



Western Health
and Social Care Trust

Western Health & Social Care Trust

Organ Donation Report for the Year 2018/2019

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Glossary

1. Foreword

The issue of organ donation has been increasingly in the public eye in recent years. In Northern Ireland, there have been a number of high profile kidney transplant cases, involving living donors. This has provided an opportunity to raise the profile of the “Gift of Life” which is part of the message of deceased organ donation. Nationally, the Welsh Assembly introduced an “assumed consent” system with the requirement for individuals to register to “opt out” of organ donation and this system is to be adopted in England.

In Northern Ireland the Assembly legislated in 2016 to require the Department of Health to promote organ donation, however in the absence of an Assembly this has not moved forward into legislation.

As chair of the Trust’s Organ Donation Committee, I want to applaud the important work done by clinical teams during this year to achieve the outcomes for people awaiting transplants and their families, and to thank deceased donors and their bereaved families who have changed other people’s lives as a result of donation. I want to acknowledge the contributions of the members of the Organ Donation Committee, and the commitment and dedication of the Clinical Lead for Organ Donation in the Trust, Dr Declan Grace, Consultant in Anaesthesia and Critical Care Medicine, who during this year was reappointed for a term of three years. I want to thank our Specialist Nurses for Organ Donation, Maria Coyle and Martina Conlon who do such valued and sensitive work with our own Trust staff and with families who are considering donation.

We currently have a gap in our committee representation, and are actively seeking to re-appoint a representative to present the interests and views of donor families. We know this can be a difficult role on the Committee, and we have invited interest and hope to appoint someone in the year ahead. I also want to thank Fr. Neil Farren, who completed his tenure as the Trust’s Chaplain’s Group representative on the Committee, and we are delighted to welcome Fr. Sean O’Donnell as his able replacement.

With all of its partners, the Western Trust is well placed to build upon the excellent progress made thus far in promoting, securing and facilitating donation. We shall continue to enable the wishes of patients to become donors after death and we are honoured to do so.

Teresa Molloy

Chairperson, Western HSC Trust, Organ Donation Committee

2. Report from the Organ Donation Committee

The Organ Donation Committee's remit is to:

- i. Ensure that all patients who might potentially be organ donors are given the opportunity to do so; and
- ii. To promote an organ donation culture within the Trust.

During 2018/19, the Organ Donation Committee met on three occasions:- 7 June 2018, 22 November 2018 and 14 March 2019.

The committee has a wide membership and invites representation from Donor families, local Donation Charities, and a range of staff and professionals from within the Trust including its Bereavement service, Critical Care, Anaesthetic and Operating Theatre departments, Mortuary service, Communications Team, and Chaplains.

The Committee receives a report at each meeting on donation activity for the relevant period, and updates on promoting and supporting donation.

The committee's composition and role is currently being reviewed and updated as part of a wider review on how to improve the effectiveness of Organ Donation Committees at a national and Northern Ireland level.

The Trust's Board receives this formal report on the work of the Committee each year.

The Donation Committee is very active in promoting organ donation to the wider community, and this forms an active part of the agenda at each Organ Donation Committee meeting. Initiatives conducted during the 2018-2019 period are outlined later in this report.

The Committee also receives reports at its meetings on clinical initiatives, policies and protocols pertaining to donation which have been reviewed, updated and made available to relevant staff both electronically and in published form. The clinical team with responsibility for organ donation make these accessible to ICU staff via the electronic ICU patient information systems that operate on the computer terminal at each patient's bedside. Similarly, staff are updated regularly on clinical and training developments as they arise.

Training of Western Trust staff

The organ donation training programme continued during this year and is delivered to relevant staff (medical and nursing) most closely involved with donation in our critical care units, anaesthetic departments and operating theatres. It is also delivered to other relevant and interested parties such as non-I.C.U. / non-Anaesthetic medical staff and Emergency Department staff. Generally medical staff are trained and updated by the Lead Clinician for Organ Donation and nursing staff by the Specialist Nurses. However, overlapping contributions are made to the training of all clinical staff both formally and informally. The training programme enhances the clinical knowledge of staff. Importantly, it contributes greatly to the development of a “donation culture” within Trust.

3. Hospital Organ Donation Team Structure

The hospital Organ Donation Team is professionally led by the Clinical Lead, and the two Specialist Nurses for Organ Donation who professionally and managerially report to NHS Blood and Transplant for these duties.

The reporting and accountability structure is set out in the appendix to this report.

4. Organ Donation Data

The number of potential and proceeding donors in the Trust’s Critical Care Units in 2018-2019 was similar to that seen in the 2017-2018 period. Quality indicators for good practice are agreed at a national level and include: rates of identification, referral, brain-stem death testing, seeking assent collaboratively¹ for donation from next of kin, obtaining assent successfully, the number of actual donors and the number of organs retrieved per donation remain robust and are in line with or exceed national figures.

Most critically the rate of obtaining assent for donation successfully from next of kin remains excellent as are the rates of approaching next of kin collaboratively. The total number of deceased donors (eight) secured by the Critical Care Units of the

¹ Collaborative approach – it is considered best practice that conversations with next of kin in which assent for donation is sought are conducted collaboratively by both the Consultant in Critical Care Medicine (Intensivist) and the Specialist Nurse for Organ Donation (S.N.O.D.).

Western H.S.C. Trust in 2018/19 represents 18% of all deceased donors in N. Ireland during this period. Furthermore, for clinical reasons an additional three DCD donations did not proceed. Thus, overall donation activity remains similar to that achieved over the past number of years, indicating that donation processes remain robust.

The number of critical care beds in the Western HSC Trust is approximately one tenth of the total Northern Ireland Critical Care bed complement. It is notable that the Trust was able to secure such a large percentage of the total number of deceased donors in N. Ireland, and this is an excellent achievement.

The Trust's clinical teams and the specialist staff involved in organ donation work hard to learn from every event where next of kin decline assent to donation. The entire process is reviewed meticulously, and the Clinical Lead and Specialist Nurse for Organ Donation are satisfied that the families made an informed decision that donation would not proceed as is their right.

Refer to appendix 2 for NHSBT summary report 2018/19.

Donation after Brain Death (DBD)

In patients suspected of having died of neurological causes death is confirmed by determining the absence of brain stem function (performing brain stem testing - BST). Brain stem testing to confirm the diagnosis of death was performed for all the relevant patients. Similarly the rates of (i) referring potential D.B.D. donors for consideration for donation, (ii) collaboratively approaching next of kin to seek their assent for donation and (iii) obtaining assent successfully remain excellent.

Donor optimisation

The Trust's donor organ optimisation outcomes (the number of organs transplanted per DBD donor - taken as a surrogate marker for good clinical care) remain excellent and reflect the high standard of clinical management of patients in both the ante- and post-mortem periods. Organ optimization protocols are reviewed serially, updated and staff are updated serially in relation to best practice. The protocol is incorporated into the bedside electronic patient management system. Thus, it is immediately available to clinical staff. The protocol mirrors closely standard clinical management protocols as have long-pertained within the Trust's Critical Care Units.

Donation after Circulatory Death (DCD)

It is accepted by the Organ Donation Committee that Western H.S.C. Trust had lagged somewhat behind other comparable Trusts in relation to the rate of referral of patients for consideration as possible DCD donors (referral rate of 67% in 2017/18), however the Clinical teams dealing with potential donations believe that in practice no patient with real potential to donate had ever been 'missed'.

Nonetheless, it is considered 'best practice' to refer for consideration for DCD all patients in whom withdrawal of life-sustaining treatments is planned and in whom it is anticipated that death will occur within four hours and in whom there are no *absolute* contraindications to solid organ donation. Thus, the Trusts specialist staff instituted various practical initiatives to increase the rate of referral of potential DCD donors and achieved 100% referral, which is a considerable achievement.

The assent rate for donation after circulatory death was 57%, which is comparable to the national average of 63%.

As alluded to in previous Annual Reports on casual inspection "raw" PDA² data pertaining to DCD can be somewhat misleading.

The data collection tended to discriminate poorly between patients:

- (i) in whom active resuscitation was unsuccessful (e.g. discontinuation of CPR),
- (ii) in whom on-going attempted curative treatment was deemed to be no longer in the patient's best interests in whom life-supporting treatment was therefore to be withdrawn but who clearly were not suitable to be donors, and
- (iii) in whom on-going attempted curative treatment was deemed as being no longer in their best interests but who might possibly be potential donors.

Improvements in data recording have reduced these anomalies somewhat. However, to the casual observer it is not immediately obvious that patients in categories (i) and (ii) cannot donate.

² PDA. = Potential Donor Audit – every step in the path to donation for every potential donor is audited

DBD - Key Facts

| | | |
|--------------------------------------|-----------|---|
| Patients meeting referral criteria | 8 | |
| Referred to SNOD | 8 | 100% - exceptional performance |
| Neurological death testing | 8 | 100% - exceptional performance ³ |
| Eligible donors | 8 | |
| Next of kin approached | 6 | |
| SNOD involvement in assent | 6 | 100% - exceptional performance ⁴ |
| Assent | 5 | 83% ⁵ |
| Actual donors | 6 | |
| Number of patients transplanted | 17 | |
| Number of organs transplanted | 20 | |
| Organs donated per donor | 3.8 | |

³ National Average is 86%

⁴ National Average 95%

⁵ National average 72%

DCD - Key Facts

| | | |
|---|----------|---|
| Patients meeting referral criteria ⁶ | 24 | |
| Referred to SNOD | 24 | 100% - exceptional performance ⁷ |
| Eligible donors ⁸ | 18 | |
| Next of kin approached ⁹ | 7 | 33% |
| SNOD involvement in assent | 6 | 71% |
| Assent | 4 | 57% |
| Actual proceeding donors | 2 | |
| Number of patients transplanted | 3 | |
| Number of organs transplanted | 3 | |

Ocular Retrieval

As outlined in the Annual Report 2017/18, the Trust had been in position to commence an ocular tissue retrieval service at the start of 2018. However, as NHS Blood and Transplant had instituted a national review of tissue services encompassing ocular retrieval, the Trust suspended this initiative pending the outcome of the national review, and ocular retrievals in Northern Ireland are currently conducted in the Royal Victoria Hospital in Belfast, with retrieval ceasing in Western HSC Trust at this point.

⁶ a patient receiving mechanical ventilation in whom imminent death is anticipated within 4 hours of discontinuing life-sustaining therapies

⁷ National Average 93%

⁸ a patient who had life-sustaining treatment withdrawn and in whom death was anticipated within four hours and in whom there were no *absolute* contraindications to solid organ donation

⁹ percentage of families of eligible D.C.D. donors approached for assent for donation – this number represents the actual number of patients who might realistically become D.C.D. donors per annum.

5. Caring for donors and their families



The Trust's Organ Donation Committee and all the clinicians directly involved in caring for potential donors strongly support the concept of the best practice "joint approach" by clinician and SNOD in seeking assent for donation from next of kin. This is reflected in both the good collaborative approach rates and assent rates.

Given the relative geographical isolation of Altnagelvin Hospital and the South West Acute Hospital and thus the not inconsiderable time required for Specialist Nurses to travel from the greater Belfast area collaborative approach rates remain excellent. On occasions it has not been possible to seek assent collaboratively because (i) families have initiated donation conversations, (ii) patients' physiological instability has precluded delaying relevant conversations or (iii) families may require decision-making in a time frame that precludes the arrival of the SNOD.

The committee and the Trust's Intensivists continue to reiterate their collective commitment to the national standard that clinicians seek actively the involvement of the SNOD. in any potential donation (DCD. or DBD) as early as possible and work collaboratively with specialist nurses when seeking assent for donation.

Review

Missed opportunities (to offer the opportunity to donate) such as failure to confirm neurological death, failure to refer possible donors to Specialist Nurses (SNOD's), failure to approach next of kin collaboratively, failure to consider possible D.C.D. prior to withdrawing life-sustaining therapies are reviewed by the Lead Clinician and S.N.O.D.'s and feedback and additional training offered to relevant staff. Opportunities to identify 'true' potential donors are rarely missed – none in 2018-2019.

Initiatives were introduced during the year to increase the referral of potential D.C.D. donors, and these included:

- (i) the embedded SNOD's accompanying routinely the Critical Care morning ward round,
- (ii) daily telephone consultation by the on-call SNOD with the Intensive Care Units to determine the presence of potential donors within the Intensive Care Units
- (iii) the positioning of reminders and aide-memoires for staff in prominent locations within the critical care units,
- (iv) empowering bedside nurses to identify potential donors and developing nurse-led referral of potential donors,
- (v) good communication, including updating staff both collectively and individually on donor issues arising.

These measures have undoubtedly contributed to the achievement of a referral rate of 100% and clinical staff in the two Critical Care Units deserve recognition for achieving this goal.

End of life care

The staff of our Intensive Care Units possess great expertise in end of life care and symptom palliation and the quality of care given to patients (and their next of kin) during patients' terminal illnesses is outstanding. Furthermore, staff receive excellent update and refresher training in end of life care.

Critical Care staff can remain proud of their achievements in facilitating (a) the wish of donors and donor families to donate and (b) enabling multiple recipients to benefit from optimised organs and tissues. An excellent donation culture exists within the Trust's Critical Care Units

6. Promotion

It is essential that we continue to garner the support and enthusiasm of the community in promoting donation. To that end, the Committee actively promotes the importance of organ donation to our local community and within the Trust to staff. Promotional activities are conducted throughout the year, focusing on national and regional campaigns, such as *Organ Donation Week*, September and 'Tell Your Loved Ones', December. This year the Trust launched 'storyboards' close to our I.C.U. Wards at both hospitals. The storyboards give a personal account from families who have experienced loss and subsequently agreed to organ donation. We also featured stories from patients who received transplants.



At each opportunity, the Trust's Communication Department will work closely with organ donation colleagues to maximise publicity. Multiple methods are used to promote the message widely such as local press, social media, Trust website, radio interviews, video interviews and NOW to communicate the Organ Donation. The Trust also has strong links with local councils, colleges and libraries. For Organ Donation Week 2018 Omagh and Fermanagh District Council and Derry City and Strabane District Council illuminated their civic buildings to further raise awareness of the importance of organ donation.

Social Media Stats September 2018 to May 2019

 Twitter – 13 posts, reaching 41.6k people

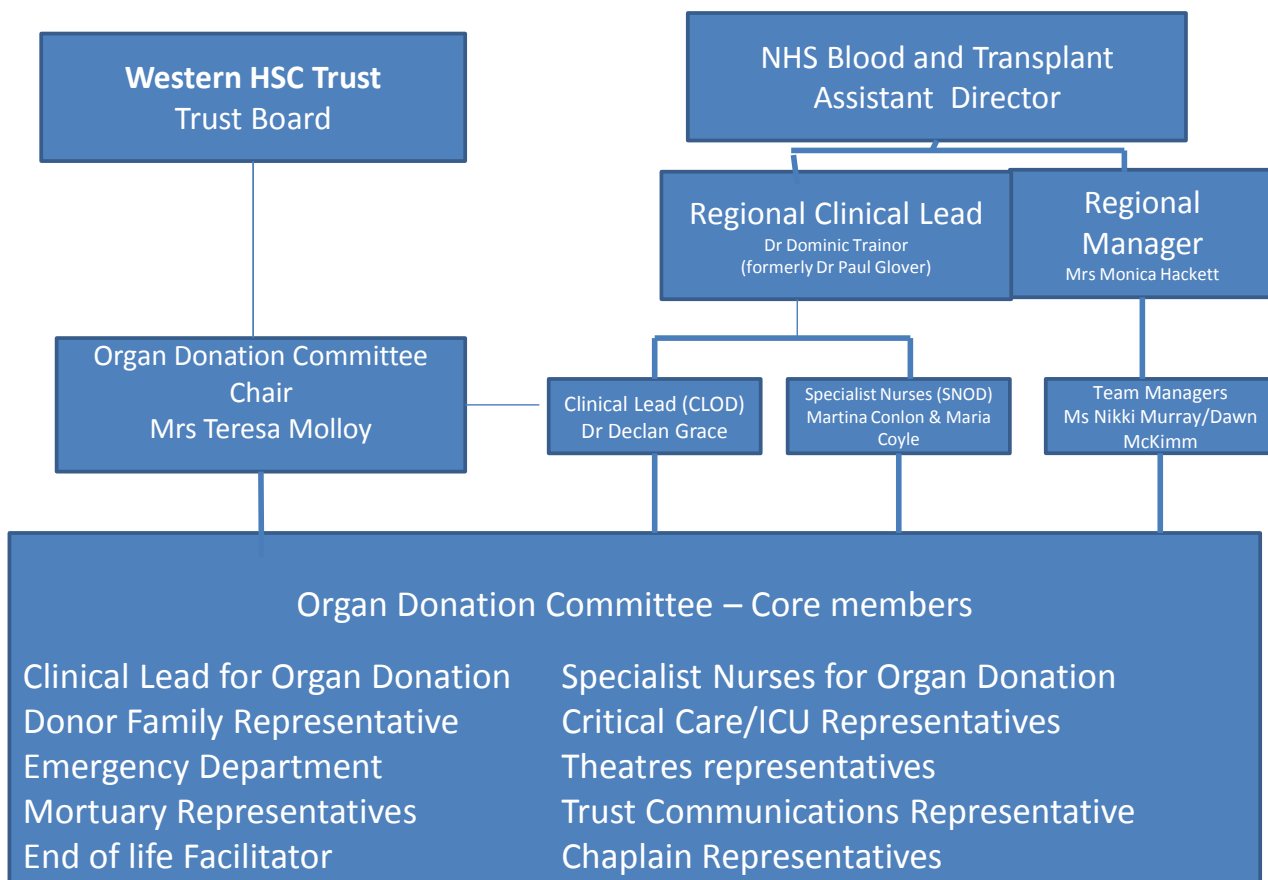
 Facebook- 8 posts, reaching **171k people**. With >34.1k video views.

Percentage of local adult population registered as potential donors in our Local Council areas is in the order of 48%.

Assent rate is approximately 80% annually (the national target year for achieving an assent rate of 80% is the year 2020)

16% of all deceased donations in Northern Ireland secured in Western HSC Trust's Critical care Units from a bed complement of 10% of Northern Ireland's Intensive Care Unit beds.

Organ Donation Team Structure





**Actual and Potential
Deceased Organ Donation
1 April 2018 - 31 March 2019**

Blood and Transplant

Western Health and Social Care Trust

Taking Organ Transplantation to 2020

In 2018/19, from 12 consented donors the Trust facilitated 8 actual solid organ donors resulting in 20 patients receiving a life-saving or life-changing transplant. Data obtained from the UK Transplant Registry. In addition to the 8 proceeding donors there were 4 consented donors that did not proceed.

Best quality of care in organ donation

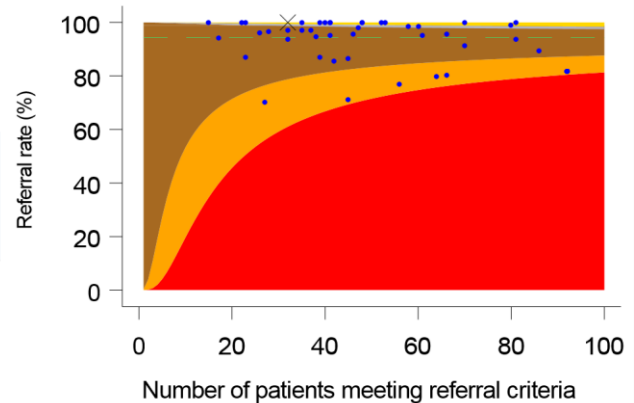
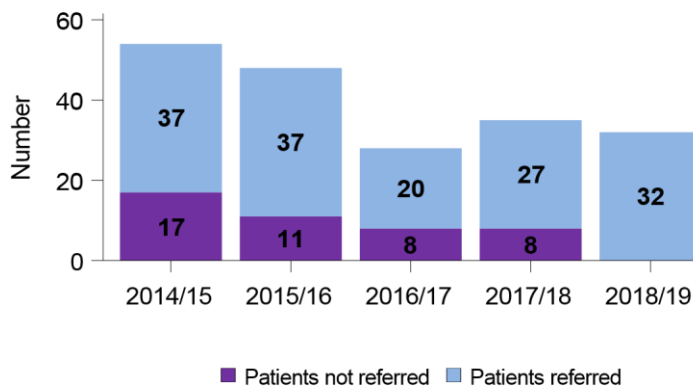
Referral of potential deceased organ donors

Goal: Every patient who meets the referral criteria should be identified and referred to NHS Blood and Transplant's Organ Donation Service

Aim: The Trust (marked with a cross) should

Aim: There should be no purple on the chart

fall within Bronze, Silver, or Gold



X Trust • Other level 2 Trusts --- UK rate

Gold Silver Bronze Amber Red

The Trust referred 32 potential organ donors during 2018/19. There were no occasions where potential organ donors were not referred.

When compared with UK performance, the Trust was exceptional (gold) for referral of potential organ donors to NHS Blood and Transplant.



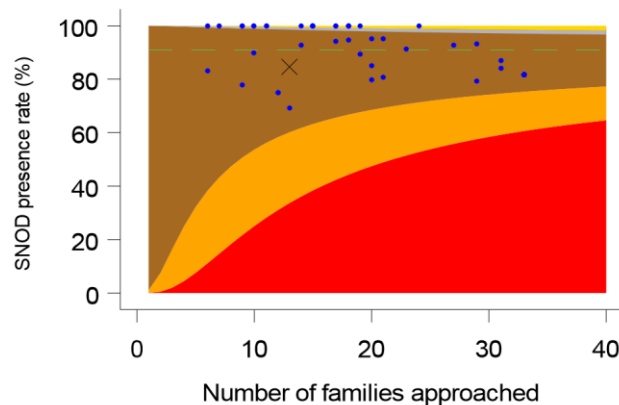
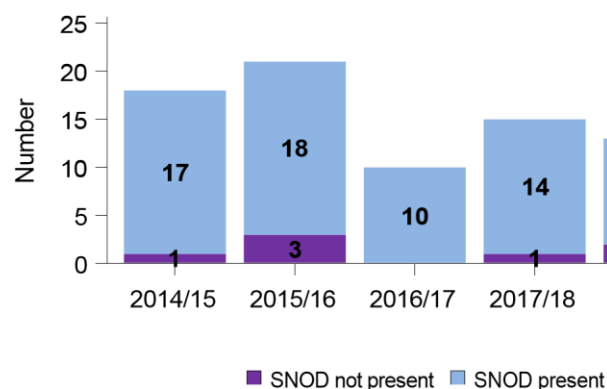
Presence of Specialist Nurse for Organ Donation

Goal: A Specialist Nurse for Organ Donation (SNOD) should be present during every organ donation discussion with families

Aim: The Trust (marked with a cross) should

Aim: There should be no purple on the chart

fall within Bronze, Silver, or Gold



X Trust • Other level 2 Trusts --- UK rate

Gold Silver Bronze Amber Red

A SNOD was present for 11 organ donation discussions with families during 2018/19. There were 2 occasions where a SNOD was not present.

When compared with UK performance, the Trust was average (bronze) for SNOD presence when approaching families to discuss organ donation.

Why it matters

- If suitable patients are not referred, the patient's decision to be an organ donor is not honoured or the family does not get the chance to support organ donation.
- The consent rate in the UK is much higher when a SNOD is present.
- The number of patients receiving a life-saving or life-changing solid organ transplant in the UK is increasing but patients are still dying while waiting.

Regional donors, transplants, waiting list, and NHS Organ Donor Register (ODR) data

| | Northern Ireland* | UK |
|---|-------------------|------------------|
| 1 April 2018 - 31 March 2019 | | |
| Deceased donors | 44 | 1,600 |
| Transplants from deceased donors | 96 | 3,943 |
| Deaths on the transplant list | 9 | 403 |
| As at 31 March 2019 | | |
| Active transplant list | 143 | 6,083 |
| Number of NHS ODR opt-in registrations (% registered)** | 870,238 (47%) | 26,496,220 (41%) |

*Regions have been defined as per former Strategic Health Authorities

** % registered based on population of 1.85 million, based on ONS 2011 census data

Further information

Further information on potential donors after brain death (DBD) and potential donors after circulatory death (DCD) at the Trust are shown below, including a UK comparison. Data obtained from the Potential Donor Audit (PDA).

| | DBD | | DCD | | Deceased donors | |
|--|---------------|------|---------------|------|-----------------|------|
| | Trust | UK | Trust | UK | Trust | UK |
| Patients meeting organ donation referral criteria ¹ | 8 | 2004 | 24 | 5974 | 32 | 7728 |
| Referred to Organ Donation Service | 8 | 1982 | 24 | 5539 | 32 | 7287 |
| <i>Referral rate %99%93%94%</i> | G 100% | | G 100% | | G 100% | |
| Neurological death tested ¹⁷¹⁵ | 8 | | | | | |
| <i>Testing rate %86%</i> | G 100% | | | | | |
| Eligible donors ²¹⁶³⁵⁴¹⁸⁰⁵⁸¹⁵ | 8 | | 18 | | 26 | |
| Family approached ¹⁴⁹³¹⁷⁵²³²⁴⁵ | 6 | | 7 | | 13 | |
| Family approached and SNOD present ¹⁴²³¹⁵²⁷²⁹⁵⁰ | 6 | | 5 | | 11 | |
| <i>% of approaches where SNOD present^{95%87%91%}</i> | G 100% | | B 71% | | B 85% | |
| Consent ascertained ¹⁰⁸²¹⁰⁹⁹²¹⁸¹ | 5 | | 4 | | 9 | |
| <i>Consent rate %72%63%67%</i> | B 83% | | B 57% | | B 69% | |
| Actual donors (PDA data) | | 970 | | 612 | | 1582 |
| <i>% of consented donors that became actual donors</i> | 100% | 90% | 50% | 56% | 78% | 73% |

¹ 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

² 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

Note that a patient that meets both the referral criteria for DBD and DCD organ donation is featured in both the DBD and DCD data but will only be counted once in the deceased donors total

Gold **Silver** **Bronze** **Amber** **Red**

For further information, including definitions, see the latest Potential Donor Audit report at www.odt.nhs.uk/statistics-and-reports/potential-donor-audit/

Glossary of Terms

| | |
|----------|----------------------------------|
| D.C.D. | Donation after circulatory death |
| D.B.D. | Donation after brain death |
| P.D.A. | Potential donor audit |
| C.P.R. | Cardiopulmonary Resuscitation |
| S.N.O.D. | Specialist Nurse Organ Donation |
| C.L.O.D. | Clinical Lead for Organ Donation |