

**POTENTIAL DONOR AUDIT  
SUMMARY REPORT FOR THE 12 MONTH PERIOD  
1 APRIL 2015 - 31 MARCH 2016**

## **1 INTRODUCTION**

This report presents Potential Donor Audit (PDA) information on the financial year 1 April 2015 to 31 March 2016.

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 2016. 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 <http://www.odt.nhs.uk/odt/potential-donor-audit/>.

On 1 December 2015, The Human Transplantation (Wales) Act 2013 became operational in Wales, introducing new legislation for a soft opt-out system for organ donation (deemed consent). More information can be found here <http://organdonationwales.org/>

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**Eligible donors after circulatory death (DCD)** are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.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

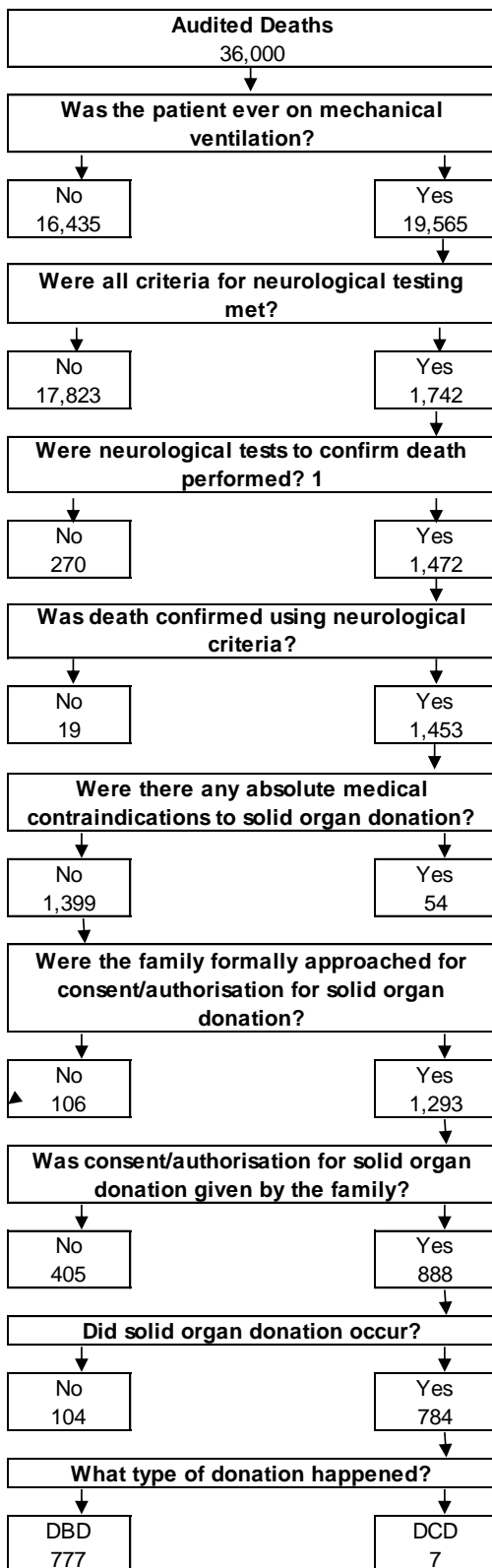
**Deemed consent** applies if a person has not registered an organ donation decision to either opt-in or opt-out or appoint a representative, is aged 18 or over, has lived for longer than 12 months and is ordinarily resident and also died in Wales, and had the capacity to understand the notion of deemed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

**The consent/authorisation rate** is the percentage of eligible donor families approached about donation that consented to/authorised donation. In Wales a family member is only able to formally consent to organ donation when the patient has not expressed a decision in life and does not meet the criteria for deemed consent. The consent rate in Wales is calculated including all expressed decisions, deemed consent and family consent. Further definitions to aid interpretation are given in **Appendix 1**.

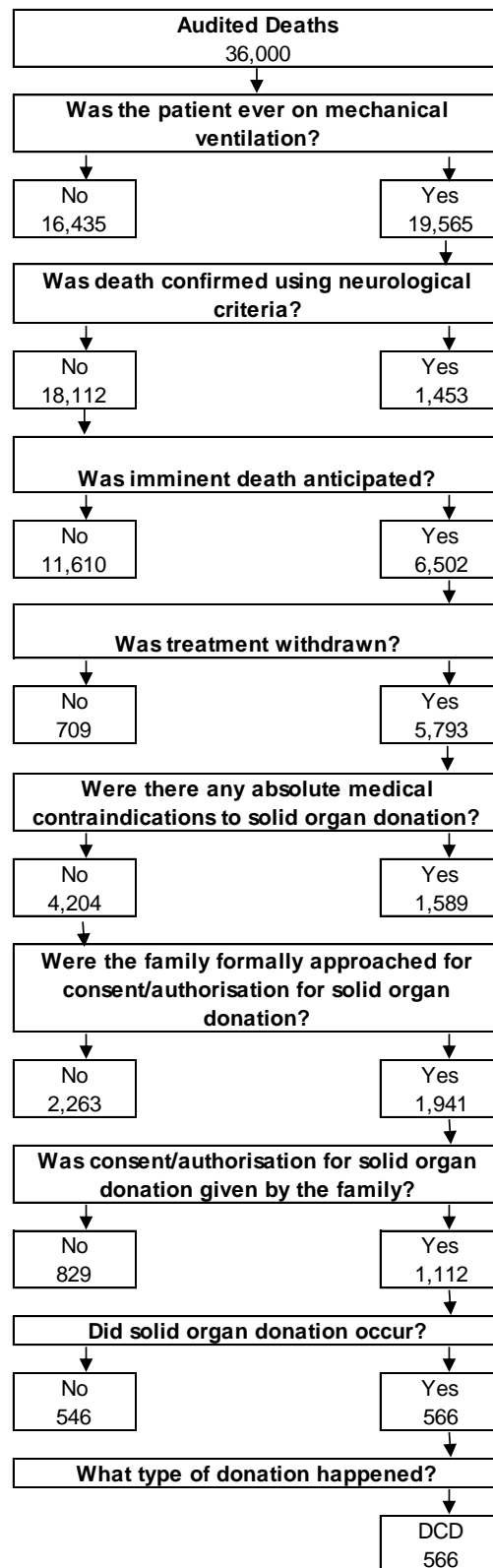
## **3 BREAKDOWN OF AUDITED DEATHS IN ICUs AND EMERGENCY DEPARTMENTS**

In the 12-month period from 1 April 2015 to 31 March 2016, there were a total of 36,000 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**



<sup>1</sup> 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

<b>Table 1 Key numbers and rates</b>		
	<b>DBD</b>	<b>DCD</b>
Patients meeting organ donation referral criteria <sup>1</sup>	1742	6502
Referred to SN-OD	1679	5399
<i>Referral rate %</i>	<i>96.4%</i>	<i>83.0%</i>
Neurological death tested	1472	-
<i>Testing rate %</i>	<i>84.5%</i>	<i>-</i>
Eligible donors <sup>2</sup>	1399	4204
Family approached	1293	1941
<i>Approach rate %</i>	<i>92.4%</i>	<i>46.2%</i>
Family approached and SN-OD involved	1177	1511
<i>% of approaches where SN-OD involved</i>	<i>91.0%</i>	<i>77.8%</i>
Consent/authorisation given	888	1112
<i>Consent/authorisation rate %</i>	<i>68.7%</i>	<i>57.3%</i>
Actual donors from each pathway	784	566
<i>% of consented/authorised donors that became actual donors</i>	<i>88.3%</i>	<i>50.9%</i>
<sup>1</sup> 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		
<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		

#### 4 NEUROLOGICAL DEATH TESTING RATE

<b>Table 2 Reasons given for neurological death tests not being performed</b>		
	<b>N</b>	<b>%</b>
Patient haemodynamically unstable	85	31.5
Clinical reason/Clinicians decision	36	13.3
Family declined donation	32	11.9
Biochemical/endocrine abnormality	25	9.3
Continuing effects of sedatives	20	7.4
Treatment withdrawn	16	5.9
Other	11	4.1
Family pressure not to test	10	3.7
Medical contraindication to donation	9	3.3
Unknown	9	3.3
Inability to test all reflexes	7	2.6
SN-OD advised that donor not suitable	6	2.2
Patient had previously expressed a wish not to donate	3	1.1
Pressure on ICU beds	1	0.4
<b>Total</b>	<b>270</b>	<b>100.0</b>

The neurological death testing rate was 85% 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 270 patients (15%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

85 (32%) patients were haemodynamically unstable and were therefore not tested. Other reasons given for not performing neurological death tests were: 36 (13%) patients was a clinical reason or it was the clinician’s decision, and for 32 (12%) families declined donation.

## 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 a Specialist Nurse - Organ Donation (SN-OD). The DBD referral rate was 96% and the DCD referral rate was 83%. **Table 3** shows the reasons given why such patients were not referred. One patient can meet the referral criteria for both DBD and DCD and therefore some patients may be counted in both columns. Referral criteria are defined in **Appendix I**.

Table 3	Reasons given why patient not referred			
		DBD		DCD
	N	%	N	%
Not identified as a potential donor/organ donation not considered	17	27.0	386	35.0
Medical contraindications	8	12.7	282	25.6
Thought to be medically unsuitable	3	4.8	255	23.1
Family declined donation after neurological testing	5	7.9	-	-
Family declined donation prior to neurological testing	4	6.3	3	0.3
Coroner/Procurator Fiscal Reason	3	4.8	3	0.3
Family declined donation following decision to withdraw treatment	3	4.8	48	4.4
Neurological death not confirmed	2	3.2	1	0.1
Pressure on ICU beds	1	1.6	5	0.5
Reluctance to approach family	0	0.0	5	0.5
Thought to be outside age criteria	0	0.0	8	0.7
Clinician assessed that patient was unlikely to become asystolic within 4 hours	0	0.0	4	0.4
Patient had previously expressed a wish not to donate	0	0.0	2	0.2
Other	17	27.0	101	9.2
<b>Total</b>	<b>63</b>	<b>100.0</b>	<b>1,103</b>	<b>100.0</b>

Of the patients who met the referral criteria and were not referred, the reason given for 27% of DBD and 35% of DCD was that the patients were not identified as potential donors and so organ donation was not considered. The reason given for 13% of DBD and 26% of DCD was medical contraindications.

## 6 APPROACH RATE

Families of eligible donors were approached in 92% and 46% of DBD and DCD cases, respectively. The information in **Table 4** shows the reasons given why the families were not approached.

For eligible DBD, in 26% of cases the reason stated was that the Coroner/Procurator Fiscal refused permission whereas this only accounted for 2% of DCD cases. In a further 26% of DBD cases, the reason stated was the patient's general medical condition.

For eligible DCD, in 45% of cases the reason stated was the patient's general medical condition and in 18% 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	25.5	35	1.5
Patient's general medical condition	27	25.5	1,021	45.1
Not identified as a potential donor / organ donation not considered	1	0.9	397	17.5
Family stated that they would not consent/authorise before they were formally approached	14	13.2	45	2.0
Other medical reason	10	9.4	268	11.8
Family untraceable	7	6.6	33	1.5
Family considered too upset to approach	2	1.9	22	1.0
Patient had previously expressed a wish not to donate	2	1.9	10	0.4
Resource failure	0	0.0	4	0.2
Pressure on ICU beds	0	0.0	13	0.6
Patient outside age criteria	0	0.0	1	0.0
Other	16	15.1	414	18.3
<b>Total</b>	<b>106</b>	<b>100.0</b>	<b>2,263</b>	<b>100.0</b>

## 7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose family was 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 69% and the 95% confidence limits for this percentage are 66% - 71%. The DCD consent/authorisation rate was 57% and the 95% confidence limits for this percentage are 55% - 59%. The overall consent/authorisation rate was 62% and the 95% confidence limits for this percentage are 60% - 64%.

When a patient was known to be registered on the Organ Donor Register (ODR) at the time of approach for consent to organ donation the DBD consent/authorisation rate was 92% compared to 58% when a patient's ODR status was not known at the time of approach. For DCD, the rates were 85% compared with 46%. Overall, these rates were 88% compared

with 51%. In total during the financial year, 120 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 51% when the SN-OD was not involved. Similarly, for DCD the rate was 67% compared with 24% when the SN-OD was not involved. The overall rate was 68% compared with 30%.

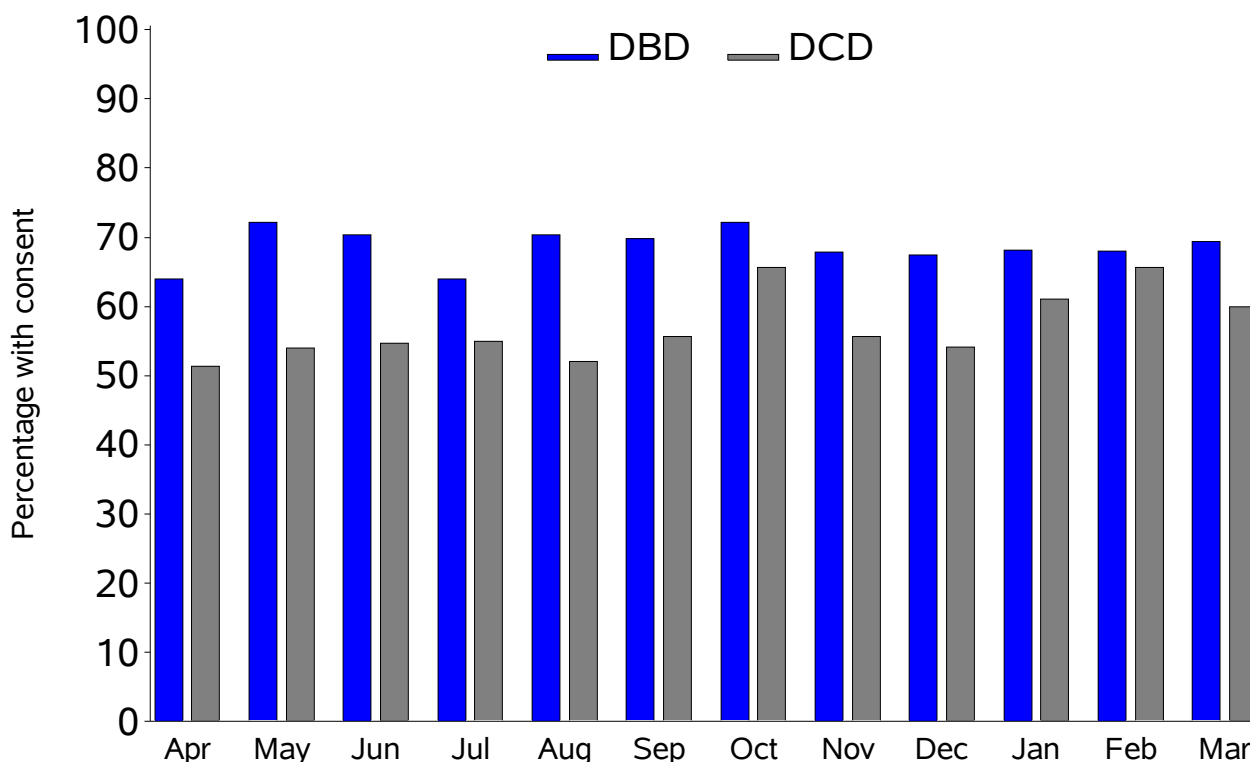
Reasons given why family did not give consent	DBD		DCD	
	N	%	N	%
Patient previously expressed a wish not to donate	96	23.7	160	19.3
Family were not sure whether the patient would have agreed to donation	47	11.6	135	16.3
Family felt the length of time for donation process was too long	17	4.2	124	15.0
Family did not want surgery to the body	36	8.9	58	7.0
Family felt the patient had suffered enough	23	5.7	68	8.2
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	33	8.1	35	4.2
Family felt it was against their religious/cultural beliefs	32	7.9	21	2.5
Strong refusal - probing not appropriate	29	7.2	48	5.8
Family did not believe in donation	20	4.9	32	3.9
Family were divided over the decision	18	4.4	34	4.1
Family concerned that organs may not be transplanted	10	2.5	13	1.6
Family wanted to stay with the patient after death	6	1.5	16	1.9
Family had difficulty understanding/accepting neurological testing	6	1.5	3	0.4
Family concerned that other people may disapprove/be offended	3	0.7	6	0.7
Patients treatment may be or has been limited to facilitate organ donation	1	0.2	0	0.0
Family concerned donation may delay the funeral	1	0.2	3	0.4
Families concerned about organ allocation			1	0.1
Other	27	6.7	72	8.7
<b>Total</b>	<b>405</b>	<b>100.0</b>	<b>829</b>	<b>100.0</b>

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 (24% and 19% 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. Often the family felt that patient had suffered enough.

## 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 May 2015 (72%) and lowest in April 2015 (64%), whereas the DCD consent/authorisation rate was highest in February 2016 (66%) and lowest in April 2015 (51%). The differences in the monthly consent/authorisation rates from 1 April 2015 to 31 March 2016 are not statistically significant for either DBD or DCD,  $p=0.97$  and  $p=0.08$ , respectively.

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



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

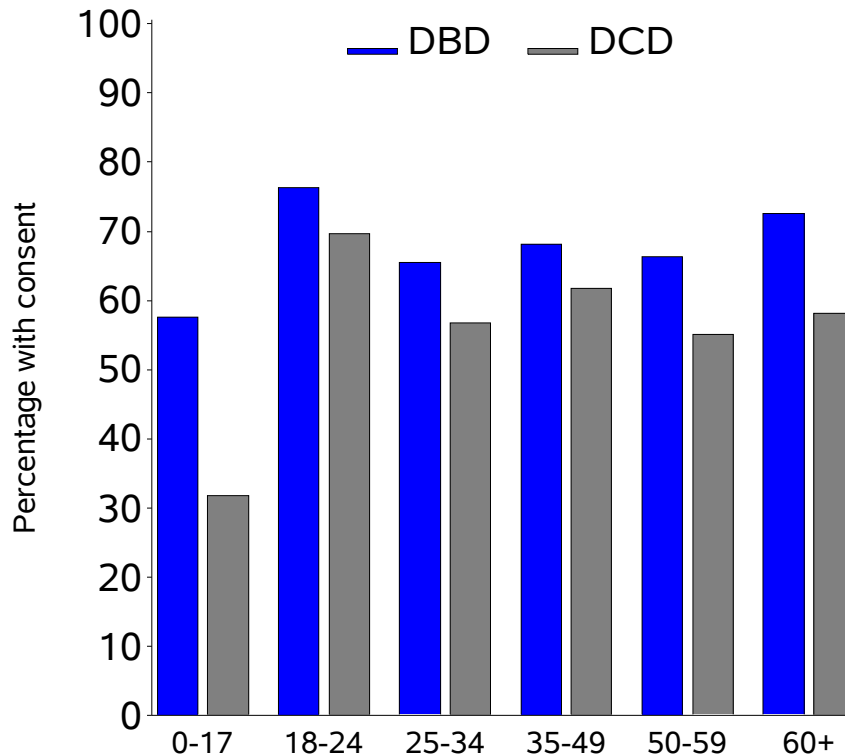
The consent/authorisation rate for the 674 male eligible DBD whose families were approached was 68% and the consent/authorisation rate for the 619 female eligible DBD was 69%. The difference is not statistically significant,  $p=0.73$ . For the 1189 male eligible DCD the consent/authorisation rate was 58% and for the 752 female eligible DCD was 56%. This difference is not statistically significant,  $p=0.23$ .

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 1,293 eligible DBD and 1,941 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 (76%) and for eligible DCD in the 18-24 age group (70%). The lowest consent/authorisation rate for eligible DBD was in the 0-17 age group (58%). The lowest consent/authorisation rate for eligible DCD was in the 0-17 age group (32%). The differences in consent/authorisation

rate across the six age groups for DBD are not statistically significant ( $p=0.07$ ) and for DCD are statistically significant ( $p<0.0001$ ).

When comparing only between adult and paediatric (<18 years), the differences in consent/authorisation rate for DBD are statistically significant ( $p=0.046$ ) and for DCD are statistically significant ( $p<0.0001$ ).

**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**. Note that there were an additional 24 DBD and 79 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 74% for white eligible donors and 35% for eligible donors from an ethnic minority group. The 95% confidence limits for DBD consent/authorisation rates are 72% - 77% for white eligible donors and 28% - 43% for eligible donors from an ethnic minority group.

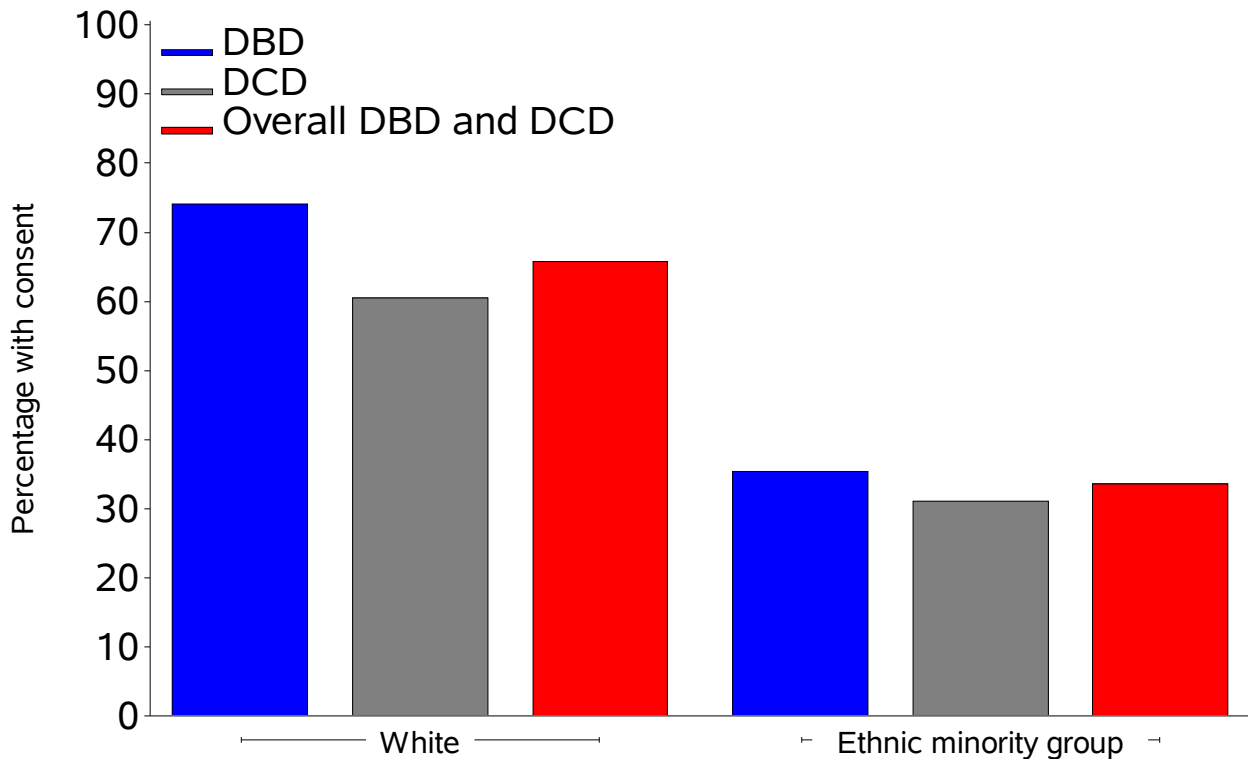
For eligible DCD, the consent/authorisation rates were 61% for white eligible DCD and 31% for eligible DCD from an ethnic minority group. The 95% confidence limits for DCD consent/authorisation rates are 58% - 63% for white eligible donors and 23% - 39% for eligible donors from an ethnic minority group.

The overall consent/authorisation rates were 66% for white eligible donors and 34% for eligible donors from an ethnic minority group. The 95% confidence limits for overall consent/authorisation rates are 64% - 68% for white eligible donors and 28% - 39% for eligible donors from an ethnic minority group.



The difference between consent/authorisation rates for white DBD eligible donors and DBD eligible donors from an ethnic minority group is statistically significant,  $p < 0.0001$ . The difference between consent/authorisation rates for white DCD eligible donors and DCD donors from a minority ethnic group is 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 family consented to/authorised donation, 88% of the eligible DBD and 51% 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 39% of cases, and 14% was declined due to coroner/procurator fiscal refusal.

Likewise, 31% of non-proceeding DCD organs were declined by recipient centres as they were deemed 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.

<b>Table 6 Reasons why solid organ donation did not happen following consent</b>					
	<b>DBD</b>		<b>DCD</b>		
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	
Organs deemed medically unsuitable by recipient centres	41	39.4	167	30.6	
Coroner/ Procurator Fiscal refusal	15	14.4	20	3.7	
Other	11	10.6	6	1.1	
Organs deemed medically unsuitable on surgical inspection	11	10.6	27	4.9	
Positive virology	10	9.6	5	0.9	
General instability	7	6.7	34	6.2	
Family changed mind	5	4.8	33	6.0	
Cardiac arrest	4	3.8	8	1.5	
Prolonged time to asystole	-	-	243	44.5	
Logistic reasons	0	0.0	2	0.4	
Retrieval team not available	0	0.0	1	0.2	
<b>Total</b>	<b>104</b>	<b>100.0</b>	<b>546</b>	<b>100.0</b>	

## 11 SUMMARY

In the year 1 April 2015 to 31 March 2016, there were 36,000 deaths audited for the PDA. Of these deaths, 1,742 and 6,502 patients met the referral criteria for DBD and/or DCD, respectively and 96% and 83% were referred to a SN-OD.

Of the 1,742 patients for whom neurological death was suspected, 85% were tested and there were 1,399 and 4,204 eligible DBD and DCD, respectively. Families of these eligible DBD and DCD were approached for consent to/authorisation for donation in 92% and 46% of cases, respectively.

Of the families approached, 69% and 57% consented to/authorised DBD and DCD donation. Of these, 88% and 51%, respectively, became actual solid organ donors. 120 families overruled their loved one's known wish to be an organ donor

There was no statistically significant difference in the consent/authorisation rates from male and female patients for DBD or DCD. The difference in the consent/authorisation rate across the different age groups was statistically significant for DCD, with paediatric patients (0-17 years) having a much lower consent/authorisation rate than the adult age groups. There was no difference in the age groups 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.

## Appendix I - Definitions

<b>POTENTIAL DONOR AUDIT / REFERRAL RECORD</b>	
Data excluded	Cardiothoracic ICUs, wards and patients aged over 75 years are excluded.
<b>Donors after brain death (DBD)</b>	
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 (ie suspected neurological death, as defined above)
DBD referral criteria	A patient with suspected neurological death. Excluding cases for which cardiac arrest occurred despite resuscitation, brainstem reflexes returned, and neonates - less than 2 months post term
Discussed with Specialist Nurse – Organ Donation	A patient with suspected neurological death discussed with the Specialist Nurse – Organ Donation (SN-OD)
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 / authorisation	Family of eligible DBD asked to make a decision on donation
Family consented / authorised	Family consented to / authorised donation
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 SN-OD
Approach rate	Percentage of eligible DBD 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

<b>Donors after circulatory death (DCD)</b>	
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 Donation	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 donation
Family approached for consent / authorisation	Family of eligible DCD asked to make a decision on 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