**CYFARFOD BWRDD PRIFYSGOL IECHYD**
**UNIVERSITY HEALTH BOARD MEETING**

| | |
|---|---|
| **DYDDIAD Y CYFARFOD:**<br>**DATE OF MEETING:** | 25 January 2024 |
| **TEITL YR ADRODDIAD:**<br>**TITLE OF REPORT:** | NHSBT Organ Donation: Review of Actual and Potential Deceased Organ Donation 01/04/2022 – 31/04/2023 |
| **CYFARWYDDWR ARWEINIOL:**<br>**LEAD DIRECTOR:** | Steve Moore, Chief Executive<br>Philip Kloer, Deputy Chief Executive<br>Andrew Carruthers, Executive Director of Operations |
| **SWYDDOG ADRODD:**<br>**REPORTING OFFICER:** | Kathy Rumbelow, Specialist Requester (SR) and Lauren Blunsden, Specialist Nurse for Organ Donation (SNOD) |

| **Pwrpas yr Adroddiad** (dewiswch fel yn addas)<br>**Purpose of the Report** (select as appropriate) |
|---|
| Ar Gyfer Trafodaeth/For Discussion |

**ADRODDIAD SCAA**
**SBAR REPORT**

## Sefyllfa / Situation

This SBAR will provide an overview of Hywel Dda University Health Board's performance against the priorities we set ourselves for March 2022 – April 2023 regarding organ donation. The detailed report is attached, together with an action plan for 2023/24.

The Board is asked to note the performance against priorities for 2022/23 and the action plan for 2023/2024.

## Cefndir / Background

In June 2022, the Welsh Government published 'Donation and Transplantation plan for Wales: 2022-2026' (attached at Appendix 1), to ensure the entire population of Wales can donate tissue or organs and receive a transplant whenever this is clinically possible. This has been published by the Wales Transplant Advisory Group in collaboration with key delivery partners and stakeholders and complements the UK Donation and Transplantation Plan 2030: Meeting the Need Plan.

Our priorities for Organ Donation for 2022/2023 were:

- To continue to educate and promote best practice to refer all patients that meet the minimum notification criteria for donation.
- To investigate any missed referrals and explore actions identified are implemented to prevent further occurrences.
- Maintain a 100% referral rate for potential Donation after Brain death and Donation after circulatory death with Specialist Requester and Specialist Nurse Organ Donation involvement for collaborative approaches.
- Maintain a 100% Neurological death testing rate.
- Continue promoting and practicing Withdrawal of life sustaining treatment in anaesthetic room for all Donation after Circulatory Death donors. This has been proven to improve organ transplantation outcomes. As a health-board we should be adhering to best practice

therefore the importance of education surrounding this is crucial to Critical care, Accident and Emergency and Theatre staff.

- Specialist Nurse Organ Donation to promote Organ Donation across all four sites, including using Organ Donation week as a secure platform to promote deemed consent and increase Organ Donor Register registrations.
- Continue to support and foster good working relationships and a sustainable, supportive and diverse workforce to promote Organ Donation and aid education in the wider community.
- Increase tissue donation and investigate the barriers involved regarding retrieval or tissues in Hywel Dda University Health Board.

With effect from October 2023, a new chair has been appointed for our Organ Donation Committee; Chantal Patel, who has taken over from Judith Hardisty.

## Asesiad / Assessment

The Annual Report, attached at Appendix 2, identifies our performance for April 2022 – March 2023.

- **To continue to educate and promote best practice to refer all patients that meet the minimum notification criteria for donation.**
  Critical care, A&E and theatre staff all receive regular teaching sessions regarding organ donation, this too including new doctors joining the Health Board. Face to face teaching is now being carried out regularly since COVID, where we have had good staff engagement and response. We are also aiming to deliver simulation training locally within the Health Board using a programme that has been developed and successfully delivered by Specialist Nurses and Clinical Leads for Organ Donation in Wales to other Health Boards.

- **To investigate any missed referrals and explore actions identified are implemented to prevent further occurrences.**
  NHSBT have a strong ambition for no missed referrals. As you can see on page 6 of the detailed report, HDdUHB had no missed referrals for the financial year 2022/23. This is excellent and a reflection of all of the hard work that has been undertaken since last year's report.

- **Maintain a 100% referral rate for potential Donation after Brainstem Death and Donation after Circulatory Death with Specialist Requester and Specialist Nurse Organ Donation involvement for collaborative approaches.**
  Again, HDdUHB had 100% referral rate with 100% Specialist Nurse Organ Donation presence for all of our Donation after Brainstem Death and Donation after Circulatory Death donors, as outlined on page 6 and 8 of the detailed report. This has improved from last year and shows the hard work of all medical and nursing teams within the Health Board and demonstrates that our teaching and education is making a positive impact on Organ Donation. This also reflects the hard work of both Specialist Nurse Organ Donation and Specialist Requestor being present on all four sites continually throughout the year.

- **Maintain a 100% Neurological Death Testing Rate.**
  Measures demonstrated on page 5 of the detailed report shows that there was one patient that was not Neurologically death tested out of the 8 that met criteria. The reason for this being that, despite the patient meeting criteria, they were haemodynamically unstable. Therefore, tests were unable to be carried out due to instability, despite best efforts to optimise.

- **Continue promoting and practicing Withdrawal of life sustaining treatment in anaesthetic room for all Donation after Circulatory Death donors. This has been proven to improve organ transplantation outcomes. As a Health Board we should be adhering to best practice therefore the importance of education surrounding this is crucial to Critical care Accident and Emergency and Theatre staff.**
  All Donation after Circulatory Death donors in HDdUHB have undergone Withdrawal of Life Sustaining Treatment in theatres. All staff are compliant with the gold standard of practice and there remains no barriers identified to this. We will continue to work closely with our theatre colleagues to ensure the success and continuation of this practice.

- **Specialist Nurse Organ Donation to promote Organ Donation across all four sites, including using Organ Donation week as a secure platform to promote deemed consent and increase Organ Donor Register registrations.**
  This year for organ donation the Team has had a day in each site using a promotional stand and gaining public engagement. Specialist Requester and Specialist Nurse Organ Donation also spent two days at the Pembrokeshire County show where a promotional stand was set up, with vast amounts of public engagement and ODR registrations to OPT-IN. We also have a patient story board of a previous donor in Withybush Hospital, which is displayed on the corridor leading into the Intensive Care Unit.

- **Continue to support and foster good working relationships and a sustainable, supportive and diverse workforce to promote organ donation and aid education in the wider community.**
  Specialist Nurse Organ Donation and Specialist Requester will continue to work closely with link staff and plan for further study events to ensure everyone is up to date with latest developments and practices in organ donation. Link staff can then disseminate training within their departments and the wider communities.

- **Increase tissue donation and investigate the barriers involved regarding retrieval or tissues in Hywel Dda University Health Board.**
  Specialist Nurse Organ Donation and Specialist Requester have a close working relationship with mortuary staff and are aware of our tissue policy and procedures. All sites now have a Tissue donation referral 'help sheet' which includes criteria for referrals, medical contraindications and also how to make a tissue referral.

## Argymhelliad / Recommendation

The Board is asked to **DISCUSS** and **APPROVE** the Annual Report and **NOTE** the Health Board's performance against the priorities set for 2022/2023 and action plan for 2023/2024.

| **Amcanion: (rhaid cwblhau)**<br>**Objectives: (must be completed)** | |
|---|---|
| Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol:<br>Datix Risk Register Reference and Score: | N/A |
| Parthau Ansawdd:<br>Domains of Quality<br>Quality and Engagement Act (sharepoint.com) | 1. Safe<br>3. Effective<br>4. Efficient<br>6. Person-Centred |
| Galluogwyr Ansawdd:<br>Enablers of Quality: | 1. Leadership<br>3. Data to knowledge |

| | |
|---|---|
| Quality and Engagement Act (sharepoint.com) | 2. Culture and valuing people<br>4. Learning, improvement and research |
| Amcanion Strategol y BIP:<br>UHB Strategic Objectives: | 4. The best health and wellbeing for our individuals, families and communities<br>2. Working together to be the best we can be<br>1. Putting people at the heart of everything we do<br>5. Safe sustainable, accessible and kind care |
| Amcanion Cynllunio<br>Planning Objectives | 6b Pathways and Value Based Healthcare |
| Amcanion Llesiant BIP:<br>UHB Well-being Objectives:<br>Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022 | 10. Not Applicable |

| **Gwybodaeth Ychwanegol:<br>Further Information:** | |
|---|---|
| Ar sail tystiolaeth:<br>Evidence Base: | Donation and Transplantation plan for Wales:2022-2026.<br>UK Donation and Transplantation Plan 2030: Meeting the Need Plan. |
| Rhestr Termau:<br>Glossary of Terms: | DBD – Donation after Brainstem Death<br>DCD – Donation after Circulatory Death<br>HBUHB – Hywel Dda University Health Board<br>ODR – Organ Donor Register<br>SNOD – Specialist Nurse Organ Donation<br>SR – Specialist Requester<br>WTAG – Welsh Transplant Advisory Group<br>NDT's – Neurological Death Testing |
| Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Cyfarfod Bwrdd Iechyd Prifysgol:<br>Parties / Committees consulted prior to University Health Board: | Organ Donation Committee |

| **Effaith: (rhaid cwblhau)<br>Impact: (must be completed)** | |
|---|---|
| **Ariannol / Gwerth am Arian:<br>Financial / Service:** | N/A |
| **Ansawdd / Gofal Claf:<br>Quality / Patient Care:** | No implications |
| **Gweithlu:<br>Workforce:** | No impact |
| **Risg:<br>Risk:** | Nil |
| **Cyfreithiol:<br>Legal:** | There are no legal implications contained within the report |
| **Enw Da:<br>Reputational:** | Media interest in view of ongoing organ donation advertising campaigns |

| | |
|---|---|
| **Gyfrinachedd:**<br>**Privacy:** | None identified |
| **Cydraddoldeb:**<br>**Equality:** | There are no equality and diversity implications contained within the report |

# Donation and Transplantation Plan for Wales: 2022-2026

‘Ensure the whole population of Wales can donate tissue or organs and receive a transplant whenever this is clinically possible’

Developed by the Wales Transplantation Advisory Group (in collaboration with key delivery partners and stakeholders)

**June 2022**

## Introduction

This plan aims to build on the improvements in donation and transplantation started following the UK Organ Donation Taskforce report in 2008 and continued through the recommendations set out in UK Taking Organ Transplantation to 2020 and the accompanying Wales action plan. It covers both living and deceased donation of both tissue and organs for adults and children.

While there have been significant increases in living and deceased donation over the past decade, progress in some areas has been slower than we would have hoped. This plan has been developed with the members of the Welsh Transplantation Advisory Group with input from additional stakeholders. In considering actions for inclusion, the group agreed that the plan should focus on those actions which will or are likely to:

- increase organ and tissue transplantation
- reduce inequalities and improve access to transplantation for patients
- improve outcomes from transplantation

This plan complements UK Organ Donation and Transplantation 2030: Meeting the Need plan[1] and supports its objectives. Given how much may change over that decade in this area, we have focused on recommendations which we anticipate can be delivered or where we can make significant progress in the coming four years. This plan seeks to avoid duplicating actions already covered in the UK strategy, particularly where actions are best taken forward on a UK wide basis, and therefore the two documents should be considered together.

NHS Blood and Transplant have been supporting a separate piece of work looking at organ utilisation, it is anticipated that the report and recommendations will be published shortly after this plan. We have attempted to take account of this work during the development of this plan, once published, the recommendations will be considered and built into the implementation process.

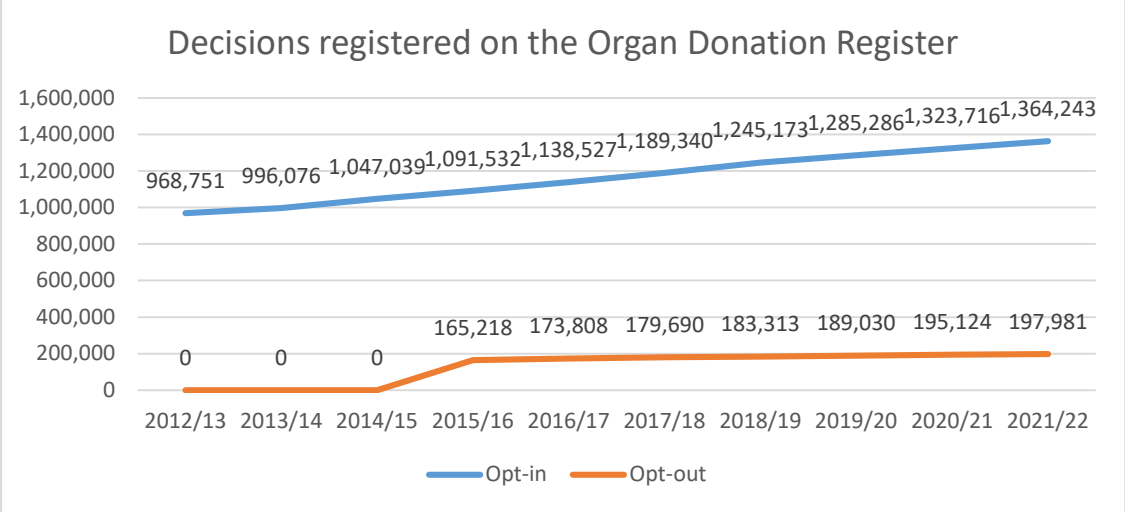
We need to recognise the context in which this plan was developed during the COVID-19 pandemic and the impact this has had on NHS services, the ongoing pressures within the NHS and the necessary changes which have taken place such as video consultations. There is an ongoing need to provide services differently both in response to COVID-19 and also to tackle the harms caused by COVID-19 such as the reduction in the number of organ donors and the increase in the transplant waiting list.

The plan does set out a number of additional Wales specific actions to be taken forward. It will be reviewed and updated, where necessary, on an annual basis. We recognise the valuable contribution and services provided by the third sector and will seek to work with them as we progress implementation. The actions within the plan have been broken down into timescales of short term within next 1 year, medium term next 2 to 3 years, long term next 4 to 5 years or action we are taking on an ongoing/continual basis.

[1] https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/

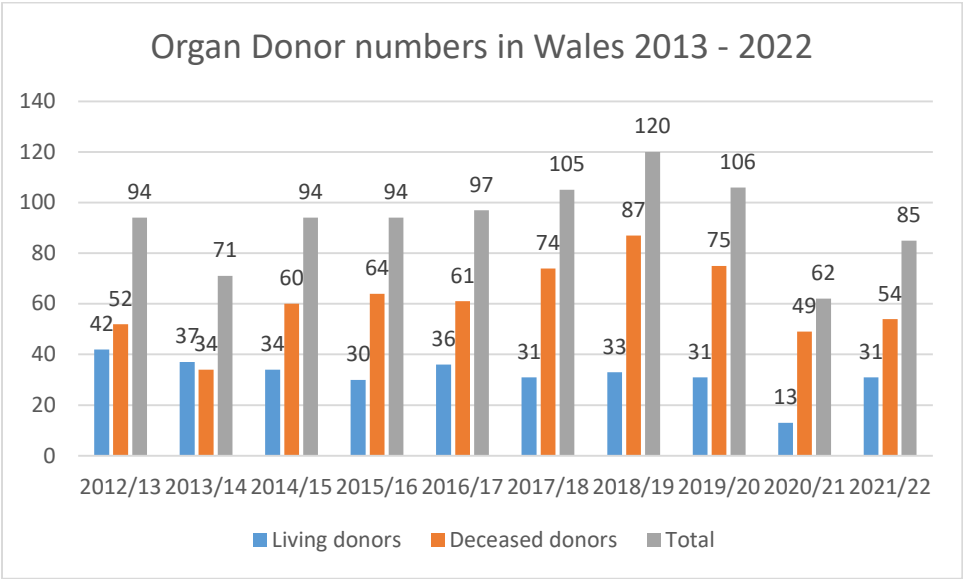
**Current position/progress**

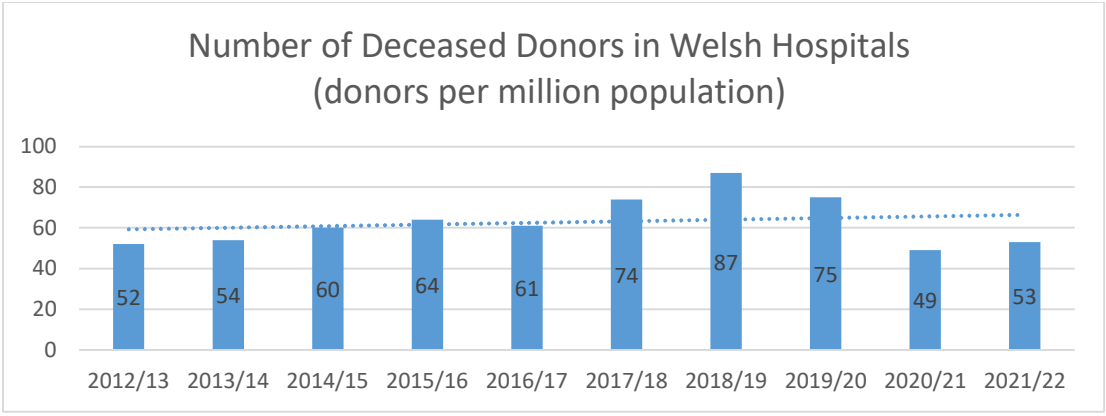
We have continued to see a steady rise in the number of people who have expressed an organ donation decision. Research has shown the majority of the Welsh population are supportive of organ donation but this does not necessarily translate into a willingness to donate. The graph below highlights the number of people who have registered a decision on the organ donation register. It should be noted that prior to 2015 people were not able to register an opt-out decision.

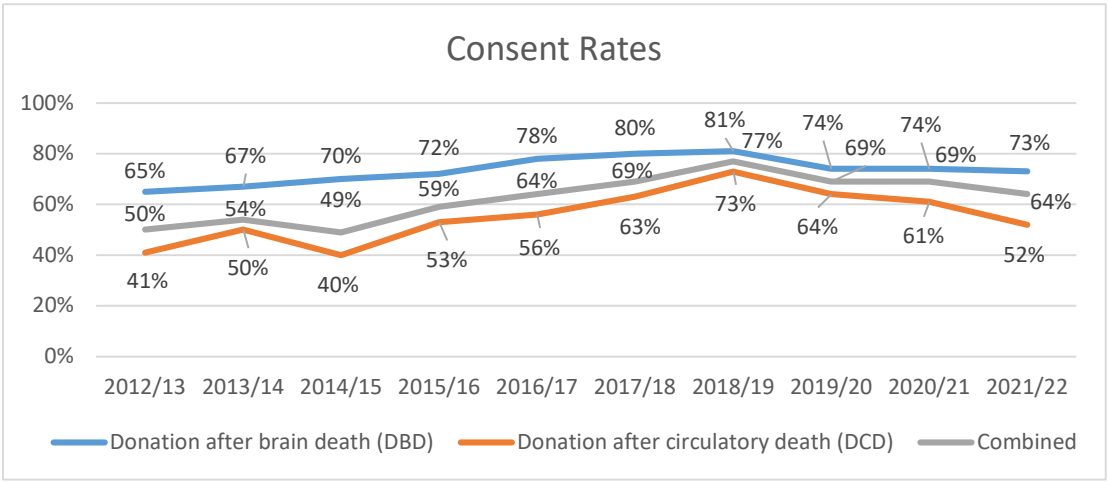


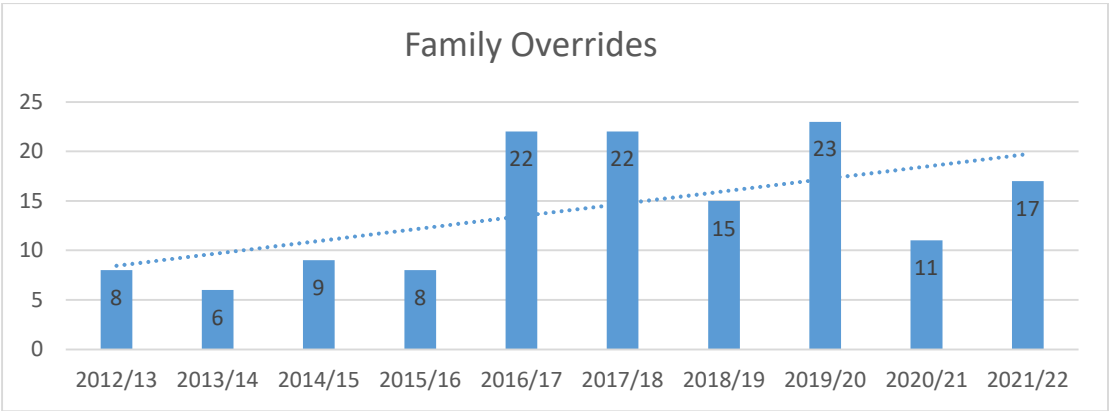

It should be noted that the pandemic, which started in March 2020 had a significant impact on both donation and transplantation as you will see demonstrated in the graphs below.

Progress has been made to increase the numbers of deceased donors in Welsh hospitals as can be seen in the graph below. We have also seen improvements in the combined consent rate, although rates do fluctuate due to the small donor numbers in Wales. Consent is an important factor which affects whether donation, and ultimately transplantation, can proceed. Each year a proportion of families either override the consent the person had previously given or refuse consent for their loved one's organs to be donated. There remains a fairly high number of family overrides.

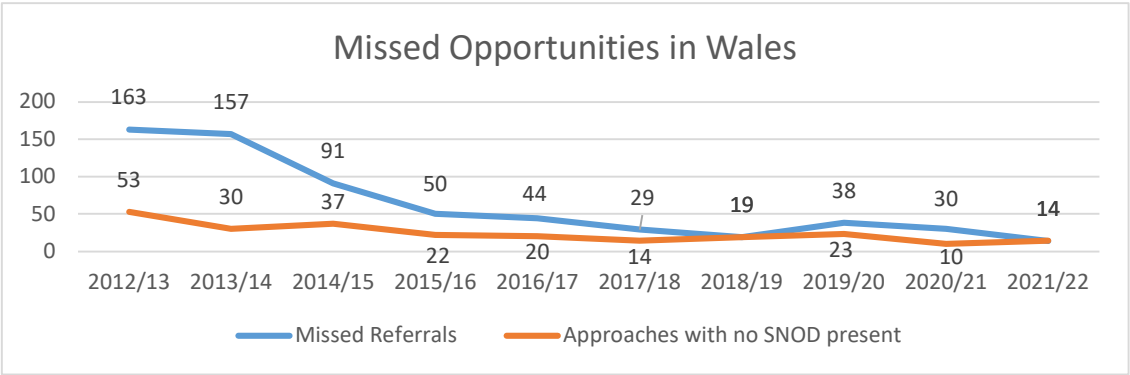




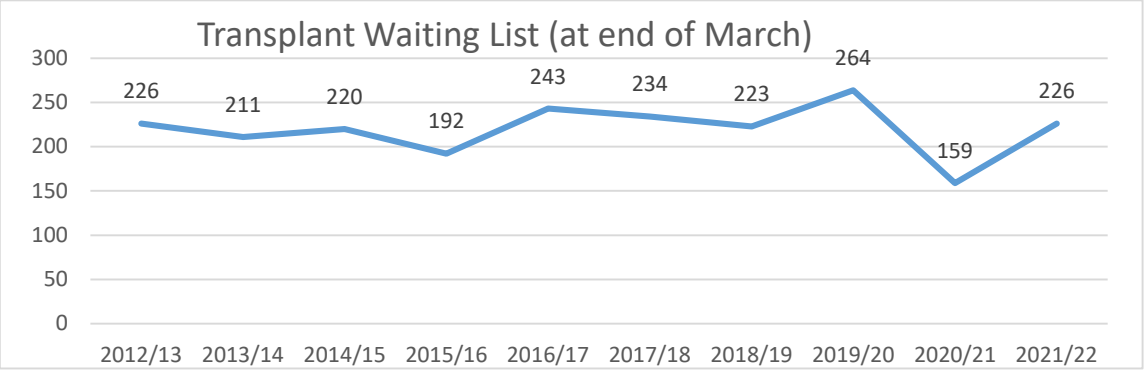



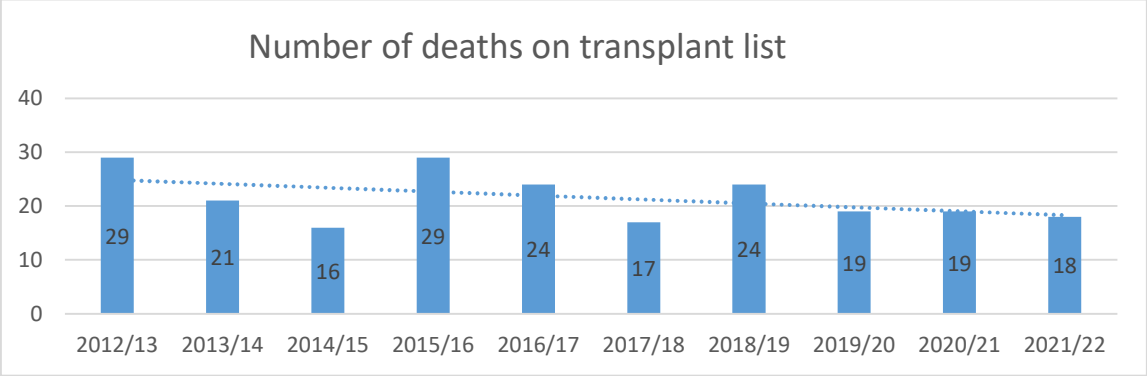



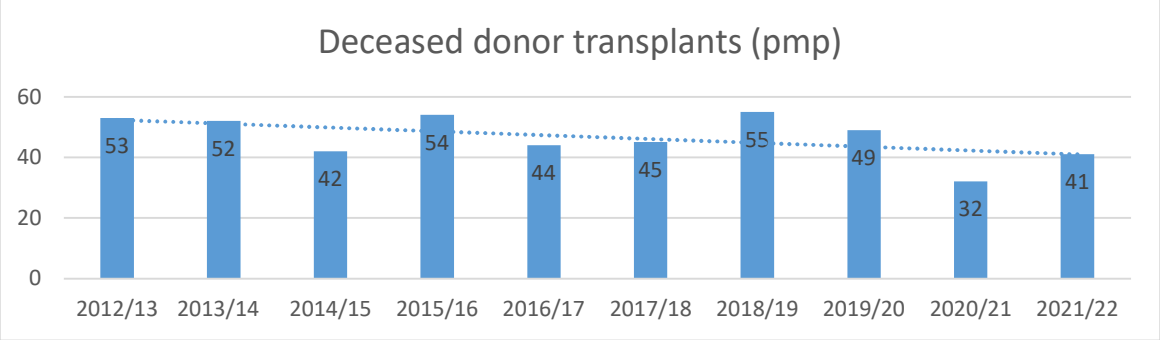

It should be noted that family overrides were calculated differently pre-1 December 2015 (just overrides of an opt in decision), post 2016/17 overrides are expressed decision or deemed consent.



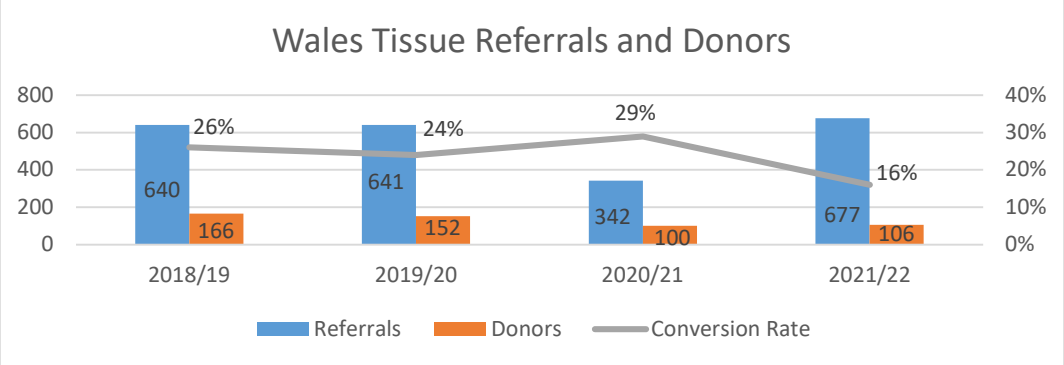
Graphs below also show the waiting list, number of transplants per million and number of people who have died waiting for a transplant. The transplant position has been relatively static in recent years with small changes potentially due to the small numbers of transplant activity due to population size. An increase in the number of organ donations in Wales does not directly correlate with an increase in the number of transplants due to the number of organs donated and the UK wide allocation schemes. Waiting list figures for 2020/21 and 2021/22 do not accurately reflect the need for an organ transplant due to the COVID-19 pandemic.




The graph below shows the rates of tissue donation in Wales.



**Priority 1 - Increasing deceased organ donation**

We want to:

- ensure all eligible donors have an opportunity to donate
- improve consent rates
- reduce family refusal rates
- reduce missed opportunities
- maximise the number of donations
- continue to increase public awareness

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 1.1 | Missed opportunities/ Maximise the number of donations | Ensure every referral is reviewed and monitor:<br>• any missed opportunity identified<br>• involvement of specialist nurses/requestors and clinical leads<br>• neurological testing is performed in all patients who meet testing criteria, regardless of donor potential | Ongoing<br><br>Health boards/ NHSBT Specialist nurse team/ WTAG |
| 1.2 | Public Awareness | Ensure regular public awareness campaigns are undertaken and targeted appropriately | Ongoing<br><br>Welsh Government/NHSBT |
| 1.3 | Optimise the timeliness of process and maximising efficiency in the donation pathway | Work with NHSBT to improve the timeliness of process and maximising efficiency in the donation pathway including monitor reasons for organ donations not proceeding and, in particular, where donations did not proceed for logistical reasons | Short to medium term<br><br>Health boards/ NHSBT/WTAG |
| 1.4 | Donor assessment and optimisation | Work with NHSBT to improve donor pathway for donor assessment and timely optimisation including carrying out medical procedures, such as echocardiography, to assist facilitating successful donation | Short to medium term<br><br>Health boards/ NHSBT/WTAG |
| 1.5 | Consent – reduce family refusals | Ensure key staff likely to be involved in approaching families about deceased donation receive training and guidance | Short to medium term<br><br>Health boards/ NHSBT/WTAG |

**Priority 2 - Increasing tissue and eye donation**

We want to:

- improve tissue and eye donation rates
- increase the number of alliance sites
- consider the potential of tissue donation for all deaths
- embed referral of potential tissue donors as part of standard end of life care
- expand opportunities for tissue and eye donation
- continue to improve health professional awareness
- continue to increase public awareness

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 2.1 | Health professional awareness | Increase awareness raising among NHS staff about potential to discuss tissue donation as part of advance planning, referring potential tissue donors and the importance of considering the potential of tissue donation for all deaths | Short term<br><br>Health board Organ Donation Committees/ NHSBT |
| 2.2 | Public Awareness | Promote public awareness about the importance of tissue and eye donation | Ongoing<br><br>Welsh Government /NHSBT/health boards/third sector |
| 2.3 | Expand opportunities | Work within wider hospital settings and hospices to enable some of those who die out of critical care/emergency departments or out of hospital also to have the opportunity to donate | Short to medium term<br><br>Health boards/ NHSBT |
| 2.4 | Alliance Sites | Collaborative working between health boards and NHSBT to ensure each area has at least one alliance site | Medium term<br><br>Health boards/ NHSBT |
| 2.5 | Embed referral | Monitor tissue referral rates and reasons for tissue donation not being authorised to try to consider if there are any further steps which should be taken to increase donation including refusal for logistical reasons | Medium term<br><br>Health boards/ NHSBT/ WTAG |

**Priority 3 - Increasing living donation and transplantation**

We want to:

- increase access to living donor transplants
- make a living donor transplant the 'default' option for all patients (both adults and children) needing a kidney transplant
- provide high quality, accessible information to patients and their families about living kidney donation
- continue to improve health professional awareness
- continue to improve public awareness
- ensure patients who might benefit from a transplant or who want to donate are supported to improve their health and fitness to allow this to happen whenever possible

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 3.1 | Living donor transplant the 'default' option | Ensure all patients approaching end-stage renal failure have a documented decision about whether they are suitable for and want to proceed with a living and/or deceased donor transplant | Short to medium term<br><br>Transplant units/ renal teams/ commissioners |
| 3.2 | Patients who might benefit are supported to improve their health and fitness | Establish a national programme for pre-habilitation, covering physical, psychological, nutritional and social wellbeing, for patients who would benefit from improvements in their fitness prior to organ donation or transplantation | Medium term<br><br>Transplant units/ renal teams/ commissioners |
| 3.3 | Public awareness/ patient information | Improve access to information about living donation both for potential donors and transplant recipients | Short to medium term<br><br>Transplant units/ renal teams/ commissioners |
| 3.4 | Improving access | Report and monitor regional variations in living donation including time to work up and work with centres to understand any differences | Short to medium term<br><br>Transplant units/ renal teams/ commissioners/ WTAG |
| 3.5 | Improving access | Explore ways to streamline the referral and assessment process both for potential donors and recipients | Short to medium term<br><br>NHSBT/HTA/ Transplant units/ renal teams/ commissioners/ WTAG |

**Priority 4 - Increasing access to transplantation**

We want to:

- continue to increase the number of transplants for Welsh patients
- reduce waiting times and provide the best possible outcomes for patients
- support the use of novel technologies such as machine perfusion
- increase organ utilisation
- improve equity of access to transplantation across Wales
- ensure that organ failure is diagnosed early wherever possible and early assessment for transplantation
- ensure a sustainable, patient-centred transplant service
- ensure that all patients likely to benefit from transplantation are offered the opportunity

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 4.1 | Novel technologies/ Organ Utilisation | Work to increase the number of viable organs by using novel technologies, such as NRP and ARCs and participation in research which maximises transplant potential such as the potential use of cell and gene therapy to help regenerate organs for transplantation | Medium term<br><br>Transplant units/ Commissioners/ NHSBT/ WTAG |
| 4.2 | Organ Utilisation | Implement the recommendations of the Organ Utilisation Group report and monitor reasons for organs being declined and, in particular, consider with units where organs have had to be declined for logistical reasons | Short to medium term<br><br>Transplant units/ Commissioners/ NHSBT/WTAG |
| 4.3 | Sustainable, patient-centred transplant service | Work to ensure sustainable, patient-centred transplant services and ensure equitable access including exploring options for improved collaboration between units | Short to medium term<br><br>Transplant units/ Commissioners/ |
| 4.4 | Organ Utilisation | Work to expand services to Welsh patients through establishment of hepatitis C positive donor programmes | Short to medium term<br><br>Transplant units/ Commissioners/ |
| 4.5 | Best possible outcomes for patients | Work to ensure units who provide services to Welsh are delivering a best in UK service including undertaking testing, pre-habilitation and follow-up as close to home as possible | Medium term<br><br>Transplant units/ Commissioners/third sector |
| 4.6 | Organ failure is diagnosed early/ early assessment for transplantation | Proactively identify and discuss transplantation with any patient who may be eligible for and benefit from a transplant. Ensuring work-up of patients who might benefit from a transplant commences early enough to allow it to be achieved at the optimal time and minimise delays. | Medium term<br><br>Transplant units/ Commissioners |

**Priority 5 - Improving transplant outcomes**

We want to:

- improve support for patients after they have been discharged from hospital post-transplant
- enable patients to receive any follow-up care they need and, where possible, to receive this closer to home
- improve transplant outcomes
- reduce the number of recipients who need subsequent transplants
- improve transplant patient experience

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 5.1 | Support for patients post-transplant | Consider whether existing aftercare services need to be improved for recipients including improved access advice on diet and physical activity | Medium Term<br><br>Transplant Units/ Health boards/ Commissioners |
| 5.2 | Support for patients post-transplant | Explore opportunities for technology, such as apps, to offer other potential means of helping monitor patients' health remotely and ensuring they are appropriately supported | Medium Term<br><br>Transplant Units/ Commissioners/ DHCW |
| 5.3 | Support for patients post-transplant | Provide appropriate psycho-social support for all transplant patients in Wales | Medium Term<br><br>Transplant Units/ Health boards/ Commissioners/ third sector |
| 5.4 | Patient Experience | Understand what PROMs and PREMs are important for Welsh transplant patients and look to start capturing and reporting them | Medium Term<br><br>Transplant Units/ Health boards/ Commissioners/ WTAG/third sector |
| 5.5 | Follow-up care closer to home | Encourage and support transplant units to develop an improved, more patient-centred 'hub and spoke' model of care to provide better continuity of care for patients and consider introduction of nominated transplant champions in health boards network of clinicians who can support improvements within health boards (without transplant units) and ensure key staff are kept up to date with developments | Medium Term<br><br>Transplant Units/ Health boards/ Commissioners/ WTAG |

**Priority 6 - Ensuring a workforce sustainable, supported and diverse**

We want to:

- ensure we have a sustainable, dedicated and specialised workforce for organ donation/transplantation
- ensure we have a culturally diverse workforce which reflects the population
- utilise the cultural diversity within the workforce to improve education and public awareness
- ensure workforce have access to appropriate and secure resources
- ensure families have the option to conduct the conversation in Welsh whenever possible
- ensure people of all background and circumstances will have timely support and access

| | Area | Action | Timescale/Lead |
|---|---|---|---|
| 6.1 | Ensure sufficient and sustainable staffing levels | Work to ensure sufficient and sustainable staffing levels | Medium term<br><br>Transplant units/ Health boards/NHSBT/ Commissioners |
| 6.2 | Appropriate and secure resources | Improve access to appropriate and secure information technology services/portals to help workforce perform their role and improve decision making including data linkage | Medium term<br><br>Transplant units/ Health boards/ NHSBT/DHSW |
| 6.3 | Diversity | Work to improve access to Welsh language and culturally appropriate resources both in relation to information provided and speakers so donors, families or transplant recipients can be supported in their language of choice | Short to medium term<br><br>Transplant units/ Health boards/ NHSBT |
| 6.4 | Diversity | Utilise cultural diversity within the workforce to help improve public education and engagement | Medium term<br><br>Transplant units/ Health boards/ NHSBT |

NHS
Blood and Transplant

# Detailed Report

# Actual and Potential Deceased Organ Donation

# 1 April 2022 - 31 March 2023

## Hywel Dda University Health Board

# Table of Contents



**Further Information**

- Appendix A.1 contains definitions of terms and abbreviations used throughout this report and summarises the main changes made to the PDA over time.
- The latest Organ Donation and Transplantation Activity Report is available at https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/transplant-activity-report/
- The latest PDA Annual Report and our Power BI reports with up to date Health Board metrics are available at https://www.odt.nhs.uk/statistics-and-reports/potential-donor-audit-report/.
- Please refer any queries or requests for further information to your local Specialist Nurse - Organ Donation (SNOD)

**Source**

NHS Blood and Transplant: UK Transplant Registry (UKTR), Potential Donor Audit (PDA) and Referral Record.
Issued May 2023 based on data meeting PDA criteria reported at 9 May 2023.

# 1. Donor Outcomes

## A summary of the number of donors, patients transplanted, average number of organs donated per donor and organs donated.

## Data in this section is obtained from the UK Transplant Registry

Between 1 April 2022 and 31 March 2023, Hywel Dda University Health Board had 7 deceased solid organ donors, resulting in 19 patients receiving a transplant. Additional information is shown in Tables 1.1 and 1.2, along with comparison data for 2021/22. Figure 1.1 shows the number of donors and patients transplanted for the previous ten periods for comparison.

**Table 1.1 Donors, patients transplanted and organs per donor, 1 April 2022 - 31 March 2023 (1 April 2021 - 31 March 2022 for comparison)**

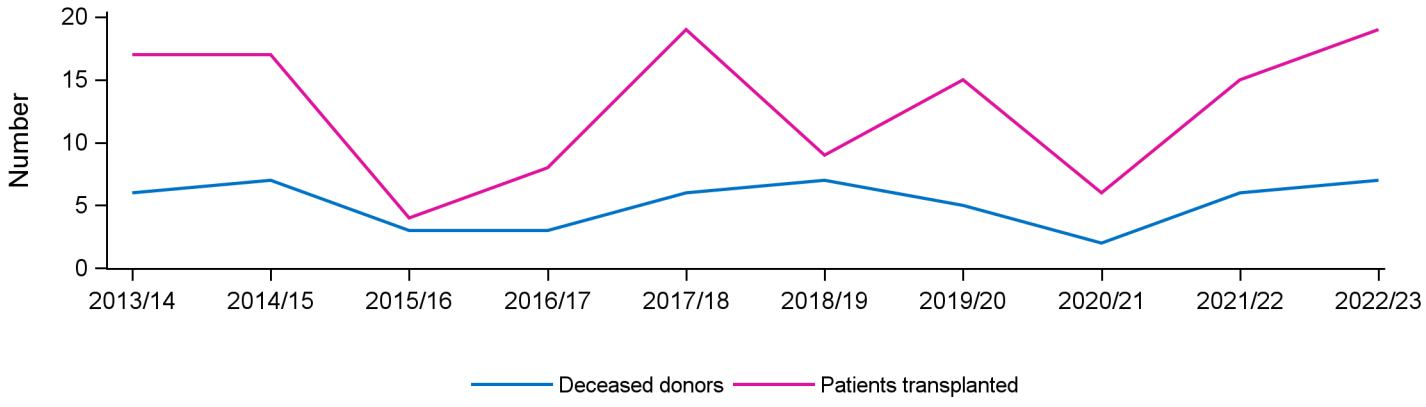
| Donor type | Number of donors | | Number of patients transplanted | | Average number of organs donated per donor: Health Board | | Average number of organs donated per donor: UK | |
|---|---|---|---|---|---|---|---|---|
| DBD | 4 | (6) | 12 | (15) | 3.5 | (3.0) | 3.5 | (3.4) |
| DCD | 3 | (0) | 7 | (0) | 3.0 | (-) | 2.9 | (2.7) |
| DBD and DCD | 7 | (6) | 19 | (15) | 3.3 | (3.0) | 3.2 | (3.1) |

In addition to the 7 proceeding donors there were 3 additional consented donors that did not proceed, one where DBD organ donation was being facilitated and 2 where DCD organ donation was being facilitated.

**Table 1.2 Organs transplanted by type, 1 April 2022 - 31 March 2023 (1 April 2021 - 31 March 2022 for comparison)**

| Donor type | Number of organs transplanted by type: Kidney | | Pancreas | | Liver | | Heart | | Lung | | Small bowel | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| DBD | 8 | (9) | 1 | (1) | 4 | (5) | 0 | (1) | 0 | (0) | 0 | (0) |
| DCD | 5 | (0) | 0 | (0) | 2 | (0) | 0 | (0) | 0 | (0) | 0 | (0) |
| DBD and DCD | 13 | (9) | 1 | (1) | 6 | (5) | 0 | (1) | 0 | (0) | 0 | (0) |

**Figure 1.1 Number of donors and patients transplanted, 1 April 2013 - 31 March 2023**



# 2. Key Numbers in Potential for Organ Donation

## A summary of the key numbers on the potential for organ donation

## Data in this section is obtained from the National Potential Donor Audit (PDA)

This section presents key numbers in potential donation activity for Hywel Dda University Health Board. This data is presented in Table 2.1 along with UK comparison data. Your Health Board has been categorised as a level 3 Health Board and therefore percentages in this section are only presented on a national level. A comparison between different level Health Boards is available in the Additional Data and Figures section.

It is acknowledged that the PDA does not capture all activity. There may be some patients referred in 2021/22 who are not included in this section onwards because they were either over 80 years of age or did not die in a unit participating in the PDA.

**Table 2.1 Key numbers comparison with national rates, 1 April 2022 - 31 March 2023**

| | DBD | | DCD | | Deceased donors | |
|---|---|---|---|---|---|---|
| | H. Board | UK | H. Board | UK | H. Board | UK |
| Patients meeting organ donation referral criteria[1] | 8 | 1980 | 21 | 5307 | 29 | 6910 |
| Referred to Organ Donation Service | 8 | 1965 | 21 | 4886 | 29 | 6482 |
| *Referral rate %* | | *99%* | | *92%* | | *94%* |
| Neurological death tested | 7 | 1556 | | | | |
| *Testing rate %* | | *79%* | | | | |
| Eligible donors[2] | 6 | 1439 | 12 | 3467 | 18 | 4906 |
| Family approached | 6 | 1244 | 7 | 1691 | 13 | 2935 |
| Family approached and SNOD present | 6 | 1190 | 7 | 1526 | 13 | 2716 |
| *% of approaches where SNOD present* | | *96%* | | *90%* | | *93%* |
| Consent ascertained | 5 | 846 | 5 | 959 | 10 | 1805 |
| *Consent rate %* | | *68%* | | *57%* | | *61%* |
| - Expressed opt in | 5 | 476 | 4 | 578 | 9 | 1054 |
| *- Expressed opt in %* | | *95%* | | *84%* | | *89%* |
| - Deemed Consent | 0 | 284 | 1 | 306 | 1 | 590 |
| *- Deemed Consent %* | | *63%* | | *52%* | | *57%* |
| - Other* | 0 | 86 | 0 | 74 | 0 | 160 |
| *- Other* %* | | *60%* | | *38%* | | *47%* |
| Actual donors (PDA data) | 4 | 783 | 3 | 636 | 7 | 1419 |
| *% of consented donors that became actual donors* | | *93%* | | *66%* | | *79%* |

[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

* Includes patients where nation specific deemed criteria are not met and the patient has not expressed a donation decision in accordance with relevant legislation

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

# 3. Best quality of care in organ donation

## Key stages in best quality of care in organ donation

## Data in this section is obtained from the National Potential Donor Audit (PDA)

This section provides information on the quality of care in your Health Board at the key stages of organ donation. The ambition is that your Health Board misses no opportunity to make a transplant happen and that opportunities are maximised at every stage.

### 3.1 Neurological death testing

**Goal: neurological death tests are performed wherever possible.**

**Figure 3.1 Number of patients with suspected neurological death, 1 April 2018 - 31 March 2023**

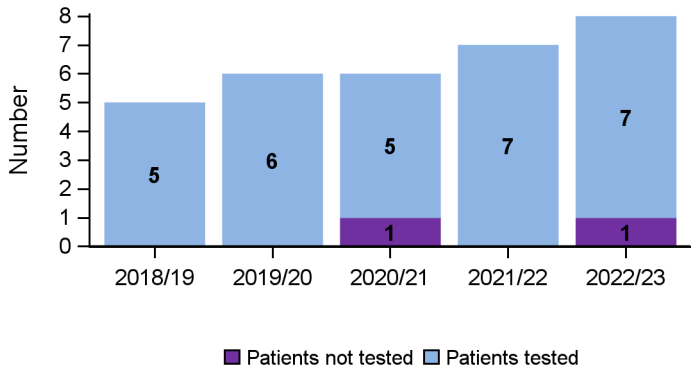



**Table 3.1 Reasons given for neurological death tests not being performed, 1 April 2022 - 31 March 2023**

| | Health Board | UK |
|---|---|---|
| Biochemical/endocrine abnormality | - | 29 |
| Clinical reason/Clinician's decision | - | 62 |
| Continuing effects of sedatives | - | 6 |
| Family declined donation | - | 28 |
| Family pressure not to test | - | 48 |
| Inability to test all reflexes | - | 20 |
| Medical contraindication to donation | - | 5 |
| Other | - | 43 |
| Patient had previously expressed a wish not to donate | - | 2 |
| Patient haemodynamically unstable | 1 | 151 |
| Pressure of ICU beds | - | 1 |
| SN-OD advised that donor not suitable | - | 8 |
| Treatment withdrawn | - | 18 |
| Unknown | - | 3 |
| **Total** | **1** | **424** |

If 'other', please contact your local SNOD or CLOD for more information, if required.

### 3.2 Referral to Organ Donation Service

**Goal: Every patient who meets the referral criteria should be identified and referred to the Organ Donation Service, as per NICE CG135[1] and NHS Blood and Transplant (NHSBT) Best Practice Guidance on timely identification and referral of potential organ donors[2].**

**Aim: There should be no purple on the following charts.**

Note that patients who met the referral criteria for both DBD and DCD donation will appear in both bar charts and both columns of the reasons table.

**Figure 3.2 Number of patients meeting referral criteria, 1 April 2018 - 31 March 2023**

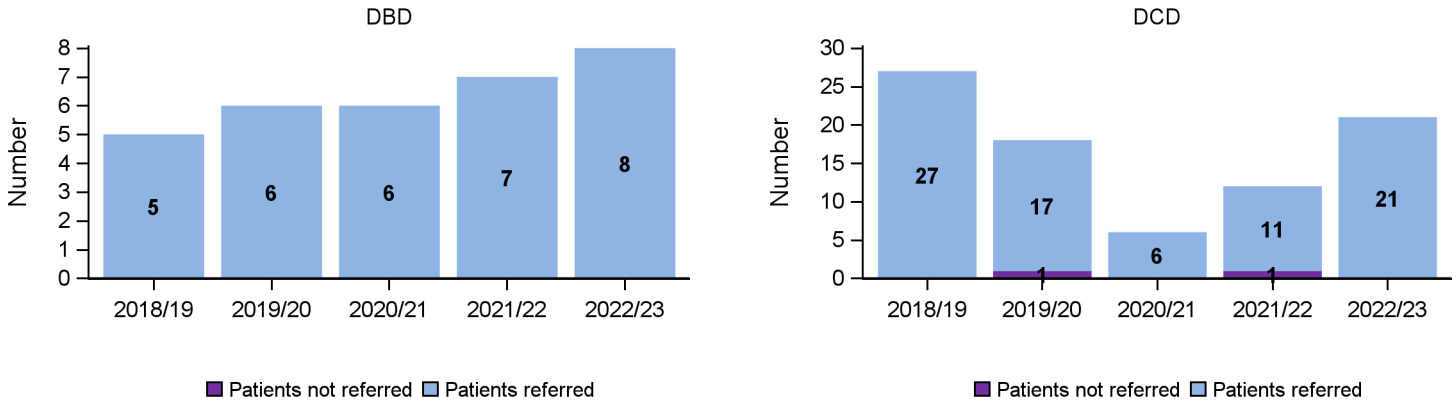



**Table 3.2 Reasons given why patient not referred to SNOD, 1 April 2022 - 31 March 2023**

| | DBD | | DCD | |
|---|---|---|---|---|
| | Health Board | UK | Health Board | UK |
| Clinician assessed that patient was unlikely to become asystolic within 4 hours | - | - | - | 2 |
| Family declined donation following decision to remove treatment | - | 1 | - | 15 |
| Family declined donation prior to neurological testing | - | 1 | - | 1 |
| Medical contraindications | - | - | - | 28 |
| Not identified as potential donor/organ donation not considered | - | 6 | - | 271 |
| Other | - | - | - | 27 |
| Patient had previously expressed a wish not to donate | - | - | - | 3 |
| Pressure on ICU beds | - | - | - | 3 |
| Reluctance to approach family | - | 1 | - | 2 |
| Thought to be medically unsuitable | - | 1 | - | 53 |
| Uncontrolled death pre referral trigger | - | 5 | - | 16 |
| **Total** | **-** | **15** | **-** | **421** |

If 'other', please contact your local SNOD or CLOD for more information, if required.

### 3.3 Contraindications

In 2022/23 there were 3 potential donors in your Health Board with an ACI reported, 1 DBD and 2 DCD donors. Please note, the number of potential DBD and DCD donors with an ACI reported may not equal the total stated as a patient can meet potential donor criteria for both DBD and DCD donation.

### 3.4 SNOD presence

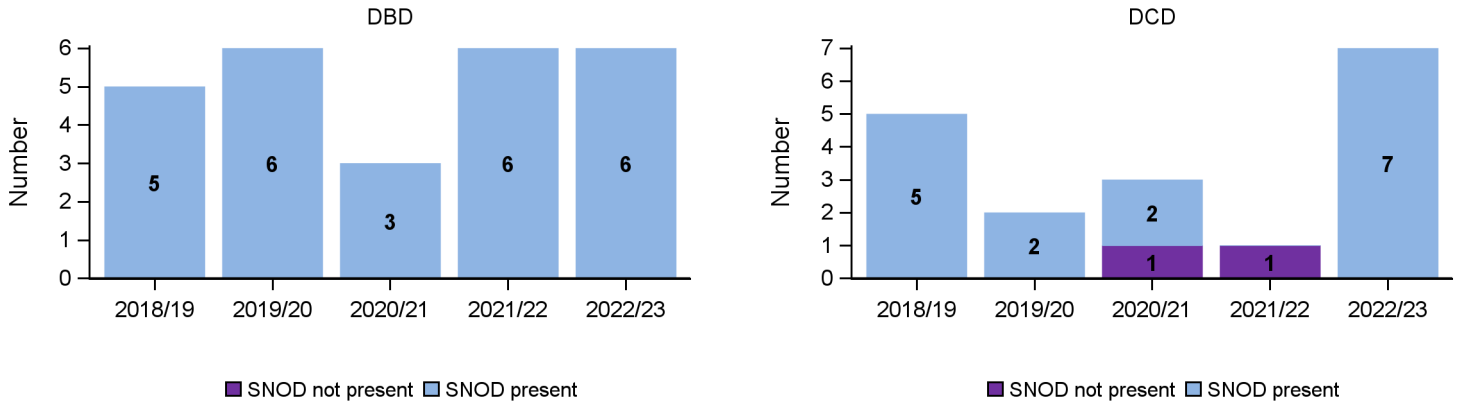
**Goal: A SNOD should be present during the formal family approach as per NICE CG135[1] and NHS Blood and Transplant (NHSBT) Best Practice Guidance.[3]**

**Aim: There should be no purple on the following charts.**

In the UK, in 2022/23, when a SNOD was not present for the approach to the family to discuss organ donation, DBD and DCD consent/authorisation rates were 31% and 19%, respectively, compared with DBD and DCD consent/authorisation rates of 70% and 61%, respectively, when a SNOD was present.

Every approach to those close to the patient should be planned with the multidisciplinary team (MDT), should involve the SNOD and should be clearly planned taking into account the known decision of the patient. The NHS Organ Donor Register (ODR) should be checked in all cases of potential donation and this information must be discussed with the family as it represents the eligible donor's legal consent to donation.

**Figure 3.3 Number of families approached by SNOD presence, 1 April 2018 - 31 March 2023**




[1] NICE, 2011.
*NICE Clinical Guidelines - CG135*
[accessed 9 May 2023]

[2] NHS Blood and Transplant, 2012.
*Timely Identification and Referral of Potential Organ Donors - A Strategy for Implementation of Best Practice*
[accessed 9 May 2023]

[3] NHS Blood and Transplant, 2013.
*Approaching the Families of Potential Organ Donors – Best Practice Guidance*
[accessed 9 May 2023]

### 3.5 Consent

In 2022/23 less than 10 families of eligible donors were approached to discuss organ donation in your Health Board therefore consent rates are not presented.

**Figure 3.4 Number of families approached, 1 April 2018 - 31 March 2023**

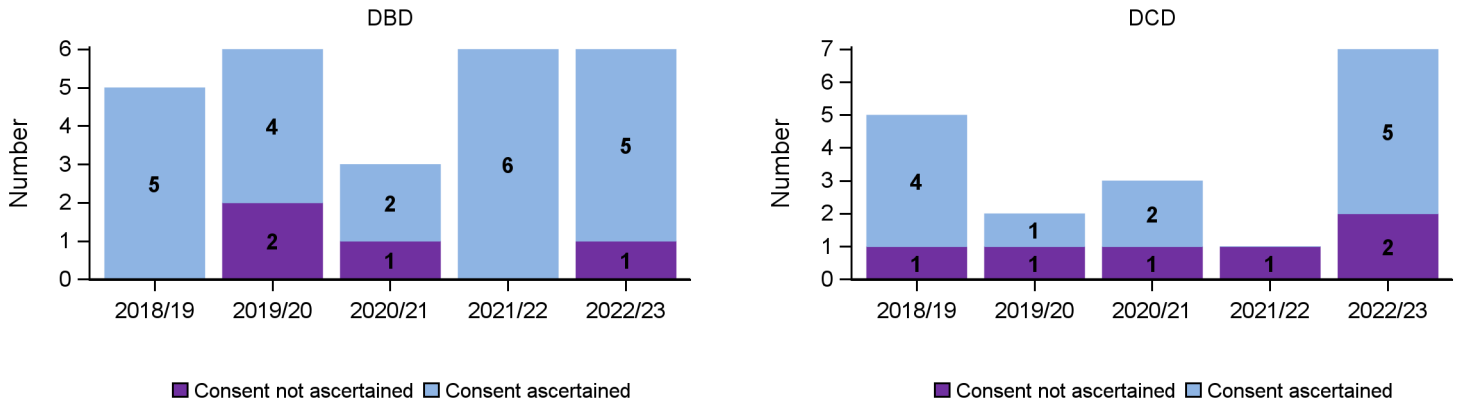



**Table 3.3 Reasons given why consent was not ascertained, 1 April 2022 - 31 March 2023**

| | DBD | | DCD | |
|---|---|---|---|---|
| | Health Board | UK | Health Board | UK |
| Family believe patient's treatment may have been limited to facilitate organ donation | - | 1 | - | - |
| Family concerned donation may delay the funeral | - | 2 | - | 1 |
| Family concerned other people may disapprove/be offended | - | 1 | - | 2 |
| Family concerned that organs may not be transplantable | - | 1 | - | 7 |
| Family did not believe in donation | - | 4 | - | 12 |
| Family did not want surgery to the body | 1 | 38 | - | 51 |
| Family divided over the decision | - | 21 | - | 18 |
| Family felt it was against their religious/cultural beliefs | - | 40 | - | 24 |
| Family felt patient had suffered enough | - | 22 | - | 62 |
| Family felt that the body should be buried whole (unrelated to religious/cultural reasons) | - | 20 | - | 13 |
| Family felt the length of time for the donation process was too long | - | 17 | - | 126 |
| Family had difficulty understanding/accepting neurological testing | - | 3 | - | - |
| Family wanted to stay with the patient after death | - | 2 | - | 16 |
| Family were not sure whether the patient would have agreed to donation | - | 44 | - | 90 |
| Other | - | 22 | - | 73 |
| Patient had previously expressed a wish not to donate | - | 121 | 2 | 175 |
| Patient had registered a decision to Opt Out | - | 22 | - | 31 |
| Strong refusal - probing not appropriate | - | 17 | - | 31 |
| **Total** | **1** | **398** | **2** | **732** |

If 'other', please contact your local SNOD or CLOD for more information, if required.

### 3.6 Solid organ donation

**Goal: NHSBT is committed to supporting transplant units to ensure as many organs as possible are safely transplanted.**

**Table 3.4 Reasons why solid organ donation did not occur, 1 April 2022 - 31 March 2023**

| | DBD | | DCD | |
|---|---|---|---|---|
| | Health Board | UK | Health Board | UK |
| Clinical - Absolute contraindication to organ donation | - | 10 | - | 8 |
| Clinical - Cardiac arrest during referral | - | 2 | - | - |
| Clinical - Considered high risk donor | - | 7 | - | 8 |
| Clinical - DCD clinical exclusion | - | - | - | 1 |
| Clinical - No transplantable organ | - | 6 | - | 12 |
| Clinical - Organs deemed medically unsuitable by recipient centres | - | 10 | 2 | 51 |
| Clinical - Organs deemed medically unsuitable on surgical inspection | 1 | 7 | - | 3 |
| Clinical - Other | - | 3 | - | 10 |
| Clinical - PTA post WLST | - | - | - | 165 |
| Clinical - Patient actively dying | - | 4 | - | 19 |
| Clinical - Patient asystolic | - | 1 | - | - |
| Clinical - Patient's general medical condition | - | 2 | - | 3 |
| Clinical - Positive virology | - | 1 | - | 3 |
| Clinical - Predicted PTA therefore not attended | - | - | - | 3 |
| Consent / Auth - Coroner/Procurator fiscal refusal | - | 5 | - | 10 |
| Consent / Auth - NOK withdraw consent / authorisation | - | 5 | - | 24 |
| Logistical - Other | - | - | - | 3 |
| **Total** | **1** | **63** | **2** | **323** |

If 'other', please contact your local SNOD or CLOD for more information, if required.

# 4. PDA data by hospital and unit

## A summary of key numbers and rates from the PDA by hospital and unit where patient died

## Data in this section is obtained from the National Potential Donor Audit (PDA)

Tables 4.1 and 4.2 show the key numbers and rates for patients who met the DBD and/or DCD referral criteria, respectively. Percentages have been excluded where numbers are less than 10.

**Table 4.1 Patients who met the DBD referral criteria - key numbers and rates, 1 April 2022 - 31 March 2023**

| Unit where patient died | Patients where neurological death was suspected | Patients tested | Neurological death testing rate (%) | Patients referred | DBD referral rate (%) | Patients confirmed dead by neurological testing | Eligible DBD donors | Eligible DBD donors whose family were approached | Approaches where SNOD present | SNOD presence rate (%) | Consent ascertained | Consent rate (%) | Actual DBD and DCD donors from eligible DBD donors |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Aberystwyth, Bronglais Hospital* | | | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 2 | 2 | - | 2 | - | 2 | 1 | 1 | 1 | - | 1 | - | 1 |
| *Carmarthen, Glangwili General Hospital* | | | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 4 | 3 | - | 4 | - | 3 | 3 | 3 | 3 | - | 3 | - | 2 |
| *Haverford West, Withybush General Hospital* | | | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 1 | 1 | - | 1 | - | 1 | 1 | 1 | 1 | - | 0 | - | 0 |
| *Llanelli, Prince Philips Hospital* | | | | | | | | | | | | | |
| General ICU/HDU | 1 | 1 | - | 1 | - | 1 | 1 | 1 | 1 | - | 1 | - | 1 |

**Table 4.2 Patients who met the DCD referral criteria - key numbers and rates, 1 April 2022 - 31 March 2023**

| Unit where patient died | Patients for whom imminent death was anticipated | Patients referred | DCD referral rate (%) | Patients for whom treatment was withdrawn | Eligible DCD donors | Eligible DCD donors whose family were approached | Approaches where SNOD present | SNOD presence rate (%) | Consent ascertained | Consent rate (%) | Actual DCD donors from eligible DCD donors |
|---|---|---|---|---|---|---|---|---|---|---|---|
| *Aberystwyth, Bronglais Hospital* | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 3 | 3 | - | 3 | 1 | 0 | 0 | - | 0 | - | 0 |
| *Carmarthen, Glangwili General Hospital* | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 11 | 11 | 100 | 11 | 6 | 5 | 5 | - | 3 | - | 2 |
| *Haverford West, Withybush General Hospital* | | | | | | | | | | | |
| A & E | 0 | 0 | - | 0 | 0 | 0 | 0 | - | 0 | - | 0 |
| General ICU/HDU | 6 | 6 | - | 5 | 4 | 1 | 1 | - | 1 | - | 1 |
| *Llanelli, Prince Philips Hospital* | | | | | | | | | | | |
| General ICU/HDU | 1 | 1 | - | 1 | 1 | 1 | 1 | - | 1 | - | 0 |

Tables 4.1 and 4.2 show the unit where the patient died. However, it is acknowledged that there are some occasions where a patient is referred in an Emergency Department but moves to a critical care unit. In total for Hywel Dda University Health Board in 2022/23 there were 0 such patients. For more information regarding the Emergency Department please see Section 5.

# 5. Emergency Department data

## A summary of key numbers for Emergency Departments

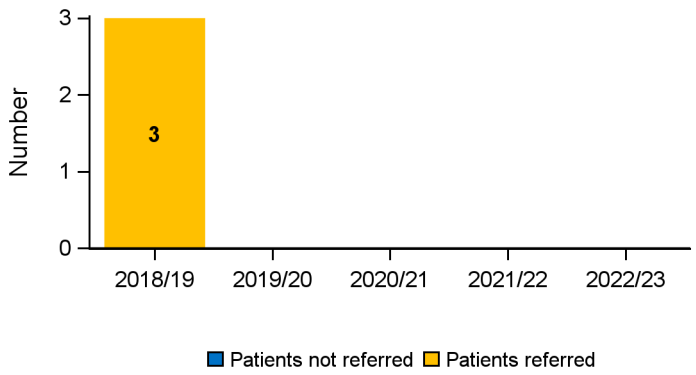
## Data in this section is obtained from the National Potential Donor Audit (PDA)

Most patients who go on to become organ donors start their journey in the emergency department (ED). Deceased donation is important, not just for those people waiting on the transplant list, but also because many people in the UK have expressed a decision in life to become organ donors after their death. The overarching principle of the NHSBT Organ donation and Emergency Department strategy [4] is that best quality of care in organ donation should be followed irrespective of the location of the patient within the hospital at the time of death.

### 5.1 Referral to Organ Donation Service

**Goal: No one dies in your ED meeting referral criteria and is not referred to NHSBT's Organ Donation Service.**
**Aim: There should be no blue on the following chart.**

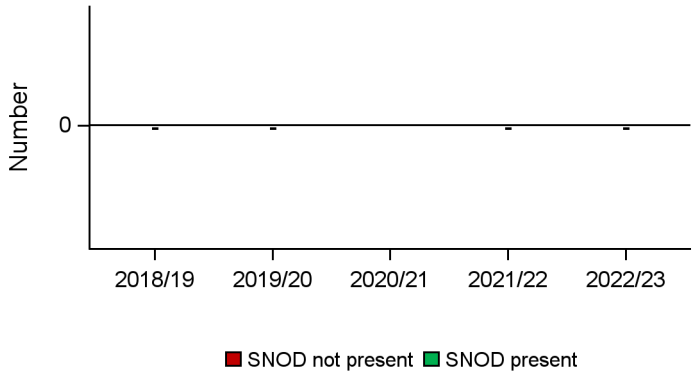
**Figure 5.1 Number of patients meeting referral criteria that died in the ED, 1 April 2018 - 31 March 2023**




### 5.2 Organ donation discussions

**Goal: No family is approached in ED regarding organ donation without a SNOD present.**
**Aim: There should be no red on the following chart.**

**Figure 5.2 Number of families approached in ED by SNOD presence, 1 April 2018 - 31 March 2023**




[4] NHS Blood and Transplant, 2016.
*Organ Donation and the Emergency Department*
[accessed 9 May 2023]

# 6. Additional data and figures

## Regional donor, transplant, and transplant list numbers

## Data in this section is obtained from the UK Transplant Registry

### 6.1 Supplementary Regional data

**Table 6.1 Regional donors, transplants, waiting list, and NHS Organ Donor Register (ODR) data**

| | Wales* | UK |
|---|---|---|
| **1 April 2022 - 31 March 2023** | | |
| Deceased donors | 64 | 1,429 |
| Transplants from deceased donors | 155 | 3,589 |
| Deaths on the transplant list | 25 | 441 |
| **As at 31 March 2023** | | |
| Active transplant list | 243 | 6,959 |
| Number of NHS ODR opt-in registrations (% registered)** | 1,402,291 (45%) | 28,567,574 (44%) |

*Regions have been defined as per former Strategic Health Authorities
** % registered based on population of 3.1 million, based on ONS 2011 census data

## Key numbers and rates on the potential for organ donation

## Data in this section is obtained from the National Potential Donor Audit (PDA)

### 6.2 Trust/Board Level Benchmarking

Hywel Dda University Health Board has been categorised as a level 3 Health Board. Levels were reallocated in July 2018 using the average number of donors in 2016/17 and 2017/18, Table 6.2 shows the criteria used and how many Trusts/Boards belong to each level.

**Table 6.2 Trust/Board level categories**

| | | Number of Trusts Boards in each level |
|---|---|---|
| Level 1 | 12 or more ( ≥ 12) proceeding donors per year | 35 |
| Level 2 | 6 or more but less than 12 ( ≥ 6 to <12) proceeding donors per year | 45 |
| Level 3 | More than 3 but less than 6 (>3 to <6) proceeding donors per year | 47 |
| Level 4 | 3 or less ( ≤ 3) proceeding donors per year | 41 |

Tables 6.3 and 6.4 show the national DBD and DCD key numbers and rates for the UK by Trust/Board level, to aid in comparison with equivalent Trusts/Boards. Note that percentages have been excluded where numbers are less than 10.

**Table 6.3 National DBD key numbers and rate by Trust/Board level, 1 April 2022 - 31 March 2023**

| | Patients where neurological death was suspected | Patients tested | Neurological death testing rate (%) | Patients referred | DBD referral rate (%) | Patients confirmed dead by neurological testing | Eligible DBD donors | Eligible DBD donors whose family were approached | Approaches where SNOD present | SNOD presence rate (%) | Consent ascertained | Consent rate (%) | Actual DBD and DCD donors from eligible DBD donors |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Your Trust | 8 | 7 | - | 8 | - | 7 | 6 | 6 | 6 | - | 5 | - | 4 |
| Level 1 | 1133 | 896 | 79 | 1124 | 99 | 879 | 831 | 714 | 677 | 95 | 474 | 66 | 438 |
| Level 2 | 441 | 340 | 77 | 439 | 100 | 331 | 307 | 267 | 259 | 97 | 182 | 68 | 171 |
| Level 3 | 287 | 229 | 80 | 283 | 99 | 224 | 216 | 188 | 184 | 98 | 135 | 72 | 124 |
| Level 4 | 119 | 91 | 76 | 119 | 100 | 90 | 85 | 75 | 70 | 93 | 55 | 73 | 50 |

**Table 6.4 National DCD key numbers and rate by Trust/Board level, 1 April 2022 - 31 March 2023**

| | Patients for whom imminent death was anticipated | Patients referred | DCD referral rate (%) | Patients for whom treatment was withdrawn | Eligible DCD donors | Eligible DCD donors whose family were approached | Approaches where SNOD present | SNOD presence rate (%) | Consent ascertained | Consent rate (%) | Actual DCD donors from eligible DCD donors |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Your Trust | 21 | 21 | 100 | 20 | 12 | 7 | 7 | - | 5 | - | 3 |
| Level 1 | 2564 | 2370 | 92 | 2464 | 1772 | 941 | 856 | 91 | 537 | 57 | 369 |
| Level 2 | 1346 | 1239 | 92 | 1313 | 841 | 373 | 333 | 89 | 209 | 56 | 132 |
| Level 3 | 979 | 910 | 93 | 944 | 571 | 269 | 241 | 90 | 155 | 58 | 97 |
| Level 4 | 418 | 367 | 88 | 408 | 283 | 108 | 96 | 89 | 58 | 54 | 38 |

# Appendices

## Appendix A.1 Definitions

### Potential Donor Audit Definitions

| | |
|---|---|
| Potential Donor Audit inclusion criteria | 1 October 2009 – 31 March 2010<br>All deaths in critical care in patients aged 75 and under, excluding cardiothoracic intensive care units<br>1 April 2010 – 31 March 2013<br>All deaths in critical and emergency care in patients aged 75 and under, excluding cardiothoracic intensive care units<br>1 April 2013 onwards<br>All deaths in critical and emergency care in patients aged 80 and under (prior to 81st birthday) |

### Donors after brain death (DBD) definitions

| | |
|---|---|
| Suspected Neurological Death | A patient who meets all of the following criteria: invasive ventilation, Glasgow Coma Scale 3 not explained by sedation, no respiratory effort, fixed pupils, no cough or gag reflex. Excluding those not tested due to reasons 'cardiac arrest despite resuscitation', 'brainstem reflexes returned', 'neonates – below 37 weeks corrected gestational age'. Previously referred to as brain death |
| Neurological death tested | Neurological death tests performed to confirm and diagnose death |
| DBD referral criteria | A patient with suspected neurological death |
| Specialist Nurse Organ Donation or Organ Donation Services Team Member (SNOD) | A member of Organ Donation Services Team including: Team Manager, Specialist Nurse Organ Donation, Specialist Requester, Donor Family Care Nurse |
| Referred to Specialist Nurse – Organ Donation | A patient with suspected neurological death referred to a SNOD. A referral is the provision of information to determine organ donation suitability. NICE CG135 (England) : Triggers for clinicians to refer a potential donor are a plan to withdraw life sustaining treatment or a plan to perform neurological death tests |
| Potential DBD donor | A patient with suspected neurological death |
| Absolute contraindications | Absolute medical contraindications identified in assessment which clinically preclude organ donation as per NHSBT criteria (POL188) Absolute medical contraindications to donation are listed here: https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf |
| Eligible DBD donor | A patient confirmed dead by neurological death tests, with no absolute medical contraindications to solid organ donation |
| Donation decision conversation | Family of eligible DBD asked to make or support patient's organ donation decision - This includes clarifying an opt out decision |
| Consent/Authorisation ascertained | Family supported opt in decision, deemed consent/authorisation, or where applicable the family or nominated/appointed representative gave consent/authorisation for organ donation |
| Actual donors: DBD | Patients who became actual DBD donors following confirmation of neurological death, as reported through the PDA (80 years and below). At least one organ donated for the purpose of transplantation (includes organs retrieved for transplant however used for research) |
| Actual donors: DCD | Patients who became actual DCD donors following confirmation of neurological death, as reported through the PDA (80 years and below). At least one organ donated for the purpose of transplantation (includes organs retrieved for transplant however used for research) |
| 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 referred to the SNOD |
| Donation decision conversation rate | Percentage of eligible DBD families or nominated/appointed representatives who were asked to make or support an organ donation decision - This includes clarifying an opt out decision |
| Consent/Authorisation rate | Percentage of donation decision conversations where consent/authorisation was ascertained |
| SNOD presence rate | Percentage of donation decision conversations where a SNOD was present (includes telephone and video call conversations) |
| Consent/Authorisation rate where SNOD was present | Percentage of donation decision conversations where a SNOD was present and consent/authorisation for organ donation was ascertained (as above) |

## Donors after circulatory death (DCD) definitions

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|---|---|
| Imminent death anticipated | A patient, not confirmed dead using neurological criteria, receiving invasive ventilation, in whom a clinical decision to withdraw treatment has been made and a controlled death is anticipated within a time frame to allow donation to occur (as determined at time of assessment) |
| DCD referral criteria | A patient for whom imminent (controlled) death is anticipated following withdrawal of life sustaining treatment (as defined above) |
| Specialist Nurse Organ Donation or Organ Donation Services Team Member (SNOD) | A member of Organ Donation Services Team including: Team Manager, Specialist Nurse Organ Donation, Specialist Requester, Donor Family Care Nurse |
| Referred to SNOD | A patient for whom imminent death is anticipated who was referred to a SNOD. A referral is the provision of information to determine organ donation suitability NICE CG135 (England) : Triggers for clinicians to refer a potential donor are a plan to withdraw life sustaining treatment or a plan to perform neurological death tests |
| Potential DCD donor | A patient who had treatment withdrawn and imminent death was anticipated within a time frame to allow donation to occur. |
| Absolute contraindications | Absolute medical contraindications identified in assessment which clinically preclude organ donation as per NHSBT criteria (POL188). Absolute medical contraindications to donation are listed here: https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf |
| Eligible DCD donor to be assessed | A patient who had treatment withdrawn and imminent (controlled) death was anticipated, with no absolute medical contraindications to solid organ donation. |
| DCD exclusion criteria | DCD specific criteria determine a patient's suitability to donation when there are no absolute medical contraindications (see absolute contraindications documentation above) |
| DCD screening process | Process by which an organ may be screened with a local and national transplant centre to determine suitability of organs for transplantation |
| Medically suitable eligible DCD donor | An eligible DCD donor to be assessed considered to be medically suitable for donation (i.e. no DCD exclusions and not deemed unsuitable by the screening process) |
| Donation decision conversation | Family of medically suitable eligible DCD donor who were asked to make or support patient's organ donation decision - This includes clarifying an opt out decision. |
| Consent/Authorisation ascertained | Family supported opt in decision, deemed consent/authorisation, or where applicable the family or nominated/appointed representative gave consent/authorisation for organ donation |
| Actual DCD | DCD patients who became actual DCD as reported through the PDA (80 years and below). At least one organ donated for the purpose of transplantation (includes organs retrieved for transplant however used for research) |
| Referral rate | Percentage of patients for whom imminent (controlled) death was anticipated who were referred to the SNOD |

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| Donation decision conversation rate | Percentage of medically suitable eligible DCD families or nominated/appointed representatives who were asked to make or support an organ donation decision - This includes clarifying an opt out decision |
| Consent/Authorisation rate | Percentage of donation decision conversations where consent/authorisation was ascertained. |
| SNOD presence rate | Percentage of donation decision conversations where a SNOD was present (includes telephone and video call conversations). |
| Consent/Authorisation rate where SNOD was present | Percentage of donation decision conversations where a SNOD was present and consent/authorisation for organ donation was ascertained (as above). |

### Deemed Consent/Authorisation

Deemed consent applies if a person who died in Wales, Jersey or England has not expressed an organ donation decision either to opt in or opt out or nominate/appoint a representative, is aged 18 or over, has lived in the country in which they died for longer than 12 months and is ordinarily resident there, and had the capacity to understand the notion of deemed consent for a significant period before their death.

Deemed authorisation applies if a person who died in Scotland has not expressed, in writing, an organ donation decision either to opt in or opt out, is aged 16 or over, has lived in Scotland for longer than 12 months and is ordinarily resident there, and had the capacity to understand the notion of deemed authorisation for a significant period before their death. Note that, in Scotland, a patient who has verbally expressed an opt in decision is included as a deemed authorisation, whereas a patient who has verbally expressed an opt out decision is not included.

### Consent/Authorisation groups

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|---|---|
| Expressed opt in | Patient had expressed an opt in decision. Opt in decisions can be expressed in writing or via the ODR in all nations and verbal opt in decisions are also included in Wales, England and Jersey. Verbally expressed opt in decisions are not included in Scotland |
| Deemed consent/authorisation | Patient meets deemed criteria specific to each nation as described above. In Scotland, this includes patients who have verbally expressed a decision to opt in |
| Expressed opt out | Patient had expressed an opt out decision. Opt out decisions can be expressed verbally, in writing or via the ODR in all nations |
| Other | Patient has expressed no decision or deemed criteria are not met. Paediatric patients are included in this group |

### UK Transplant Registry (UKTR) definitions

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|---|---|
| Donor type | Type of donor: Donation after brain death (DBD) or donation after circulatory death (DCD) |
| Number of actual donors | Total number of donors reported to the UKTR |
| Number of patients transplanted | Total number of patients transplanted from these donors |
| Organs per donor | Number of organs donated divided by the number of donors. |
| Number of organs transplanted | Total number of organs transplanted by organ type |

## Appendix A.2 Data Description

This report provides a summary of data relating to potential and actual organ donors as recorded by NHS Blood and Transplant via the Potential Donor Audit (PDA), the accompanying Referral Record, and the UK Transplant Registry (UKTR) for the specified Trust, Board, Organ Donation Services Team, or nation.

This report is provided for information and to facilitate case based discussion about organ donation by the Organ Donation Committee at your Trust/Board.

As part of the PDA, patients over 80 years of age and those who did not die on a critical care unit or emergency department are not audited nationally and are therefore excluded from the majority of this report. Data from neonatal intensive care units (ICU) have also been excluded from this report. In addition, some information may be outstanding due to late reporting and difficulties obtaining patient notes. Donations not captured by the PDA will still be included in the data supplied from the accompanying Referral Record or from the UKTR, as appropriate.

Percentages have not been calculated for level 3 or 4 Trust/Boards and where stated when numbers are less than 10.

## Appendix A.3 Table and Figure Description

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| 1 Donor outcomes | |
| Table 1.1 | The number of actual donors, the resulting number of patients transplanted and the average number of organs donated per donor have been obtained from the UK Transplant Registry (UKTR) for your Trust/Board. Results have been displayed separately for donors after brain death (DBD) and donors after circulatory death (DCD). |
| Table 1.2 | The number of organs transplanted by type from donors at your Trust/Board has been obtained from the UKTR. Further information can be obtained from your local Specialist Nurse – Organ Donation (SNOD), specifically regarding organs that were not transplanted. Results have been displayed separately for DBD and DCD. |
| Figure 1.1 | The number of actual donors and the resulting number of patients transplanted obtained from the UKTR for your Trust/Board for the past 10 equivalent time periods are presented on a line chart. |

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| 2 Key numbers in potential for organ donation | |
| Table 2.1 | A summary of DBD, DCD and deceased donor data and key numbers have been obtained from the PDA. A UK comparison is also provided. Appendix A.1 gives a fuller explanation of terms used. |

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| 3 Best quality of care in organ donation | |
| Figure 3.1 | A stacked bar chart displays the number of patients with suspected neurological death who were tested and the number who were not tested in your Trust/Board for the past five equivalent time periods. |
| Table 3.1 | The reasons given for neurological death tests not being performed in your Trust/Board, have been obtained from the PDA, if applicable. A UK comparison is also provided. |
| Figure 3.2 | Stacked bar charts display the number of DBD and DCD patients meeting referral criteria who were referred to the Organ Donation Service and the number who were not referred in your Trust/Board for the past five equivalent time periods. |
| Table 3.2 | The reasons given for not referring patients to the Organ Donation Service in your Trust/Board, have been obtained from the PDA, if applicable. A UK comparison is also provided. |
| Table 3.3 | The primary absolute medical contraindications to solid organ donation for DBD and DCD patients have been obtained from the PDA, if applicable. A UK comparison is also provided. |
| Figure 3.3 | Stacked bar charts display the number of families of DBD and DCD patients approached where a SNOD was present and the number approached where a SNOD was not present in your Trust/Board for the past five equivalent time periods. |
| Figure 3.4 | Stacked bar charts display the number of families of DBD and DCD patients approached where consent/authorisation for organ donation was ascertained and the number approached where consent/authorisation was not ascertained in your Trust/Board for the past five equivalent time periods. |
| Table 3.4 | The reasons why consent/authorisation was not ascertained for solid organ donation in your Trust/Board, have been obtained from the PDA, if applicable. A UK comparison is also provided. |
| Table 3.5 | The reasons why solid organ donation did not occur in your Trust/Board, have been obtained from the PDA, if applicable. A UK comparison is also provided. |

| 4 PDA data by hospital and unit | |
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| Table 4.1 | DBD key numbers and rates by unit where the patient died have been obtained from the PDA. Percentages have been excluded where numbers are less than 10. |
| Table 4.2 | DCD key numbers and rates by unit where the patient died have been obtained from the PDA. Percentages have been excluded where numbers are less than 10. |

| 5 Emergency department data | |
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| Figure 5.1 | Stacked bar charts display the number of patients that died in the emergency department (ED) who met the referral criteria and were referred to the Organ Donation Service and the number who were not referred in your Trust/Board for the past five equivalent time periods. |
| Figure 5.2 | Stacked bar charts display the number of families of patients in ED approached where a SNOD was present and the number approached where a SNOD was not present in your Trust/Board for the past five equivalent time periods. |

| 6 Additional data and figures | |
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| Table 6.1 | A summary of deceased donor, transplant, transplant list and ODR opt-in registration data for your region have been obtained from the UKTR. Your region has been defined as per former Strategic Health Authority. A UK comparison is also provided. |
| Table 6.2 | Trust/board level categories and the relevant expected number of proceeding donors per year are provided for information. |
| Table 6.3 | National DBD key numbers and rates for level 1, 2, 3 and 4 Trusts/Boards are displayed alongside your local data to aid comparison with equivalent Trusts/Boards. Percentages have been excluded where numbers are less than 10. |
| Table 6.4 | National DCD key numbers and rates for level 1, 2, 3 and 4 Trusts/Boards are displayed alongside your local data to aid comparison with equivalent Trusts/Boards. Percentages have been excluded where numbers are less than 10. |