

**ANNUAL REPORT ON DONATION AND TRANSPLANTATION IN PAEDIATRIC  
PATIENTS  
SUMMARY REPORT FOR THE 12 MONTH PERIOD  
1 APRIL 2015 - 31 MARCH 2016**

## **1 INTRODUCTION**

This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2015 to 31 March 2016 and summaries of the following are provided:-

- POTENTIAL DONOR AUDIT
- TRANSPLANT LIST
- TRANSPLANT ACTIVITY

The dataset used to compile the PDA section of this report includes all audited paediatric deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 9 May 2016. Paediatric patients have been defined as all patients under 18 years of age. Patients who die on a ward have not been audited.

The report summarises the main findings of the PDA over the 12-month period, in particular the reasons why patients were lost along the pathway.

Information on paediatric transplant list and transplant activity, as reported in the Annual Report on Organ Donation and Transplantation 2015/16 (NHSBT), has been provided. All transplant list and transplant activity data have been obtained from the UKTR. Organ specific paediatric definitions are provided with the data.

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**Eligible donors after circulatory death (DCD)** are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.

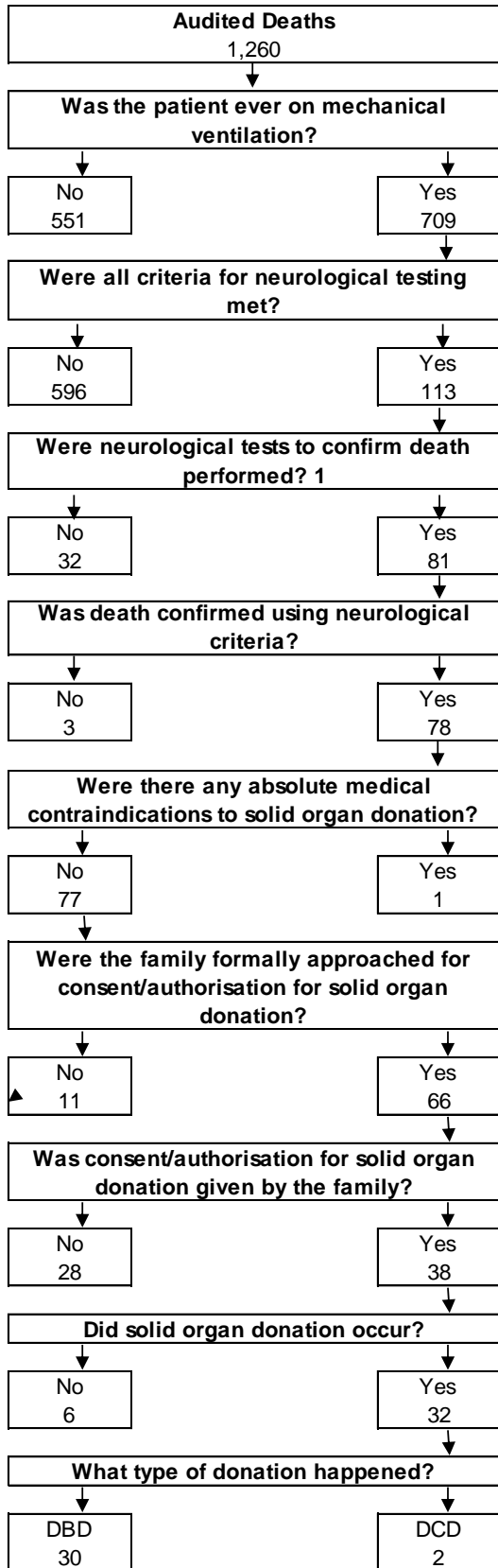
**Absolute medical contraindications** to organ donation are listed here:  
[http://www.odt.nhs.uk/pdf/contraindications\\_to\\_organ\\_donation.pdf](http://www.odt.nhs.uk/pdf/contraindications_to_organ_donation.pdf)

Further definitions to aid interpretation are given in **Appendix 1**.

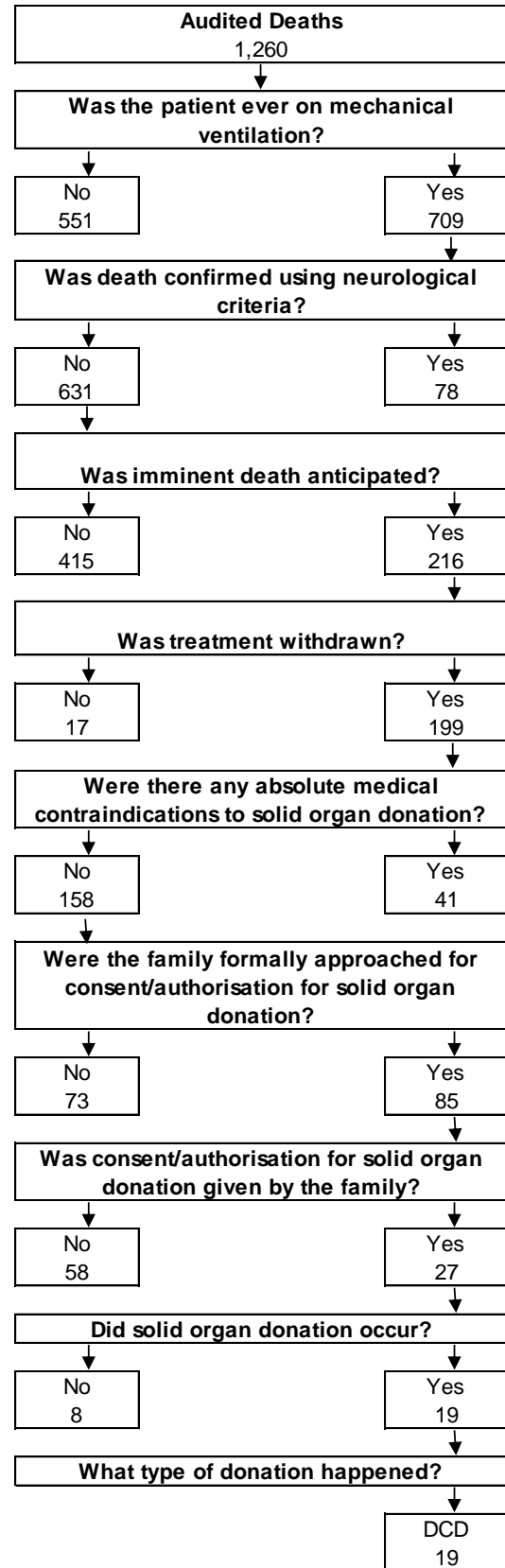
## **3 BREAKDOWN OF AUDITED PAEDIATRIC DEATHS**

In the 12-month period from 1 April 2015 to 31 March 2016, there were a total of 1,260 audited patient deaths 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 37 weeks corrected gestational age 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>   |  | 113          | 216          |
| Referred to SN-OD  |  | 97           | 155          |
| <i>Referral rate %</i>   |  | <i>85.8%</i> | <i>71.8%</i> |
| Neurological death tested  |  | 81           |              |
| <i>Testing rate %</i>  |  | <i>71.7%</i> |              |
| Eligible donors <sup>2</sup>   |  | 77           | 158          |
| Family approached  |  | 66           | 85           |
| <i>Approach rate %</i>   |  | <i>85.7%</i> | <i>53.8%</i> |
| Family approached and SN-OD involved   |  | 57           | 52           |
| <i>% of approaches where SN-OD involved</i>  |  | <i>86.4%</i> | <i>61.2%</i> |
| Consent/authorisation given  |  | 38           | 27           |
| <i>Consent/authorisation rate %</i>  |  | <i>57.6%</i> | <i>31.8%</i> |
| Actual donors from each pathway  |  | 32           | 19           |
| <i>% of consented/authorised donors that became actual donors</i>  |  | <i>84.2%</i> | <i>70.4%</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 37 weeks corrected gestational age<br>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<br>DCD - Imminent death anticipated and treatment withdrawn with no absolute contraindications to solid organ donation  |  |              |              |

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

The neurological death testing rate was 72% 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 for whom cardiac arrest occurred despite resuscitation, brainstem reflexes returned or those less than 37 weeks corrected gestational age were not possible to test and were therefore excluded. Neurological death tests were not performed in 32 patients (28%) for whom neurological death was suspected. The primary reason given for not testing is shown in **Table 2**.

For 9 (28%) patients not tested, the reason was that the patient was haemodynamically unstable. Other common reasons given for not performing neurological tests were that the family declined, there was family pressure not to test, treatment was withdrawn and there was a continuing effect of sedatives.

|   | <b>N</b>  | <b>%</b>     |
|---|-----------|--------------|
| Patient haemodynamically unstable                     | 9         | 28.1         |
| Other   | 5         | 15.6         |
| Family declined donation                              | 3         | 9.4          |
| Family pressure not to test                           | 3         | 9.4          |
| Treatment withdrawn                                   | 3         | 9.4          |
| Continuing effects of sedatives                       | 3         | 9.4          |
| Unknown   | 3         | 9.4          |
| Biochemical/endocrine abnormality                     | 1         | 3.1          |
| Inability to test all reflexes                        | 1         | 3.1          |
| Patient had previously expressed a wish not to donate | 1         | 3.1          |
| <b>Total</b>  | <b>32</b> | <b>100.0</b> |

## **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 86% and the DCD referral rate was 72%. **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**.

Of the patients who met the referral criteria and were not referred, the reason given for 25% of DBD and 28% of DCD was that the patient was not identified as a potential donor/organ donation was not considered.

|   | DBD       |              | DCD       |              |
|---|-----------|--------------|-----------|--------------|
|   | N         | %            | N         | %            |
| Not identified as a potential donor/organ donation not considered | 4         | 25.0         | 17        | 27.9         |
| Family declined donation prior to neurological testing            | 3         | 18.8         | 2         | 3.3          |
| Other   | 3         | 18.8         | 10        | 16.4         |
| Coroner/Procurator Fiscal Reason                                  | 2         | 12.5         | 0         | 0.0          |
| Neurological death not confirmed                                  | 2         | 12.5         | 0         | 0.0          |
| Family declined donation after neurological testing               | 1         | 6.3          | 0         | 0.0          |
| Medical contraindications   | 1         | 6.3          | 7         | 11.5         |
| Family declined donation following decision to withdraw treatment | 0         | 0.0          | 4         | 6.6          |
| Thought to be medically unsuitable                                | 0         | 0.0          | 16        | 26.2         |
| Thought to be outside age criteria                                | 0         | 0.0          | 5         | 8.2          |
| <b>Total</b>  | <b>16</b> | <b>100.0</b> | <b>61</b> | <b>100.0</b> |

## 6 APPROACH RATE

Families of eligible donors were approached in 86% and 54% of DBD and DCD cases, respectively. The information in **Table 4** shows the reasons given why families were not approached.

For eligible DBD, in 45% of cases the reason stated was that the Coroner/Procurator Fiscal refused permission. For eligible DCD, in 38% of cases the reason stated was the patient's general medical condition.

|  | DBD       |              | DCD       |              |
|--|-----------|--------------|-----------|--------------|
|  | N         | %            | N         | %            |
| Coroner/Procurator Fiscal refused permission   | 5         | 45.5         | 4         | 5.5          |
| Family stated that they would not consent/authorise before they were formally approached | 3         | 27.3         | 3         | 4.1          |
| Other  | 2         | 18.2         | 11        | 15.1         |
| Not identified as a potential donor / organ donation not considered                      | 1         | 9.1          | 15        | 20.5         |
| Family considered too upset to approach  | 0         | 0.0          | 2         | 2.7          |
| Patient's general medical condition  | 0         | 0.0          | 28        | 38.4         |
| Other medical reason   | 0         | 0.0          | 10        | 13.7         |
| <b>Total</b>   | <b>11</b> | <b>100.0</b> | <b>73</b> | <b>100.0</b> |

## 7 OVERALL CONSENT/AUTHORISATION RATE

The consent/authorisation rate is based on eligible donors whose family were formally approached for consent/authorisation for organ donation. The consent/authorisation rate is the proportion of these families where consent/authorisation for solid organ donation was ascertained.

During the financial year, the DBD consent/authorisation rate was 58% and the 95% confidence limits for this percentage are 46% - 69%. The DCD consent/authorisation rate was 32% and the 95% confidence limits for this percentage are 22% - 42%. The overall consent/authorisation rate was 43% and the 95% confidence limits for this percentage are 33% - 54%.

Nine children were known to have registered their wish to donate on the Organ Donor Register (ODR) at the time of approach for consent to organ donation. Two of these children were less than 10 years old, three were aged between 10 and 15 and four were 16 or 17 years old. Consent/authorisation was obtained for all four DBD donors registered on the ODR and three of the five DCD donors. The DBD consent/authorisation rate was 55% when a patient's ODR status was not known at the time of approach and 30% for DCD. In total during the financial year, 2 families overruled their loved one's known wish to be an organ donor. One family felt the length of time was too long and the other family wanted to stay with the patient.

For the nine DBD families approached where the SN-OD was not involved, 3 families consented to/authorised donation. Similarly, just 2 of the 33 families of DCD patients consented to/authorised donation when the SN-OD was not involved. Overall the consent/authorisation rate was 55% when the SN-OD was involved compared to 12% when the SN-OD was not involved.

The reasons why the family did not support organ donation are shown in **Table 5**. The main reason that families of eligible DBD patients did not support organ donation was that the family felt the body needed to be buried whole (21%). The main reason that families of eligible DCD patients did not support organ donation was that they did not want surgery to the body (17%) and they felt the length of time for the donation process was too long (15%)

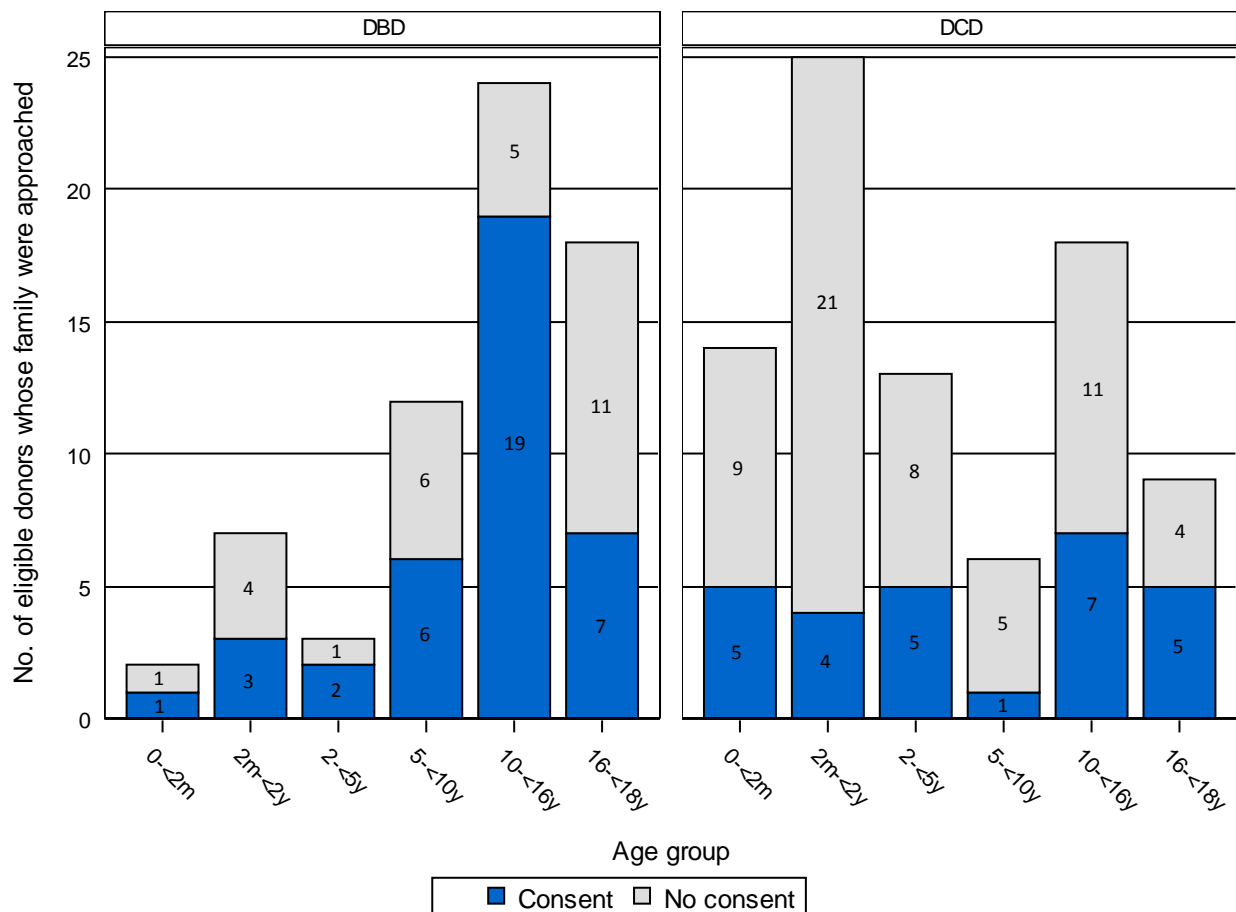
**Table 5** Reasons given why family did not give consent

|  | DBD       |              | DCD       |              |
|--|-----------|--------------|-----------|--------------|
|  | N         | %            | N         | %            |
| Family felt the body needs to be buried whole (unrelated to religious or cultural reasons) | 6         | 21.4         | 2         | 3.4          |
| Family felt it was against their religious/cultural beliefs                                | 5         | 17.9         | 4         | 6.9          |
| Family did not want surgery to the body  | 5         | 17.9         | 10        | 17.2         |
| Patient previously expressed a wish not to donate  | 2         | 7.1          |           |              |
| Family were divided over the decision  | 2         | 7.1          | 1         | 1.7          |
| Family felt the patient had suffered enough  | 2         | 7.1          | 8         | 13.8         |
| Other  | 2         | 7.1          | 10        | 17.2         |
| Family did not believe in donation   | 1         | 3.6          | 1         | 1.7          |
| Family wanted to stay with the patient after death   | 1         | 3.6          | 6         | 10.3         |
| Family had difficulty understanding/accepting neurological testing                         | 1         | 3.6          | 0         | 0.0          |
| Strong refusal - probing not appropriate   | 1         | 3.6          | 5         | 8.6          |
| Family were not sure whether the patient would have agreed to donation                     | 0         | 0.0          | 1         | 1.7          |
| Family felt the length of time for donation process was too long                           | 0         | 0.0          | 8         | 13.8         |
| Family concerned that organs may not be transplanted                                       | 0         | 0.0          | 1         | 1.7          |
| Family concerned donation may delay the funeral  | 0         | 0.0          | 1         | 1.7          |
| <b>Total</b>   | <b>28</b> | <b>100.0</b> | <b>58</b> | <b>100.0</b> |

## 8 CONSENT/AUTHORISATION RATE BY PATIENT DEMOGRAPHICS

Age is represented by a categorical variable with intervals <2 months, 2 months - <2 years, 2-<5 years, 5-<10 years, 10-<16 years and 16-<18 years. The consent/authorisation rates for the six age groups (for the 66 eligible DBD and 85 eligible DCD whose families were approached) are illustrated in **Figure 4**. The highest consent/authorisation rate for eligible DBD occurred in the 10-<16 year old age group (79%) and for eligible DCD in the 16-<18 year old age group (56%). The lowest consent/authorisation rate for eligible DBD was in the 16-<18 year old age group (39%). The lowest consent/authorisation rate for eligible DCD was in the 2 months- <2 years old age group (16%).

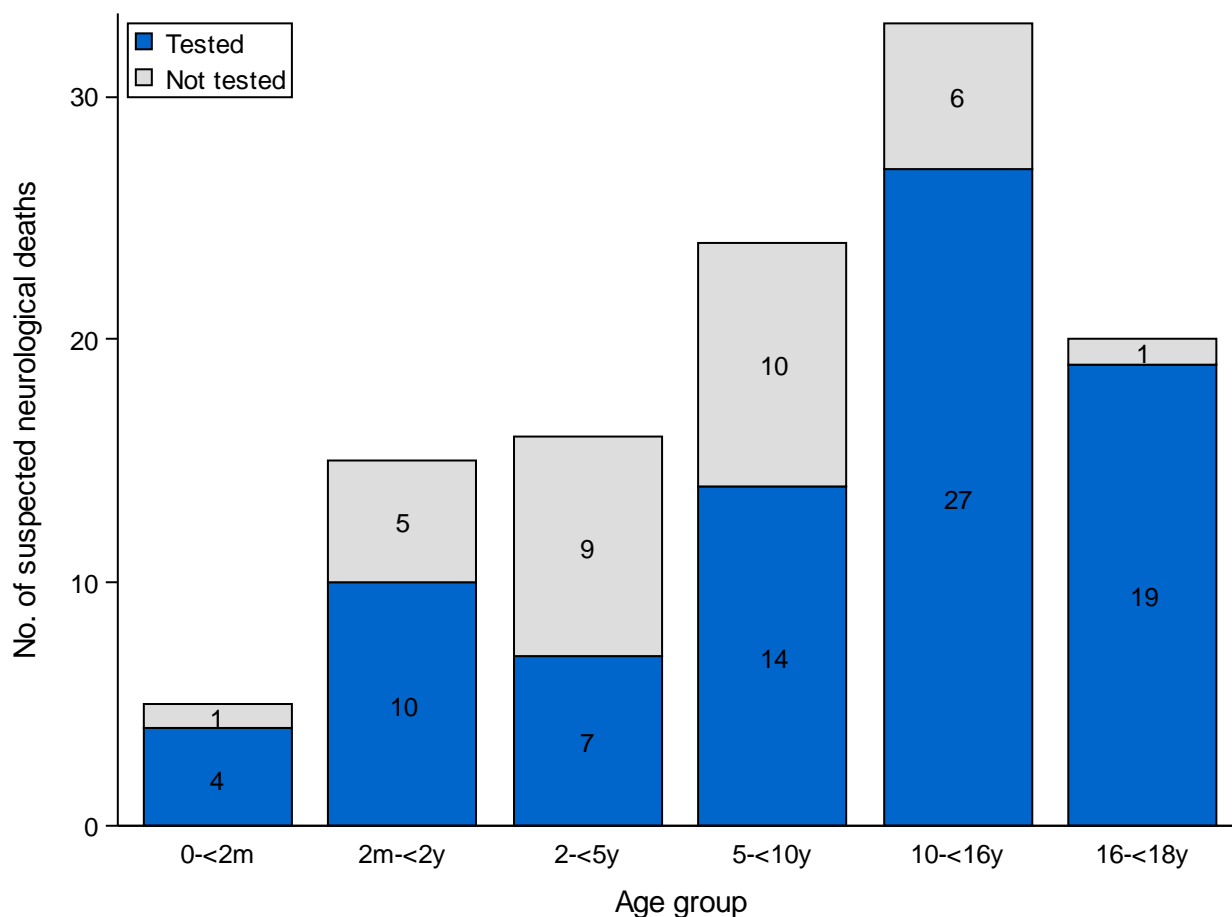
**Figure 4 Age variation in consent/authorisation rate**



There were a total of 113 neurological deaths suspected in paediatric patients in the UK between 1 April 2015 and 31 March 2016 and a total of 81 deaths where neurological tests were performed (72%). **Figure 5** shows the percentage of neurological death tests performed by age group. The largest proportion tested were in the 16-<18 year old group (95%).



**Figure 5 Age distribution where neurological death tests performed**

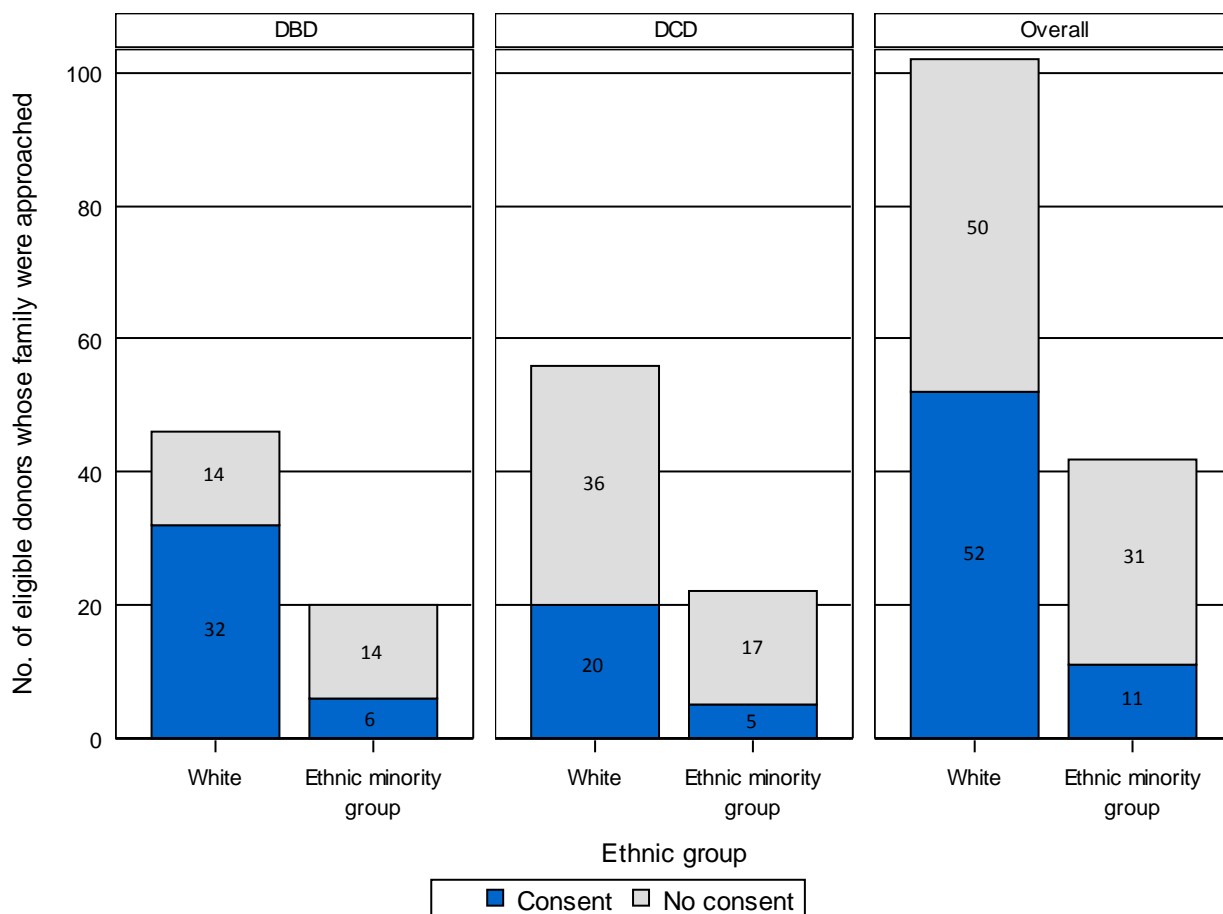


To conduct a meaningful analysis on ethnicity, patients have been categorised as white or in an ethnic minority group and the rates are shown in **Figure 6**. Note that there were an additional 7 DCD families approached where ethnicity was not known or not reported which have been excluded from the ethnicity figures below.

For eligible DBD, the consent/authorisation rates were 70% for white eligible donors and 30% for eligible donors from an ethnic minority group. For eligible DCD, the consent/authorisation rates were 36% for white eligible DCD and 23% for eligible DCD from an ethnic minority group.

The overall consent/authorisation rates were 51% for white eligible donors and 26% for eligible donors from an ethnic minority group. The 95% confidence limits for overall consent/authorisation rates are 41% - 61% for white eligible donors and 13% - 39% for eligible donors from an ethnic minority group.

**Figure 6 Ethnic group variation in consent/authorisation rate**



## 10 SOLID ORGAN DONATION

Of the eligible donors whose family consented to/authorised donation, 84% of the eligible DBD and 70% 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 and DCD the main reason given for solid organ donation not proceeding was organs deemed medically unsuitable, both 50% (3 and 4 cases, respectively).

|   | DBD      |              | DCD      |              |
|---|----------|--------------|----------|--------------|
|   | N        | %            | N        | %            |
| Organs deemed medically unsuitable by recipient centres | 3        | 50.0         | 4        | 50.0         |
| Coroner/ Procurator Fiscal refusal                      | 2        | 33.3         | 0        | 0.0          |
| Other   | 1        | 16.7         | 1        | 12.5         |
| Family changed mind                                     | 0        | 0.0          | 1        | 12.5         |
| Prolonged time to asystole                              | 0        | 0.0          | 1        | 12.5         |
| General instability                                     | 0        | 0.0          | 1        | 12.5         |
| <b>Total</b>  | <b>6</b> | <b>100.0</b> | <b>8</b> | <b>100.0</b> |

## 11 TRANSPLANT LIST

**Table 7** shows the number of paediatric patients on the active transplant list at 31 March 2016. In total there were 164 patients waiting for a transplant, 69 of which were waiting for a kidney transplant. The number of paediatric patients waiting for a transplant was similar at 31 March 2015, with 161 patients waiting.

|   | Active transplant list |      |
|---|------------------------|------|
| <b>Cardiothoracic paediatric patients (&lt; 16 years at time of registration)</b>   |                        |      |
| Non-urgent heart  | 23                     | (22) |
| Urgent heart  | 12                     | (5)  |
| Heart and lung  | 0                      | (1)  |
| Lung  | 7                      | (11) |
| <b>Renal paediatric patients (&lt; 18 years at time of registration)</b>  |                        |      |
| Kidney <sup>1</sup>   | 69                     | (73) |
| <b>Liver paediatric patients (&lt; 17 years at time of registration)</b>  |                        |      |
| Liver   | 49                     | (45) |
| <b>Intestinal paediatric patients (&lt; 18 years at time of registration)</b>   |                        |      |
| Intestinal <sup>2</sup>   | 4                      | (4)  |
| Data taken from <i>Annual Activity Report on Organ Donation and Transplantation 2015/2016 (NHSBT)</i> , except where otherwise indicated. |                        |      |
| <sup>1</sup> <i>Annual Report on Kidney Transplantation 2015/2016 (NHSBT)</i>   |                        |      |
| <sup>2</sup> <i>Annual Report on Intestine Transplantation 2015/2016 (NHSBT)</i>  |                        |      |

In the 12-month period, there were a total of 271 transplants performed in paediatric patients. Of these 174 were deceased donor transplants and 97 were from living donors. Nearly half of all the transplants were kidney transplants.

## 12 TRANSPLANT ACTIVITY

| <b>Table 8 Paediatric transplants in the UK, 1 April 2015 – 31 March 2016 (2014/2015)</b>             |                           |
|---|---------------------------|
|   | <b>Transplant numbers</b> |
| <b>Cardiothoracic paediatric patients (&lt; 16 years at time of transplant)</b>                       |                           |
| Non-urgent heart only   | 4 (4)                     |
| Urgent heart only   | 30 (34)                   |
| Heart and lung  | 0 (0)                     |
| Lung only – DBD   | 7 (6)                     |
| Lung only – DCD   | 2 (1)                     |
| <b>Total cardiothoracic</b>   | <b>43 (45)</b>            |
| <b>Renal paediatric patients (&lt; 18 years at time of transplant)</b>                                |                           |
| Kidney – DBD  | 47 (42)                   |
| Kidney – DCD  | 4 (6)                     |
| Kidney – living donor   | 78 (91)                   |
| <b>Total kidney</b>   | <b>129 (139)</b>          |
| <b>Liver paediatric patients (&lt; 17 years at time of transplant)</b>                                |                           |
| Liver – DBD   | 72 (58)                   |
| Liver – DCD   | 5 (4)                     |
| Liver – living donor  | 19 (20)                   |
| <b>Total liver</b>  | <b>96 (82)</b>            |
| <b>Intestinal paediatric patients (&lt; 18 years at time of transplant)</b>                           |                           |
| Intestinal  | 3 (9)                     |
| Data taken from <i>Annual Activity Report on Organ Donation and Transplantation 2015/2016 (NHSBT)</i> |                           |

## 13 SUMMARY

In the year 1 April 2015 to 31 March 2016, there were 1,260 deaths audited for the PDA. Of these deaths, 113 and 216 patients met the referral criteria for DBD and/or DCD, respectively and 86% and 72% were referred to a SN-OD.

Of the 113 patients for whom neurological death was suspected, 72% were tested and there were 77 and 158 eligible DBD and DCD, respectively. Families of these eligible DBD and DCD were approached for consent to/authorisation for donation in 86% and 54% of cases, respectively.

Of the families approached, 58% and 32% consented to/authorised DBD and DCD donation. Of these, 84% and 70%, respectively, became actual solid organ donors. Two families overruled their loved one's known wish to be an organ donor

At 31 March 2016, there were a total of 164 paediatric patients on the transplant list. In the year 1 April 2015 to 31 March, 271 paediatric patients received a transplant. The number of paediatric patients on the transplant list at the end of the year and transplanted during the 12-month period has remained consistent with the previous year.

**Sue Madden**  
NHS Blood and Transplant

**December 2016**

## 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  |