# POTENTIAL DONOR AUDIT SUMMARY REPORT FOR THE 12 MONTH PERIOD 1 APRIL 2013 - 31 MARCH 2014

# 1 INTRODUCTION

This report presents Potential Donor Audit (PDA) information on the financial year 1 April 2013 to 31 March 2014.

The dataset used to compile this report includes all audited patient deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 12 May 2014. Patients aged over 80 years and patients who died 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 along the pathway, and should be read in conjunction with the PDA section of the Organ Donation and Transplantation Activity Report, available at <a href="http://www.odt.nhs.uk/odt/potential-donor-audit/">http://www.odt.nhs.uk/odt/potential-donor-audit/</a>.

#### 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Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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: http://www.odt.nhs.uk/pdf/contraindications to organ donation.pdf

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 2013 to 31 March 2014, there were a total of 35,454 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

**Audited Deaths** 35,454 Was the patient ever on mechanical ventilation? Yes No 18,954 16,500 Were all criteria for neurological testing met? No Yes 1,787 17,167  $\forall$ Were neurological tests to confirm death performed? Yes No 1,422 365 Was death confirmed using neurological criteria? No Yes 29 1,393 Were there any absolute medical contraindications to solid organ donation? No Yes 1,351 42 Were the family formally approached for consent/authorisation for solid organ donation? No Yes 93 1,258 Was consent/authorisation for solid organ donation given by the family? No Yes 401 857 Did solid organ donation occur? No Yes 69 788 What type of donation happened? DBD DCD 15 773

Figure 2 Donation after circulatory death

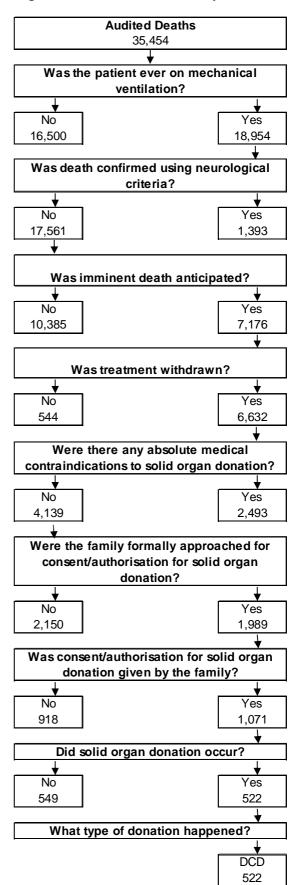


Table 1 Key numbers and rates		
Patients meeting organ donation referral criteria <sup>1</sup>	<b>DBD</b> 1787	<b>DCD</b> 7176
Referred to SN-OD  Referral rate %	1688 <i>94.5%</i>	5090 70.9%
Neurological death tested  Testing rate %	1422 79.6%	
Eligible donors <sup>2</sup> Family approached	1351 1258	4139 1989
Approach rate %	93.1%	48.1%
Family approached and SN-OD involved % of approaches where SN-OD involved	1062 <i>84.4%</i>	1420 71.4%
Consent/authorisation given Consent/authorisation rate %	857 68.1%	1071 <i>5</i> 3.8%
Actual donors from each pathway % of consented/authorised donors that became actual donors	788 91.9%	522 48.7%

#### **NEUROLOGICAL DEATH TESTING RATE** 4

Table 2 Reasons given for neurological death tests not being performed				
	N	%		
Patient haemodynamically unstable	95	26.0		
Clinical reason/Clinicians decision	49	13.4		
Family declined donation	37	10.1		
Cardiac arrest despite resuscitation	36	9.9		
Biochemical/endocrine abnormality	32	8.8		
Continuing effects of sedatives	30	8.2		
Other	20	5.5		
Family pressure not to test	14	3.8		
Treatment withdrawn	14	3.8		
Hypothermia	9	2.5		
Medical contraindication to donation	9	2.5		
Neonates - Less than 2 months post term	6	1.6		
Unknown	5	1.4		
Inability to test all reflexes	4	1.1		
Brain stem reflexes returned	3	0.8		
Pressure on ICU beds	1	0.3		
SN-OD advised that donor not suitable	1	0.3		
Total	365	100.0		

<sup>&</sup>lt;sup>1</sup> DBD - A patient with suspected neurological death 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

<sup>&</sup>lt;sup>2</sup> 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

The neurological death testing rate was 80% 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. Neurological death tests were not performed in 365 patients (20%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 95 (26%) patients not tested, the reason given was the patient was haemodynamically unstable. Of these, 87 (92%) had their blood pressure supported by fluid and/or inotropes. There was a clinical reason or it was the clincian's decision not to perform tests for 49 (13%) patients.

#### 5 REFERRAL RATE

A patient who meets the four criteria for neurological death tests 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 a Specialist Nurse - Organ Donation (SN-OD). The DBD referral rate was 94% and the DCD referral rate was 71%. **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.

Of the patients who met the referral criteria and were not referred, the reason given for 28% of DBD and 31% of DCD was that the patient was not identified as a potential donor or organ donation was not considered. The reason given for 29% of DCD was medical contraindications.

Table 3 Reasons given why patient not referred					
		DBD	DCD		
	N	%	N	%	
Not identified as a potential donor/organ donation not considered	28	28.3	646	31.0	
Other	23	23.2	191	9.2	
Family declined donation prior to neurological testing	12	12.1	9	0.4	
Neurological death not confirmed	12	12.1	1	0.0	
Family declined donation after neurological testing	6	6.1			
Thought to be medically unsuitable	6	6.1	497	23.8	
Family declined donation following decision to withdraw treatment	5	5.1	85	4.1	
Medical contraindications	4	4.0	605	29.0	
Coroner/Procurator Fiscal Reason	1	1.0	4	0.2	
Reluctance to approach family	1	1.0	11	0.5	
Thought to be outside age criteria	1	1.0	18	0.9	
Pressure on ICU beds			1	0.0	
Donation after circulatory death not supported by ICU			18	0.9	
Total	99	100.0	2,086	100.0	

#### 6 APPROACH RATE

Families of eligible donors were approached in 93% and 48% of DBD and DCD cases, respectively. The information in **Table 4** shows the reasons given why the family was not approached.

For eligible DBD, in 28% of cases the reason stated was that the Coroner or Procurator Fiscal refused permission, whereas this reason only accounted for 1% of DCD cases.

The families of 43% of eligible DCD were not approached because of the patient's general medical condition.

Table 4 Reasons given why family not formally approached					
	D	BD	DCD		
	N	%	N	%	
Coroner/Procurator Fiscal refused permission	26	28.0	27	1.3	
Family stated that they would not consent/authorise before they were formally approached	21	22.6	79	3.7	
Patient's general medical condition	16	17.2	920	42.8	
Other	10	10.8	277	12.9	
Family untraceable	9	9.7	34	1.6	
Other medical reason	5	5.4	203	9.4	
Not identified as a potential donor / organ donation not considered	4	4.3	554	25.8	
Family considered too upset to approach	2	2.2	25	1.2	
Resource failure	-	-	5	0.2	
Pressure on ICU beds	-	-	8	0.4	
Patient outside age criteria	-	-	18	0.8	
Total	93	100.0	2,150	100.0	

#### 7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose families were formally approached for consent to/authorisation for donation. The consent/authorisation rate is the proportion of these families who consented to/authorised solid organ donation.

During the financial year, the DBD consent/authorisation rate was 68% and the 95% confidence limits for this percentage are 66% - 71%. The DCD consent/authorisation rate was 54% and the 95% confidence limits for this percentage are 52% - 56%. The overall consent/authorisation rate was 59% and the 95% confidence limits for this percentage are 57% - 62%.

When a patient is known to have expressed a wish to donate, for example they were registered on the Organ Donor Register (ODR), carried a donor card or expressed a wish to donate verbally or in writing and the patient's wish was known at the time of potential donation, the DBD consent/authorisation rate was 93% compared to 55% when a patient hadn't expressed a wish to donate or the patient's ODR status was not known at the time of potential donation. For DCD, the rates were 86% compared with 39%. Overall, these rates were 89% compared with 45%. In total during the financial year, 119 families overruled their loved one's known wish to be an organ donor.

When a SN-OD was involved in the approach to the family, the DBD consent/authorisation rate was 70% compared with 58% when the SN-OD was not involved. Similarly, for DCD the rate was 65% compared with 25% when the SN-OD was not involved. The overall rate was 67% compared with 34%.

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 that the patient had stated in the past that they did not wish to be a donor (17%). For eligible DBD and DCD, 16% and 14% of families did not give consent/authorisation because they were not sure whether the patient would have agreed to donation. Furthermore, for eligible DCD, 15% of families did not give consent/authorisation because they felt the length of the donation process was too long.

Table 5 Reasons given why family did not give consent/authorisation				
		)BD	DCD	
	N	%	N	%
Patient had stated in the past that they did not wish to be a donor	67	16.7	154	16.8
Family were not sure whether the patient would have agreed to donation	64	16.0	125	13.6
Family felt it was against their religious/cultural beliefs	42	10.5	24	2.6
Family did not want surgery to the body	41	10.2	78	8.5
Family were divided over the decision	32	8.0	47	5.1
Strong refusal - probing not appropriate	30	7.5	85	9.3
Other	22	5.5	84	9.2
Family did not believe in donation	21	5.2	32	3.5
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	21	5.2	24	2.6
Family felt the length of time for donation process was too long	20	5.0	135	14.7
Family felt the patient had suffered enough	19	4.7	85	9.3
Family wanted to stay with the patient after death	6	1.5	10	1.1
Family had difficulty understanding/accepting neurological testing	6	1.5	1	0.1
Family concerned that organs may not be transplanted	4	1.0	21	2.3
Family concerned donation may delay the funeral	3	0.7	2	0.2
Family concerned that other people may disapprove/be offended	1	0.2	4	0.4
Patients treatment may be or has been limited to facilitate organ donation	1	0.2	3	0.3
Families concerned about organ allocation	1	0.2	3	0.3
Refused virology testing although patient wished to donate			1	0.1
Total	401	100.0	918	100.0

## 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 2014 (75%) and lowest in June 2013 (60%), whereas the DCD consent/authorisation rate was highest in October 2013 (58%) and lowest in December 2013 (49%). The differences in the monthly consent/authorisation rates from 1 April 2013 to 31 March 2014 are not statistically significant for either DBD or DCD, p=0.6780 and p=0.8007, respectively.

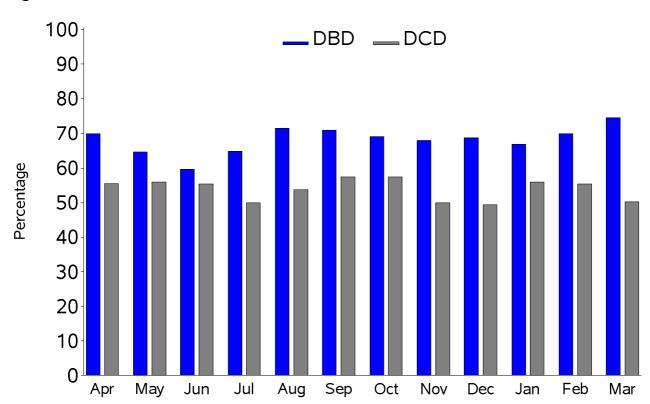


Figure 3 Month-to-month variation in consent/authorisation rate

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

The consent/authorisation rate for the 649 male eligible DBD was 68% and the consent/authorisation rate for the 609 female eligible DBD was also 68%. For the 1182 male eligible DCD the consent/authorisation rate was 55% and for the 807 female eligible DCD was 52%. This difference is not statistically significant, p=0.0895.

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 1,258 eligible DBD and 1,989 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest consent/authorisation rate for eligible DBD occurred in the 0-17 year age group (72%) and for eligible DCD in the 25-34 year age group (63%). The lowest consent/authorisation rate for eligible DBD was in the 35-49 year age group (65%). The lowest consent/authorisation rate for eligible DCD was in the 0-17 year age group (37%). The differences in consent/authorisation rate across the six age groups for DBD are not statistically significant (p=0.4809) and for DCD are statistically significant (p=0.0029).

Furthermore, when comparing only between adult and paediatric patients (<18 years), the differences in consent/authorisation rate for DBD are not statistically significant (p=0.4729) and for DCD are statistically significant (p=0.0030).

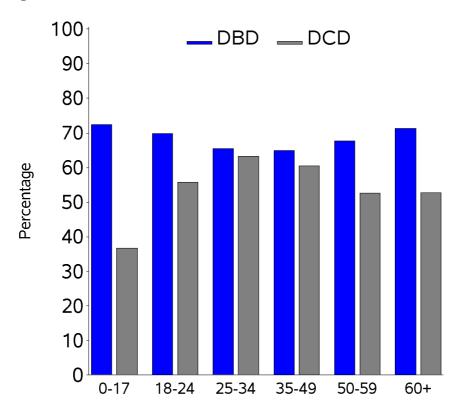


Figure 4 Age variation in consent/authorisation rate

To conduct a meaningful analysis on ethnicity, patients have been categorised as white or in an ethnic minority group and the rates are shown in **Figure 5**. For eligible DBD, the consent/authorisation rates (for the 1,236 eligible donors out of 1,258 for whom ethnicity was recorded) were 74% for white eligible donors and 38% for eligible donors from an ethnic minority group. The 95% confidence limits for DBD consent/authorisation rates are 71% - 76% for white eligible donors and 31% - 45% for eligible donors from an ethnic minority group.

For eligible DCD, the consent/authorisation rates (for the 1,900 eligible donors out of 1,989 for whom ethnicity was recorded) were 57% for white eligible DCD and 33% for eligible DCD from an ethnic minority group. The 95% confidence limits for DCD consent/ authorisation rates are 55% - 59% for white eligible donors and 26% - 41% for eligible donors from an ethnic minority group.

The overall consent/authorisation rates (for the 3,136 eligible donors out of 3,247 for whom ethnicity was recorded) were 63% for white eligible donors and 36% for eligible donors from an ethnic minority group. The 95% confidence limits for overall consent/authorisation rates are 62% - 65% for white eligible donors and 31% - 41% for eligible donors from an ethnic minority group.

The difference between consent/authorisation rates for white eligible DBD donors and eligible DBD donors from an ethnic minority group is statistically significant, p<0.0001. The difference between consent/authorisation rates for white eligible DCD donors and eligible DCD donors from an ethnic minority group is also statistically significant, p<0.0001. The ethnicity effect remains highly significant after allowing for age, sex and month of death.

100₁ \_\_ DBD  $_{=}$  DCD 90-Overall DBD and DCD 80 70 60 Percentage 50 40 30 20 10 0 White Ethnic minority group

Figure 5 Ethnic group variation in consent/authorisation rate

## 10 SOLID ORGAN DONATION

Of the eligible donors whose family consented to/authorised donation, 92% of the eligible DBD and 49% 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 medically unsuitable by recipient centres (32%). This reason also accounted for 30% of consented/authorised DCD donors. The main reason given for consented/authorised eligible DCD not proceeding to donation was prolonged time to asystole (48%).

Table 6 Reasons why solid organ donation did not happen				
	DBD		DCD	
	N	%	N	%
Organs deemed medically unsuitable by recipient centres	22	31.9	165	30.1
Coroner/ Procurator Fiscal refusal	11	15.9	21	3.8
Organs deemed medically unsuitable on surgical inspection	9	13.0	14	2.6
Cardiac arrest	8	11.6	5	0.9
Other	7	10.1	20	3.6
Family changed mind	6	8.7	27	4.9
General instability	3	4.3	24	4.4
Positive virology	3	4.3	10	1.8
Prolonged time to asystole	-	-	261	47.5
Logistic reasons	-	-	2	0.4
Total	69	100.0	549	100.0

#### 11 SUMMARY

In the year 1 April 2013 to 31 March 2014, there were 35,454 deaths audited for the PDA. Of these deaths, 1,787 and 7,176 patients met the referral criteria for DBD and/or DCD, respectively and 94% and 71% were referred to a SN-OD.

Of the 1,787 patients for whom neurological death was suspected, 80% were tested and there were 1,351 and 4,139 eligible DBD and DCD, respectively. Families of these eligible DBD and DCD were approached for consent to/authorisation for donation in 93% and 48% of cases, respectively.

Of the families approached, 68% and 54% consented to/authorised DBD and DCD donation. Of these, 92% and 49%, respectively, became actual solid organ donors. 119 families overruled their loved one's known wish 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 rates across the different age groups was statistically significant for DCD, with paediatric patients (0 to 17 years) having a much lower consent/authorisation rate than the adult age groups. This was not statistically significant for DBD. There was a statistically significant difference in both the DBD and DCD consent/ authorisation rate between white patients and patients from an ethnic minority group and this effect remains after adjusting for patient age, sex and month of patient death.

Joanne Allen and William Hulme NHS Blood and Transplant

May 2014

# **Appendix I - Definitions**

POTENTIAL DONOR AUDIT / REFERRAL RECORD

Data excluded Patients who died on a ward 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.

A patient with suspected neurological death discussed with the Specialist

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

> suspected neurological death, as defined above) A patient with suspected neurological death

DBD referral criteria Discussed with Specialist Nurse - Organ

Donation

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 consent / Family of eligible DBD asked to make a decision on donation

authorisation

Family consented / authorised Family consented to / authorised donation

Actual donors: DBD Neurological death confirmed patients who became actual DBD as reported

Nurse - Organ Donation (SN-OD)

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 SN-OD

Percentage of eligible DBD families approached for consent /authorisation Approach rate

for donation

Consent / authorisation rate Percentage of families approached about donation that consented to /

authorised donation

SN-OD involvement rate Percentage of family approaches where a SN-OD was involved

SN-OD consent / authorisation rate Percentage of families approached about donation by a SN-OD that

consented to / authorised donation

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 4 hours

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

Discussed with Specialist Nurse - Organ Patients for whom imminent death was anticipated who were discussed with

the SN-OD

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

Family of eligible DCD asked to make a decision on donation

donation

Family approached for consent /

authorisation

Donation

Family consented / authorised Family consented to / authorised donation

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 approached about donation that consented to /

authorised donation

SN-OD involvement rate Percentage of family approaches where a SN-OD was involved SN-OD consent / authorisation rate Percentage of families approached about donation by a SN-OD that

consented to / authorised donation