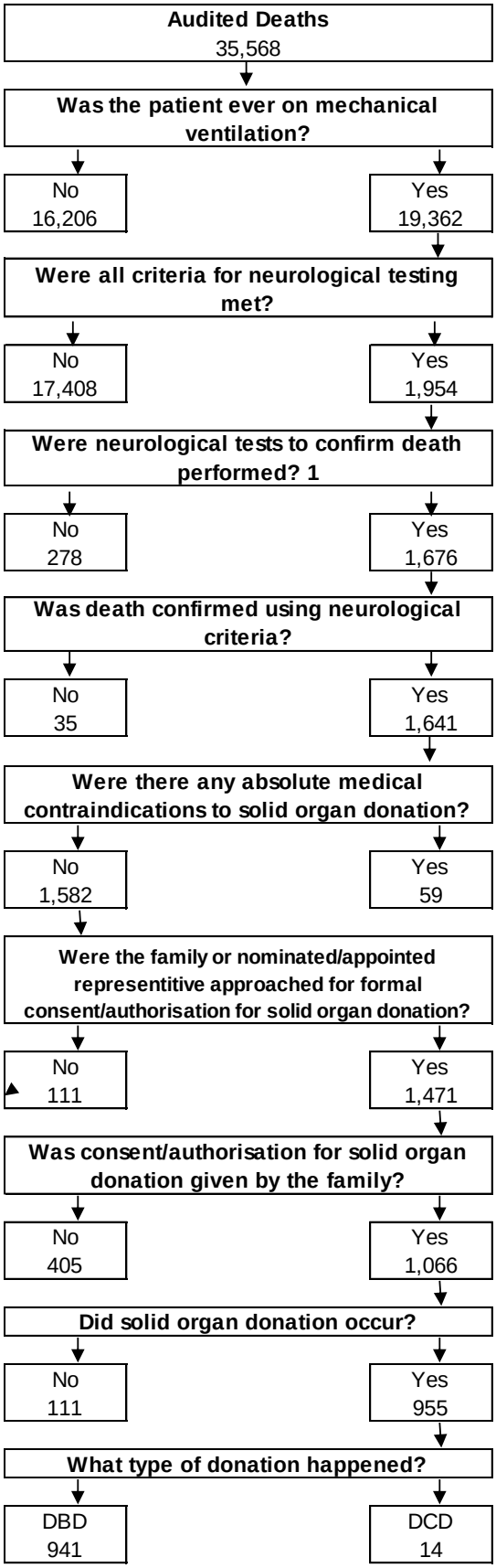
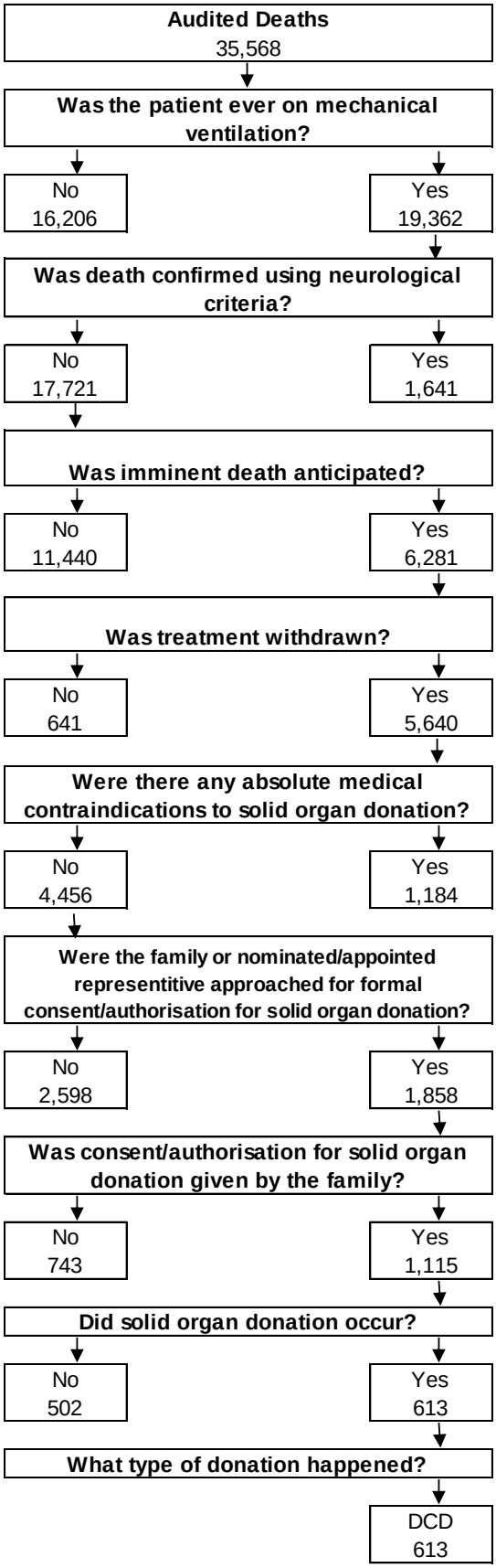



**Figure 2 Donation after circulatory death**




[1] Patients for whom tests were not performed due to: Cardiac arrest despite resuscitation occurred, brainstem reflexes returned, 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** |
| Patients meeting organ donation referral criteria[1] | 1954 | 6281 |
| Referred to NHS Blood and Transplant | 1929 | 5615 |
| *Referral rate %* | *98.7%* | *89.4%* |
| Neurological death tested | 1676 | - |
| *Testing rate %* | *85.8%* | - |
| Family approached | 1471 | 1858 |
| Family approached and SN-OD present | 1394 | 1591 |
| *% of approaches where SN-OD present* | *94.8%* | *85.6%* |
| Consent/authorisation given | 1066 | 1115 |
| *Consent/authorisation rate %* | *72.5%* | *60.0%* |
| Actual donors from each pathway | 955 | 613 |
| *% of consented/authorised donors that became actual donors* | *89.6%* | *55.0%* |

[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 death tests not being performed | | |
|---|---|---|
| | **N** | **%** |
| Patient haemodynamically unstable | 69 | 24.8 |
| Clinical reason/Clinicians decision | 64 | 23.0 |
| Biochemical/endocrine abnormality | 26 | 9.4 |
| Family pressure not to test | 21 | 7.6 |
| Family declined donation | 18 | 6.5 |
| Other | 18 | 6.5 |
| Continuing effects of sedatives | 17 | 6.1 |
| Inability to test all reflexes | 12 | 4.3 |
| Treatment withdrawn | 9 | 3.2 |
| SN-OD advised that donor not suitable | 9 | 3.2 |
| Medical contraindication to donation | 6 | 2.2 |
| Pressure on ICU beds | 3 | 1.1 |
| Unknown | 3 | 1.1 |
| Patient had previously expressed a wish not to donate | 2 | 0.7 |
| Hypothermia | 1 | 0.4 |
| **Total** | **278** | **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, 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 278 patients (14%)

for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

69 (25%) patients were haemodynamically unstable and were therefore not tested. Other reasons given for not performing neurological death tests were: 64 (23%) patients had a clinical reason or it was the clinician's decision, and for 26 (9%) patients had biochemical or endocrine abnormalities.

## 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 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.

**Table 3 Reasons given why patient not referred**

| | DBD | | DCD | |
|---|---|---|---|---|
| | **N** | **%** | **N** | **%** |
| Not identified as a potential donor/organ donation not considered | 10 | 40.0 | 320 | 48.0 |
| Other | 5 | 20.0 | 76 | 11.4 |
| Family declined donation prior to neurological testing | 2 | 8.0 | 3 | 0.5 |
| Family declined donation after neurological testing | 2 | 8.0 | | |
| Reluctance to approach family | 2 | 8.0 | 8 | 1.2 |
| Coroner/Procurator Fiscal Reason | 1 | 4.0 | 3 | 0.5 |
| Medical contraindications | 1 | 4.0 | 110 | 16.5 |
| Thought to be medically unsuitable | 1 | 4.0 | 106 | 15.9 |
| Neurological death not confirmed | 1 | 4.0 | | |
| Family declined donation following decision to withdraw treatment | | | 24 | 3.6 |
| Pressure on ICU beds | | | 7 | 1.1 |
| Clinician assessed that patient was unlikely to become asystolic within 4 hours | | | 7 | 1.1 |
| Patient had previously expressed a wish not to donate | | | 2 | 0.3 |
| **Total** | **25** | **100.0** | **666** | **100.0** |

Of the patients who met the referral criteria and were not referred, the reason given for 40% of DBD and 48% of DCD was that the patients were not identified as potential donors and so organ donation was not considered. The reason given for 20% of DBD and 11% of DCD was other reason.

## 6 APPROACH RATE

Families of eligible donors were approached for formal organ donation discussion in 93% 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 24% of cases was that the Coroner/Procurator Fiscal refused permission. In a further 20% of DBD cases, the reason stated was the patient's general medical condition.

For eligible DCD donors not approached, the main reasons stated were the patient's general medical condition (41%) or other reason (27%), the majority of these cases are result of the DCD assessment process which identifies patients unsuitable for donation prior to the approach. In a further, 14% of cases, the patient was not identified as a potential donor.

**Table 4 Reasons given why family not formally approached**

| | DBD | | DCD | |
|---|---|---|---|---|
| | **N** | **%** | **N** | **%** |
| Coroner / Procurator Fiscal refused permission | 27 | 24.3 | 44 | 1.7 |
| Patient's general medical condition | 22 | 19.8 | 1,072 | 41.3 |
| Other | 18 | 16.2 | 699 | 26.9 |
| Family stated that they would not support donation before they were formally approached | 16 | 14.4 | 51 | 2.0 |
| Other medical reason | 10 | 9.0 | 292 | 11.2 |
| Patient had previously expressed a wish not to donate | 7 | 6.3 | 21 | 0.8 |
| Family considered too upset to approach | 6 | 5.4 | 16 | 0.6 |
| Family untraceable | 3 | 2.7 | 26 | 1.0 |
| Not identified as a potential donor / organ donation not considered | 2 | 1.8 | 354 | 13.6 |
| Resource failure | | | 4 | 0.2 |
| Pressure on ICU beds | | | 16 | 0.6 |
| Patient outside age criteria | | | 3 | 0.1 |
| **Total** | **111** | **100.0** | **2,598** | **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 60% and the 95% confidence limits for this percentage are 58% - 62%. The overall consent/authorisation rate was 66% and the 95% confidence limits for this percentage are 63% - 68%.

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 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 89% compared with 47%. Overall, these rates were 92% compared with 52%.

In total during the financial year, 101 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 74% compared with 37% when the SN-OD was not present. Similarly, for DCD the rate was 67% compared with 18% when the SN-OD was not present. The overall rate was 71% compared with 22%.

**Table 5 Reasons given why family did not give consent**

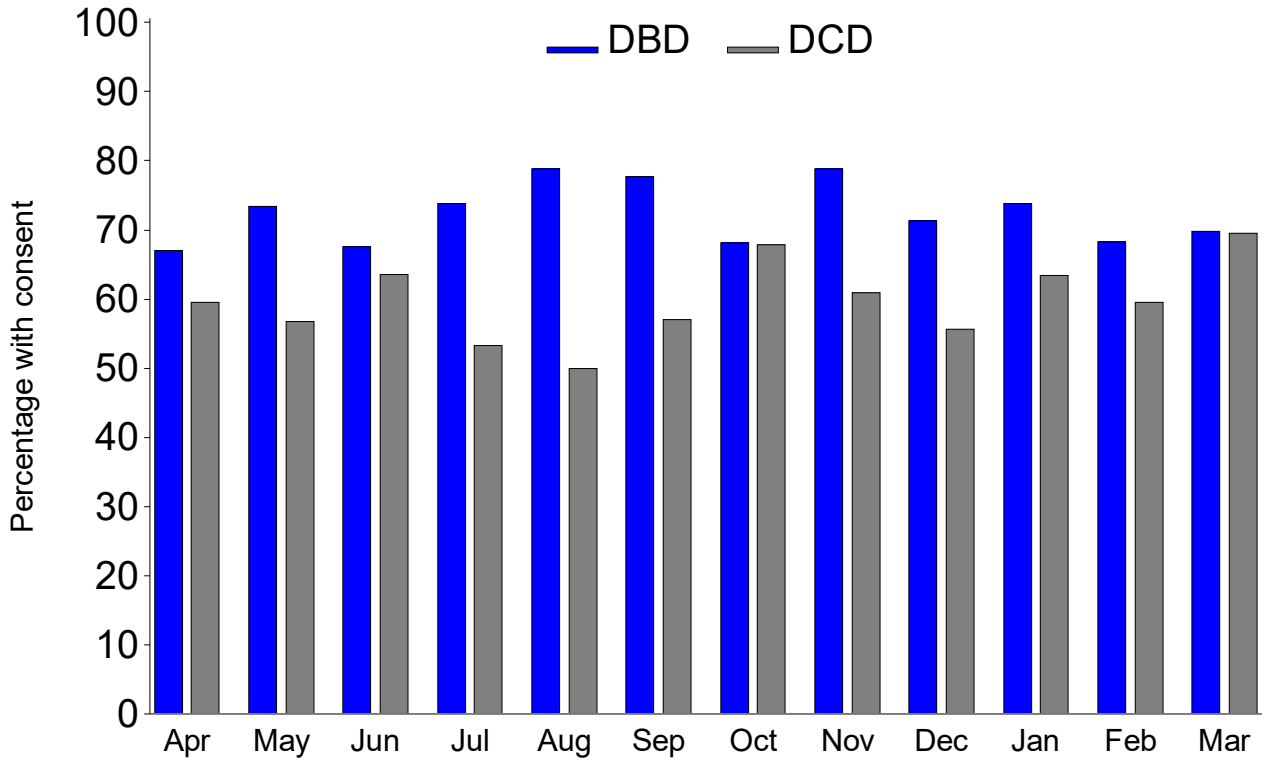
| | DBD | | DCD | |
|---|---|---|---|---|
| | **N** | **%** | **N** | **%** |
| Patient previously expressed a wish not to donate | 91 | 22.5 | 162 | 21.8 |
| Family were not sure whether the patient would have agreed to donation | 65 | 16.0 | 103 | 13.9 |
| Family did not want surgery to the body | 52 | 12.8 | 72 | 9.7 |
| Family felt it was against their religious/cultural beliefs | 44 | 10.9 | 25 | 3.4 |
| Family felt the body needs to be buried whole (unrelated to religious or cultural reasons) | 39 | 9.6 | 24 | 3.2 |
| Other | 24 | 5.9 | 79 | 10.6 |
| Family felt the length of time for donation process was too long | 23 | 5.7 | 128 | 17.2 |
| Family were divided over the decision | 21 | 5.2 | 26 | 3.5 |
| Family felt the patient had suffered enough | 15 | 3.7 | 57 | 7.7 |
| Family did not believe in donation | 13 | 3.2 | 29 | 3.9 |
| Strong refusal - probing not appropriate | 11 | 2.7 | 16 | 2.2 |
| Family had difficulty understanding/accepting neurological testing | 3 | 0.7 | | |
| Family concerned that organs may not be transplanted | 2 | 0.5 | 11 | 1.5 |
| Family concerned donation may delay the funeral | 2 | 0.5 | 1 | 0.1 |
| Family wanted to stay with the patient after death | | | 9 | 1.2 |
| Families concerned about organ allocation | | | 1 | 0.1 |
| **Total** | **405** | **100.0** | **743** | **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 (23% and 22% respectively). Other common reasons why the family did not consent were that the families were not sure whether the patient would have agreed to organ donation or they didn't want the patient to go through surgery to the body. Amongst DCD patients, families felt that the length of time for donation was 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 August 2017 (79%) and lowest in April 2017 (67%), whereas the DCD consent/authorisation rate was highest in March 2018 (69%) and lowest in August 2017 (50%). The differences in the monthly consent/authorisation rates from 1 April 2017 to 31 March 2018 are not statistically significant for DBD, p=0.35 but are statistically significant for DCD, p=0.02.

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




## 9 EFFECT OF DEMOGRAPHIC VARIABLES ON THE CONSENT/AUTHORISATION RATE

There were 2 donors where the gender was not known or not reported and these have been excluded from the gender figures below.

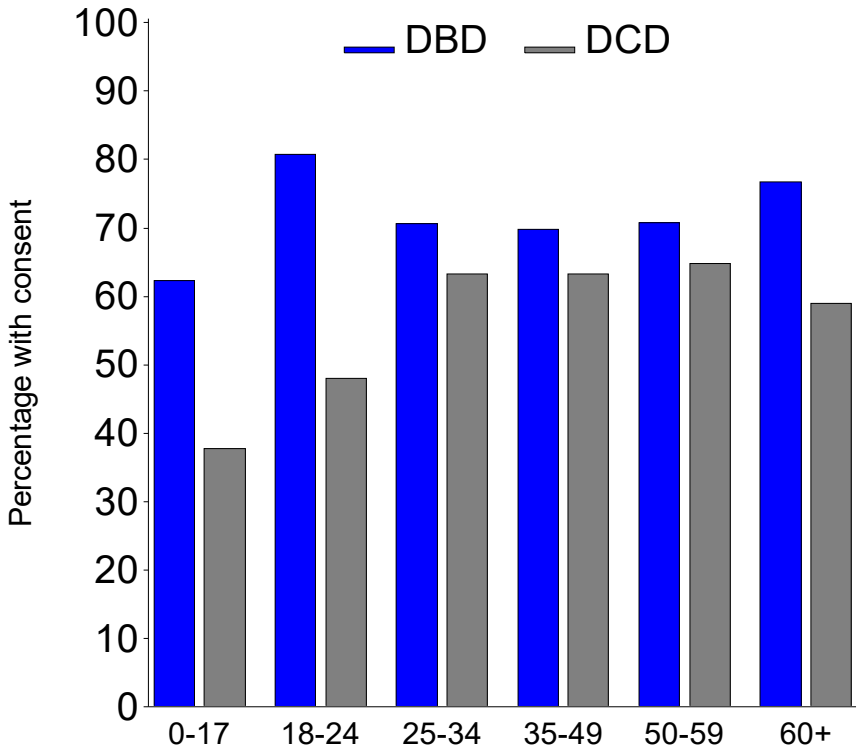
The consent/authorisation rate for the 777 male eligible DBD was 73% and the consent/authorisation rate for the 694 female eligible DBD was 71%. The difference is not statistically significant, p=0.3540. For the 1142 male eligible DCD the consent/authorisation rate was 61% and for the 714 female eligible DCD was 59%. This difference is not statistically significant, p=0.4393.

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 1,471 eligible DBD and 1,856 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 (81%) and for eligible DCD in the 50-59 age group (65%). The lowest consent/authorisation rate for eligible DBD and DCD was in the 0-17 age group 62% and 38%, respectively. The differences in consent/authorisation rate across the six age groups for DBD and DCD are statistically significant, p=0.04 and p=<0.0001 respectively.

When comparing only between adult and paediatric (<18 years), the differences in consent/authorisation rate for DBD are not statistically significant (p=0.07) and for DCD are statistically significant (p=<0.0001).

**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 32 DBD and 76 DCD families approached where the ethnicity was not known or not reported which have been excluded from the ethnicity figures below.

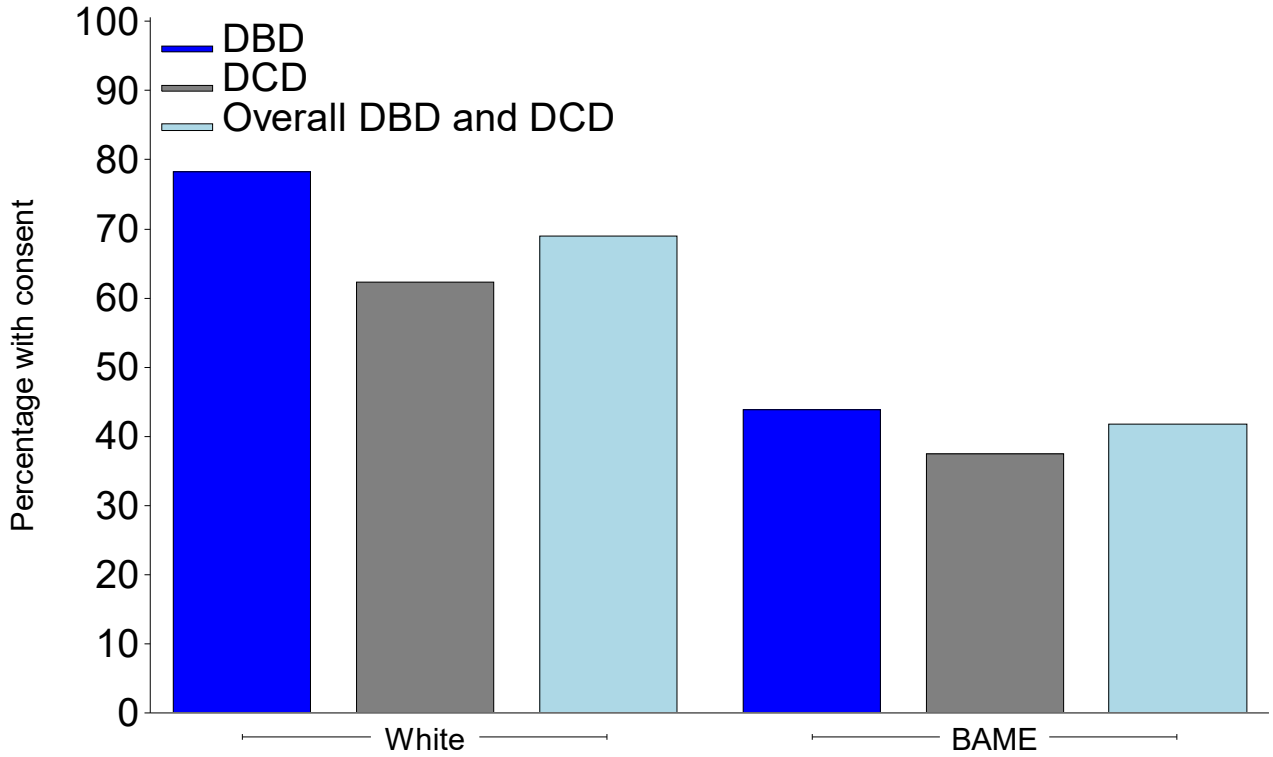
For eligible DBD, the consent/authorisation rates were 78% for eligible white donors compared to 44% for eligible BAME donors. The 95% confidence limits for these DBD consent/authorisation rates are 76% - 81% and 37% - 50%, respectively.

For eligible DCD, the consent/authorisation rates were 62% for eligible white DCD and 38% for eligible BAME DCD donors. The 95% confidence limits for these DCD consent/authorisation rates are 60% - 65% and 29% - 46%, respectively.

The overall consent/authorisation rates were 69% for eligible white donors and 42% for eligible BAME donors. The 95% confidence limits for overall consent/authorisation rates are 67% - 71% 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<0.0001. The difference between consent/authorisation rates for white and BAME eligible donors is also statistically significant, p<0.0001. 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 55% 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 36% of cases. A further 17% were declined due to coroner/procurator fiscal refusal, 15% due to the organs being deemed medically unsuitable on surgical inspection and 15% due to general instability.

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.

| Table 6 Reasons why solid organ donation did not happen following consent | | | | |
|---|---|---|---|---|
| | DBD | | DCD | |
| | N | % | N | % |
| Organs deemed medically unsuitable by recipient centres | 40 | 36.0 | 146 | 29.1 |
| Coroner/ Procurator Fiscal refusal | 19 | 17.1 | 15 | 3.0 |
| Organs deemed medically unsuitable on surgical inspection | 17 | 15.3 | 8 | 1.6 |
| General instability | 17 | 15.3 | 36 | 7.2 |
| Positive virology | 9 | 8.1 | 9 | 1.8 |
| Family changed mind | 4 | 3.6 | 25 | 5.0 |
| Other | 3 | 2.7 | 35 | 7.0 |
| Logistic reasons | 1 | 0.9 | 1 | 0.2 |
| Family placed conditions on donation | 1 | 0.9 | | |
| Prolonged time to asystole | | | 221 | 44.0 |
| Cardiac arrest | | | 6 | 1.2 |
| **Total** | **111** | **100.0** | **502** | **100.0** |

## 11 SUMMARY

In the year 1 April 2017 to 31 March 2018, there were 35,568 deaths audited for the PDA. Of these deaths, 1,954 and 6,281 patients met the referral criteria for DBD and/or DCD, respectively and 99% and 89% were referred to NHS Blood and Transplant. Of the 1,954 patients for whom neurological death was suspected, 86% were tested.

Of the families approached, 72% and 60% consented to/authorised DBD and DCD donation. Of these, 90% and 55%, respectively, became actual solid organ donors. 101 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 statistically significant for DBD and DCD, with paediatric patients (0-17 years) having 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.

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**May 2018**

## 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 |