



## CYFARFOD BWRDD PRIFYSGOL IECHYD UNIVERSITY HEALTH BOARD MEETING

<b>DYDDIAD Y CYFARFOD: DATE OF MEETING:</b>	26 January 2023
<b>TEITL YR ADRODDIAD: TITLE OF REPORT:</b>	NHSBT (NHS Blood and Transplant) Organ Donation: Review of Actual and Potential Deceased Organ Donation 01/04/2021 – 31/04/2022
<b>CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:</b>	Andrew Carruthers, Director of Operations
<b>SWYDDOG ADRODD: REPORTING OFFICER:</b>	Kathy Rumbelow, Specialist Requester (SR) and Lauren Blunsden, Specialist Nurse for Organ Donation (SNOD)

**Pwrpas yr Adroddiad (dewiswch fel yn addas)**

**Purpose of the Report (select as appropriate)**

Ar Gyfer Penderfyniad/For Decision

### ADRODDIAD SCAA SBAR REPORT

#### Sefyllfa / Situation

This covering report will provide an overview of Hywel Dda University Health Board (HDdUHB) performance against the priorities we set ourselves for 2021/2022 regarding organ donation. A more detailed report is attached, together with an action plan.

The Board is asked to note the performance against these for 2021/2022 and the action plan for 2022/2023.

#### Cefndir / Background

In June 2022, the Welsh Government published 'Donation and Transplantation plan for Wales: 2022-2026', 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 (WTAG) 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 2021/2022 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 DBD (Donation after Brain death) and DCD (Donation after circulatory death) with Specialist Requester (SR) and Specialist Nurse Organ Donation (SNOD) involvement for collaborative approaches.
- Maintain 100% NDT (Neurological Death testing) rate.
- Continue promoting and practicing WLST (Withdrawal of life sustaining treatment) in anaesthetic room for all DCD 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 and Theatre staff.

- SNOD to promote organ donation across all four sites, including using organ donation week as a secure platform to promote deemed consent and increase ODR (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 HDdUHB.

### Asesiad / Assessment

The annual report, attached, identifies our performance for 2021/2022.

• **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 recommencing and our main aim is to ensure that organ donation teaching is delivered to all appropriate departments.

• **To investigate any missed referrals and explore actions identified are implemented to prevent further occurrences.**

NHSBT have a strong ambition to have no missed referrals. As you can see on page 6 of the detailed report published by NHSBT, HDdUHB have had one missed DCD referral as the patient was thought to be medically unsuitable. An action from this is that the Clinical Lead for Organ Donation (CLOD) was informed, and the staff involved were reminded of the referral criteria.

• **Maintain a 100% referral rate for potential DBD and DCD with Specialist Requester (SR) and Specialist Nurse Organ Donation (SNOD) involvement for collaborative approaches.**

Page 8 of the detailed report shows that HDdUHB had a SR/SN present for all DBD approaches with one incident of a consultant only approach for DCD. When this was investigated, the SN (Specialist Nurse) was enroute to the hospital, yet the consultant was approached prior to their arrival. This has been discussed, with a reminder that the gold standard is that there should be a SR/SN present during the formal family approach as per NICE (National Institute Clinical Excellence) Clinical Guidelines (CG)135 and NHSBT best practice guidelines.

• **Maintain 100% Neurological Death testing (NDT) rate.**

Measures on page 5 of the detailed report show that a 100% neurological death testing rate was maintained in all patients suspected to be neurologically dead.

• **Continue promoting and practicing WLST (Withdrawal of life sustaining treatment) in anaesthetic room for all DCD 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 and Theatre staff.**

All DCD donors in the HDdUHB have undergone WLST in theatres. All staff compliant with the gold standard of practice. No barriers have been identified. We will continue to work closely with theatre colleagues to ensure the success and continuation of this practice.

- **SNOD to promote organ donation across all four sites, including using organ donation week as a secure platform to promote deemed consent and increase ODR registrations.**  
The Health Board now has a new embedded SNOD who has just completed the intense training program. The SNOD works very closely alongside the SR for the Health Board. We are also working very closely alongside Swansea Bay University Health Board for a collaborative working approach with the embedded SNOD there.

- **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.**

SN and SR 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 HDdUHB.**

This is a work in progress as the service continues to develop and improve nationally, following which, local implementation and improving practices will be addressed.

#### 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 2021/2022 and action plan for 2022/2023.

#### **Amcanion: (rhaid cwblhau)**

#### **Objectives: (must be completed)**

Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	N/A
Safon(au) Gofal ac Iechyd: Health and Care Standard(s):	2. Safe Care 3. Effective Care 4. Dignified Care 5. Timely Care
Amcanion Strategol y BIP: UHB Strategic Objectives:	4. The best health and wellbeing for our individuals, families, and communities 2. Working together to be the best we can be 1. Putting people at the heart of everything we do 5. Safe sustainable, accessible, and kind care
Amcanion Cynllunio Planning Objectives	5A_22 NHS Wales Delivery Framework Targets
Amcanion Llesiant BIP: UHB Well-being Objectives: <a href="#">Hyperlink to HDdUHB Well-being Objectives Annual Report 2018-2019</a>	10. Not Applicable

<b>Gwybodaeth Ychwanegol: Further Information:</b>	
Ar sail tystiolaeth: Evidence Base:	Donation and Transplantation plan for Wales: 2022-2026. UK Donation and Transplantation Plan 2030: Meeting the Need Plan.
Rhestr Termau: Glossary of Terms:	CG – Clinical Guidelines CLOD – Clinical Lead for Organ Donation DBD – Donation after Brainstem Death DCD – Donation after Circulatory Death HDdUHB – Hywel Dda University Health Board NICE – National Institute Clinical Excellence NDT – Neurological Death Testing ODR – Organ Donor Register SNOD – Specialist Nurse Organ Donation SR – Specialist Requester WTAG – Wales Transplant Advisory Group
Partion / Pwyllgorau â ymgynhorwyd ymlaen llaw y Cyfarfod Bwrdd Iechyd Prifysgol: Parties / Committees consulted prior to University Health Board:	Organ Donation Committee

<b>Effaith: (rhaid cwblhau) Impact: (must be completed)</b>	
<b>Ariannol / Gwerth am Arian: Financial / Service:</b>	N/A.
<b>Ansawdd / Gofal Claf: Quality / Patient Care:</b>	No implications.
<b>Gweithlu: Workforce:</b>	No impact.
<b>Risg: Risk:</b>	Nil.
<b>Cyfreithiol: Legal:</b>	There are no legal implications contained within the report.
<b>Enw Da: Reputational:</b>	Media interest in view of ongoing organ donation advertising campaigns.
<b>Gyfrinachedd: Privacy:</b>	None identified.
<b>Cydraddoldeb: Equality:</b>	There are no equality and diversity implications contained within the report.

**Detailed Report**  
**Actual and Potential Deceased Organ Donation**  
**1 April 2021 - 31 March 2022**

**Hywel Dda University Health Board**



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## Further Information

- We acknowledge that the data presented includes the period most significantly impacted by COVID-19 and appreciate that the COVID-19 pandemic affected Trusts/Boards differently across the UK.
- 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 is available at <http://www.odt.nhs.uk/statistics-and-reports/potential-donor-audit/>
- 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 2022 based on data meeting PDA criteria reported at 9 May 2022.

# 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 2021 and 31 March 2022, Hywel Dda University Health Board had 6 deceased solid organ donors, resulting in 15 patients receiving a transplant. Additional information is shown in Tables 1.1 and 1.2, along with comparison data for 2020/21. Figure 1.1 shows the number of donors and patients transplanted for the previous ten periods for comparison.

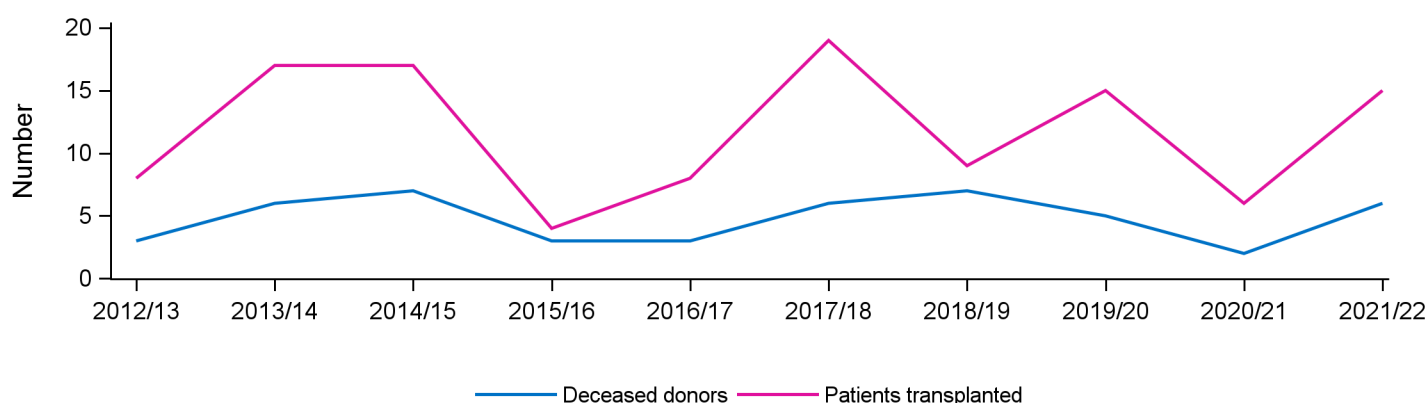
**Table 1.1 Donors, patients transplanted and organs per donor, 1 April 2021 - 31 March 2022 (1 April 2020 - 31 March 2021 for comparison)**

Donor type	Number of donors		Number of patients transplanted		Average number of organs donated per donor	
					Health Board	UK
DBD	6	(2)	15	(6)	3.0 (4.0)	3.5 (3.3)
DCD	0	(0)	0	(0)	- (-)	2.8 (2.6)
DBD and DCD	6	(2)	15	(6)	3.0 (4.0)	3.2 (3.0)

**Table 1.2 Organs transplanted by type, 1 April 2021 - 31 March 2022 (1 April 2020 - 31 March 2021 for comparison)**

Donor type	Number of organs transplanted by type									
	Kidney		Pancreas		Liver		Heart		Lung	
DBD	9	(3)	1	(0)	5	(2)	1	(0)	0	(0)
DCD	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)
DBD and DCD	9	(3)	1	(0)	5	(2)	1	(0)	0	(0)

**Figure 1.1 Number of donors and patients transplanted, 1 April 2012 - 31 March 2022**



## 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 2021 - 31 March 2022**

	DBD		DCD		Deceased donors	
	H. Board	UK	H. Board	UK	H. Board	UK
Patients meeting organ donation referral criteria <sup>1</sup>	7	1919	12	5198	19	6767
Referred to Organ Donation Service	7	1894	11	4700	18	6258
<i>Referral rate %</i>		99%		90%		92%
Neurological death tested	7	1530				
<i>Testing rate %</i>		80%				
Eligible donors <sup>2</sup>	6	1373	6	2972	12	4345
Family approached	6	1239	1	1445	7	2684
Family approached and SNOD present	6	1188	0	1306	6	2494
<i>% of approaches where SNOD present</i>		96%		90%		93%
Consent ascertained	6	861	0	902	6	1763
<i>Consent rate %</i>		69%		62%		66%
- Expressed opt in	5	522	0	550	5	1072
<i>- Expressed opt in %</i>		95%		90%		92%
- Deemed Consent	1	260	0	267	1	527
<i>- Deemed Consent %</i>		63%		56%		59%
- Other*	0	78	0	83	0	161
<i>- Other* %</i>		66%		47%		55%
Actual donors (PDA data)	6	787	0	602	6	1389
<i>% of consented donors that became actual donors</i>		91%		67%		79%

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

DCD - A patient in whom imminent death is anticipated, ie a patient receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within 4 hours

<sup>2</sup> DBD - Death confirmed by neurological tests and no absolute contraindications to solid organ donation

DCD - Imminent death anticipated and treatment withdrawn with no absolute contraindications to solid organ donation

\* 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 2017 - 31 March 2022

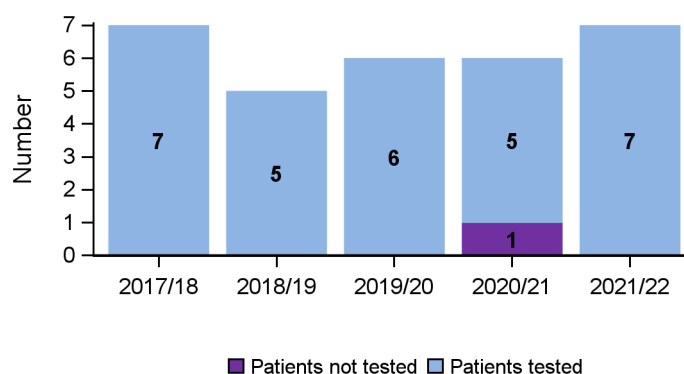


Table 3.1 Reasons given for neurological death tests not being performed, 1 April 2021 - 31 March 2022

	Health Board	UK
Biochemical/endocrine abnormality	-	21
Clinical reason/Clinician's decision	-	48
Continuing effects of sedatives	-	10
Family declined donation	-	20
Family pressure not to test	-	27
Hypothermia	-	2
Inability to test all reflexes	-	17
Medical contraindication to donation	-	7
Other	-	37
Patient had previously expressed a wish not to donate	-	1
Patient haemodynamically unstable	-	162
Pressure of ICU beds	-	8
SN-OD advised that donor not suitable	-	10
Treatment withdrawn	-	14
Unknown	-	5
<b>Total</b>	<b>-</b>	<b>389</b>

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

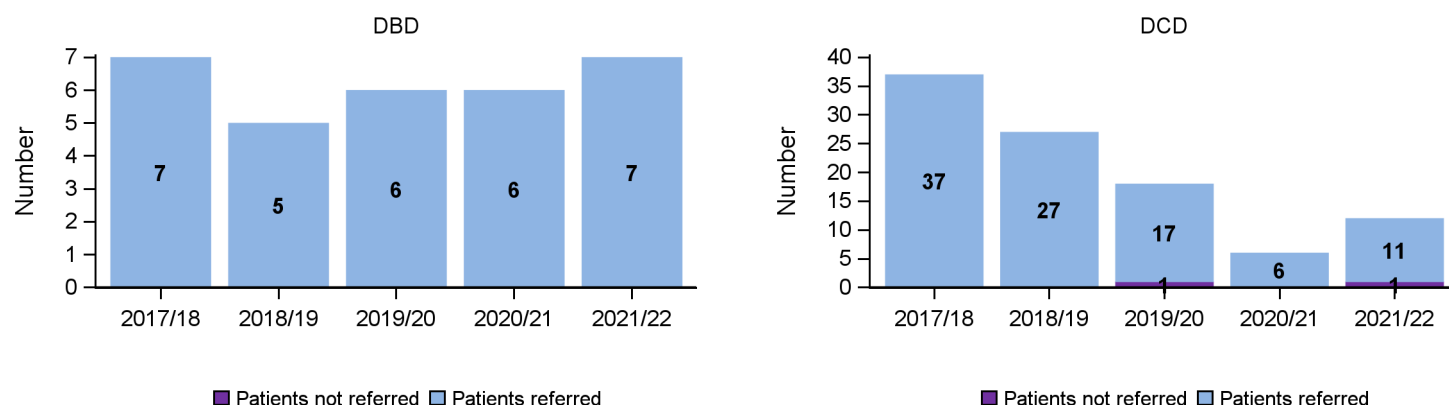
### 3.2 Referral to Organ Donation Service

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

**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 2017 - 31 March 2022**



**Table 3.2 Reasons given why patient not referred to SNOD, 1 April 2021 - 31 March 2022**

	DBD		DCD	
	Health Board	UK	Health Board	UK
Clinician assessed that patient was unlikely to become asystolic within 4 hours	-	-	-	2
Coroner / Procurator Fiscal reason	-	-	-	1
Family declined donation after neurological testing	-	2	-	-
Family declined donation following decision to remove treatment	-	-	-	7
Family declined donation prior to neurological testing	-	1	-	1
Medical contraindications	-	3	-	78
Not identified as potential donor/organ donation not considered	-	12	-	275
Other	-	1	-	51
Patient had previously expressed a wish not to donate	-	1	-	-
Pressure on ICU beds	-	-	-	5
Reluctance to approach family	-	-	-	4
Thought to be medically unsuitable	-	2	1	65
Uncontrolled death pre referral trigger	-	3	-	9
<b>Total</b>	-	<b>25</b>	<b>1</b>	<b>498</b>

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

### 3.3 Contraindications

In 2021/22 there were 3 potential donors in your Health Board with an ACI reported, 0 DBD and 3 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

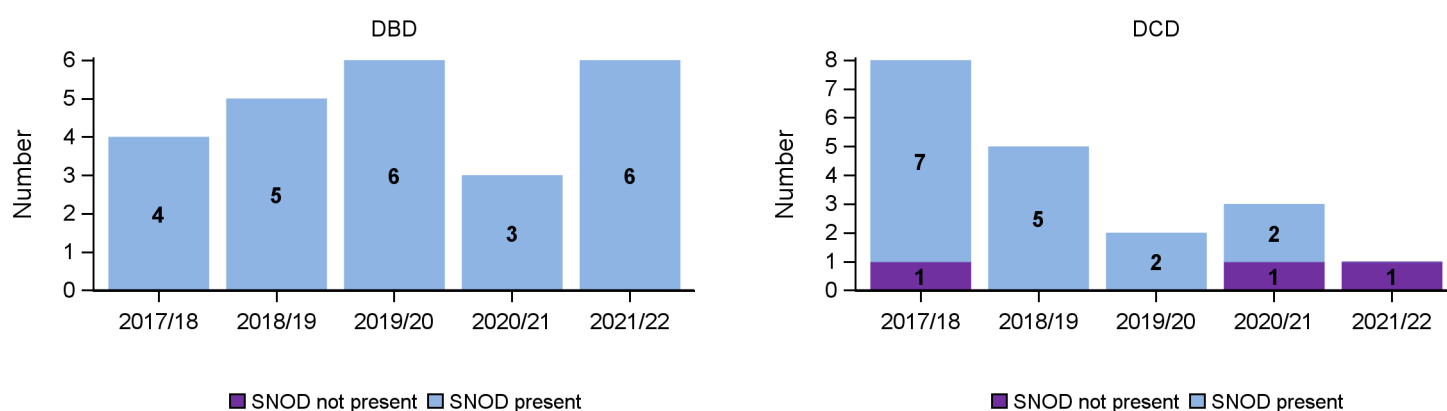
**Goal: A SNOD should be present during the formal family approach as per NICE CG135<sup>1</sup> and NHS Blood and Transplant (NHSBT) Best Practice Guidance.<sup>3</sup>**

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

In the UK, in 2021/22, when a SNOD was not present for the approach to the family to discuss organ donation, DBD and DCD consent/authorisation rates were 35% and 19%, respectively, compared with DBD and DCD consent/authorisation rates of 71% and 67%, 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 wishes 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 2017 - 31 March 2022**



<sup>1</sup> NICE, 2011.  
*NICE Clinical Guidelines - CG135*  
[accessed 9 May 2022]

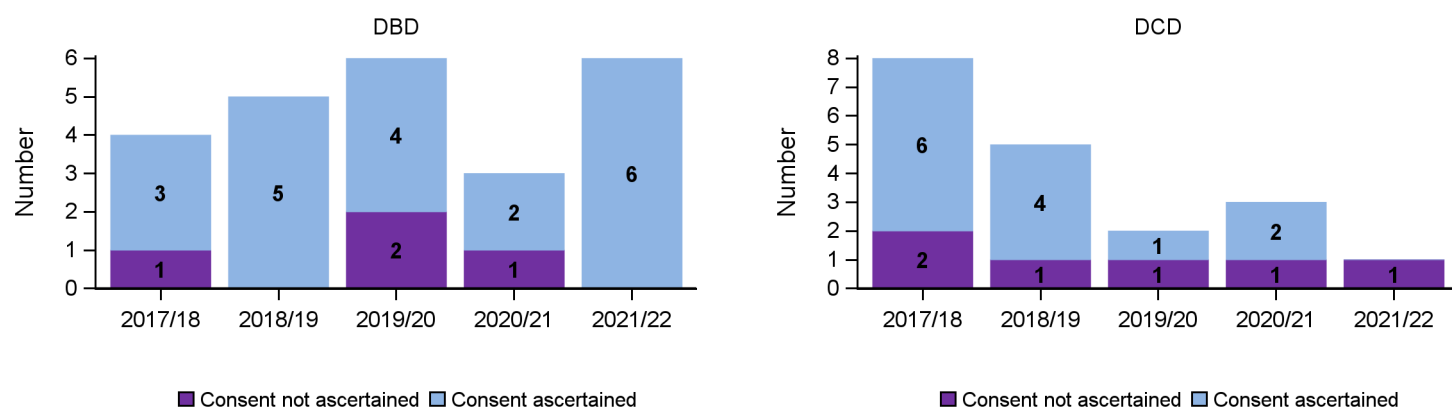
<sup>2</sup> NHS Blood and Transplant, 2012.  
*Timely Identification and Referral of Potential Organ Donors - A Strategy for Implementation of Best Practice*  
[accessed 9 May 2022]

<sup>3</sup> NHS Blood and Transplant, 2013.  
*Approaching the Families of Potential Organ Donors – Best Practice Guidance*  
[accessed 9 May 2022]

### 3.5 Consent

In 2021/22 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 2017 - 31 March 2022**



**Table 3.3 Reasons given why consent was not ascertained, 1 April 2021 - 31 March 2022**

	DBD		DCD	
	Health Board	UK	Health Board	UK
Family concerned donation may delay the funeral	-	-	-	2
Family concerned other people may disapprove/be offended	-	3	-	1
Family concerned that organs may not be transplantable	-	1	-	4
Family did not believe in donation	-	10	-	13
Family did not want surgery to the body	-	35	-	46
Family divided over the decision	-	13	-	11
Family felt it was against their religious/cultural beliefs	-	39	-	24
Family felt patient had suffered enough	-	26	-	42
Family felt that the body should be buried whole (unrelated to religious/cultural reasons)	-	16	-	9
Family felt the length of time for the donation process was too long	-	15	-	85
Family had difficulty understanding/accepting neurological testing	-	2	-	-
Family wanted to stay with the patient after death	-	2	-	5
Family were not sure whether the patient would have agreed to donation	-	35	-	64
Other	-	20	-	45
Patient had previously expressed a wish not to donate	-	125	-	148
Patient had registered a decision to Opt Out	-	23	1	20
Strong refusal - probing not appropriate	-	13	-	23
<b>Total</b>	-	<b>378</b>	<b>1</b>	<b>542</b>

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 2021 - 31 March 2022**

	DBD		DCD	
	Health Board	UK	Health Board	UK
Clinical - Absolute contraindication to organ donation	-	4	-	6
Clinical - Considered high risk donor	-	3	-	5
Clinical - No transplantable organ	-	5	-	21
Clinical - Organs deemed medically unsuitable by recipient centres	-	25	-	70
Clinical - Organs deemed medically unsuitable on surgical inspection	-	8	-	4
Clinical - Other	-	3	-	10
Clinical - PTA post WLST	-	-	-	135
Clinical - Patient actively dying	-	6	-	14
Clinical - Patient's general medical condition	-	-	-	6
Clinical - Positive virology	-	3	-	5
Consent / Auth - Coroner/Procurator fiscal refusal	-	11	-	11
Consent / Auth - Known wish not to donate	-	1	-	1
Consent / Auth - NOK withdraw consent / authorisation	-	5	-	8
Consent / Auth - Other	-	-	-	2
Logistical - No critical care bed available	-	-	-	1
Logistical - Other	-	-	-	1
<b>Total</b>	-	<b>74</b>	-	<b>300</b>

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 2021 - 31 March 2022**

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
<i>Aberystwyth, Bronglais Hospital</i>													
A & E	0	0	-	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	0	0	-	0	-	0	0	0	0	-	0	-	0
<i>Carmarthen, Glangwili General Hospital</i>													
A & E	0	0	-	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	3	3	-	3	-	2	2	2	2	-	2	-	2
<i>Haverford West, Withybush General Hospital</i>													
A & E	0	0	-	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	4	4	-	4	-	4	4	4	4	-	4	-	4
<i>Llanelli, Prince Philips Hospital</i>													
General ICU/HDU	0	0	-	0	-	0	0	0	0	-	0	-	0

**Table 4.2 Patients who met the DCD referral criteria - key numbers and rates, 1 April 2021 - 31 March 2022**

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
<i>Aberystwyth, Bronglais Hospital</i>											
A & E	0	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	3	3	-	3	1	0	0	-	0	-	0
<i>Carmarthen, Glangwili General Hospital</i>											
A & E	0	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	6	6	-	6	4	1	0	-	0	-	0
<i>Haverford West, Withybush General Hospital</i>											
A & E	0	0	-	0	0	0	0	-	0	-	0
General ICU/HDU	2	1	-	2	0	0	0	-	0	-	0
<i>Llanelli, Prince Philips Hospital</i>											
General ICU/HDU	1	1	-	1	1	0	0	-	0	-	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 2021/22 there were 1 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

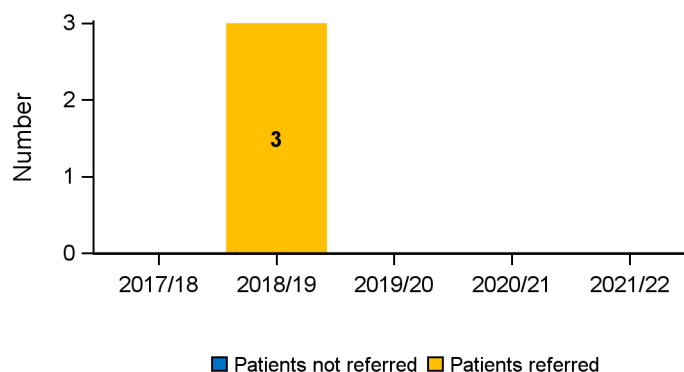
Data in this section is obtained from the National Potential Donor Audit (PDA)

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 wish in life to become organ donors after their death. The overarching principle of the NHSBT Organ donation and Emergency Department strategy 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.

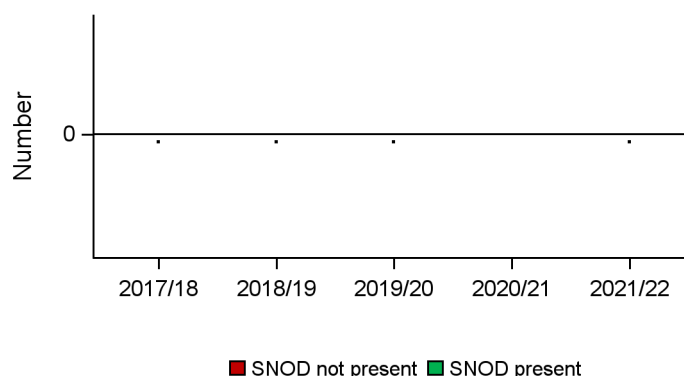
Figure 5.1 Number of patients meeting referral criteria that died in the ED, 1 April 2017 - 31 March 2022



### 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 2017 - 31 March 2022



\* NHS Blood and Transplant, 2016.  
*Organ Donation and the Emergency Department*  
 [accessed 9 May 2022]



# 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
<b>1 April 2021 - 31 March 2022</b>		
Deceased donors	54	1,397
Transplants from deceased donors	129	3,410
Deaths on the transplant list	18	422
<b>As at 31 March 2022</b>		
Active transplant list	226	6,269
Number of NHS ODR opt-in registrations (% registered)**	1,364,620 (44%)	27,751,289 (43%)

\*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 ( $\geq 12$ ) proceeding donors per year	35
Level 2	6 or more but less than 12 ( $\geq 6$ 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 ( $\leq 3$ ) 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 2021 - 31 March 2022**

Your Trust	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	7	7	-	7	-	6	6	6	6	-	6	-	6
Level 1	1044	840	80	1034	99	827	748	679	646	95	470	69	434
Level 2	455	361	79	445	98	355	318	284	274	96	187	66	173
Level 3	286	225	79	282	99	221	208	189	184	97	147	78	128
Level 4	134	104	78	133	99	103	99	87	84	97	57	66	52

**Table 6.4 National DCD key numbers and rate by Trust/Board level,  
1 April 2021 - 31 March 2022**

Your Trust	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	12	11	92	12	6	1	0	-	0	-	0
Level 1	2391	2224	93	2289	1498	818	728	89	513	63	347
Level 2	1451	1261	87	1383	750	335	310	93	197	59	137
Level 3	915	827	90	882	464	184	174	95	130	71	76
Level 4	441	388	88	425	260	108	94	87	62	57	42

# Appendices

## Appendix A.1 Definitions

### Potential Donor Audit Definitions

Potential Donor Audit inclusion criteria	<p>1 October 2009 – 31 March 2010 All deaths in critical care in patients aged 75 and under, excluding cardiothoracic intensive care units</p> <p>1 April 2010 – 31 March 2013 All deaths in critical and emergency care in patients aged 75 and under, excluding cardiothoracic intensive care units</p> <p>1 April 2013 onwards All deaths in critical and emergency care in patients aged 80 and under (prior to 81st birthday)</p>
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### 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: <a href="https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf">https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf</a>
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

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: <a href="https://nhsbt.dbc.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf">https://nhsbt.dbc.blob.core.windows.net/umbraco-assets-corp/17160/clinical-contraindications-to-approaching-families-for-possible-organ-donation-pol188.pdf</a>
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

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

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

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

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.

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.

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	
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	
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	
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.





# **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**

# Donation and Transplantation Plan for Wales: 2022-2026

## 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<sup>1</sup> 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.

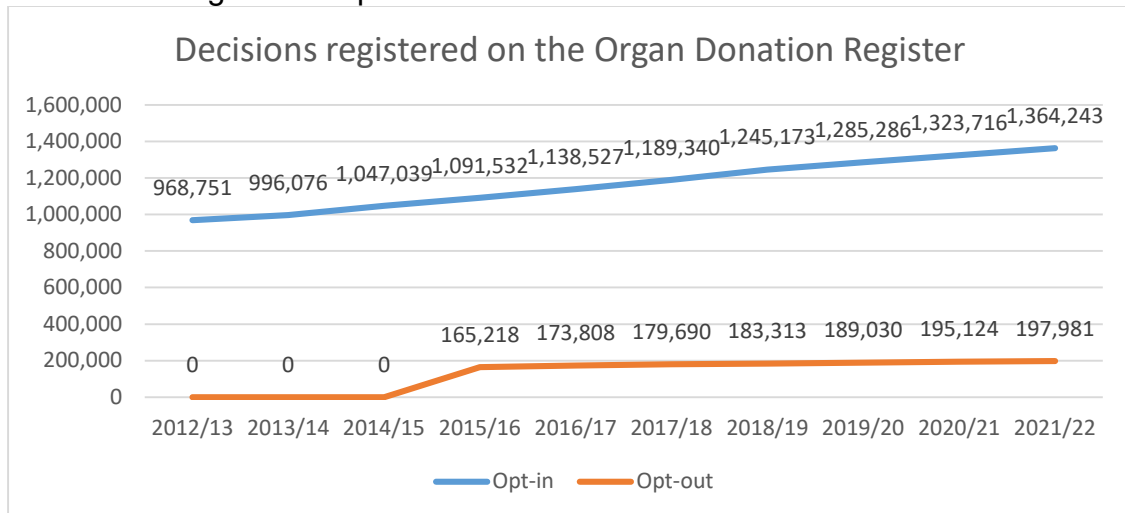
The plan does set out a number of additional Wales specific actions to be taken forward. It will be reviewed and updated, where necessary, on an annual basis. We recognise the valuable contribution and services provided by the third sector and will seek to work with them as we progress implementation. 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.

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<sup>1</sup> <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/>

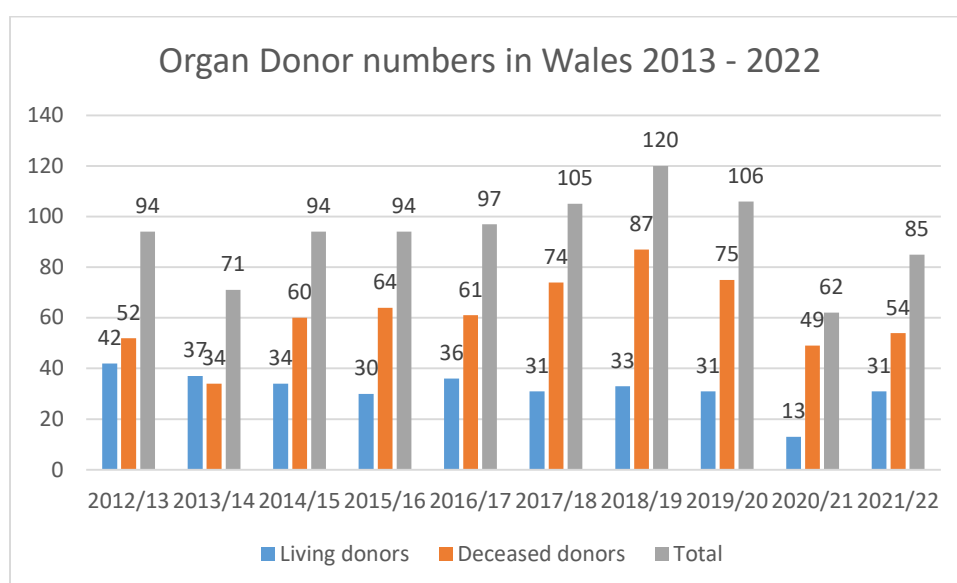
## Current position/progress

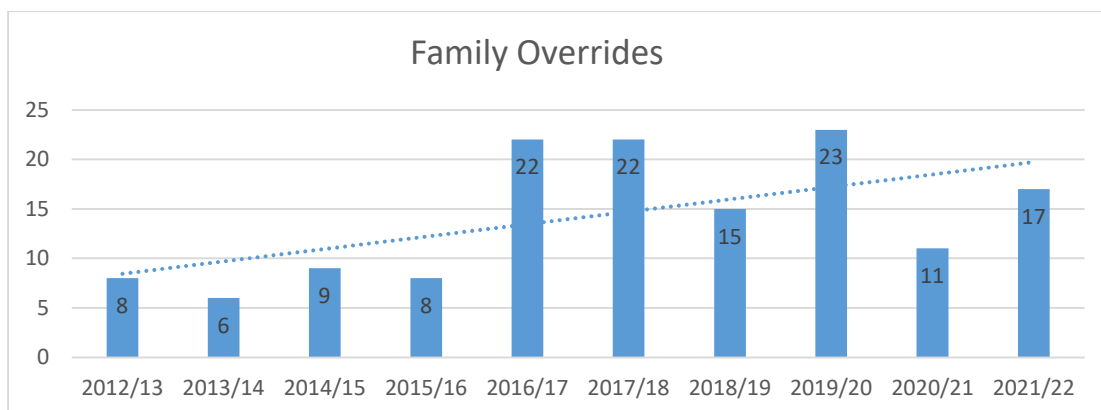
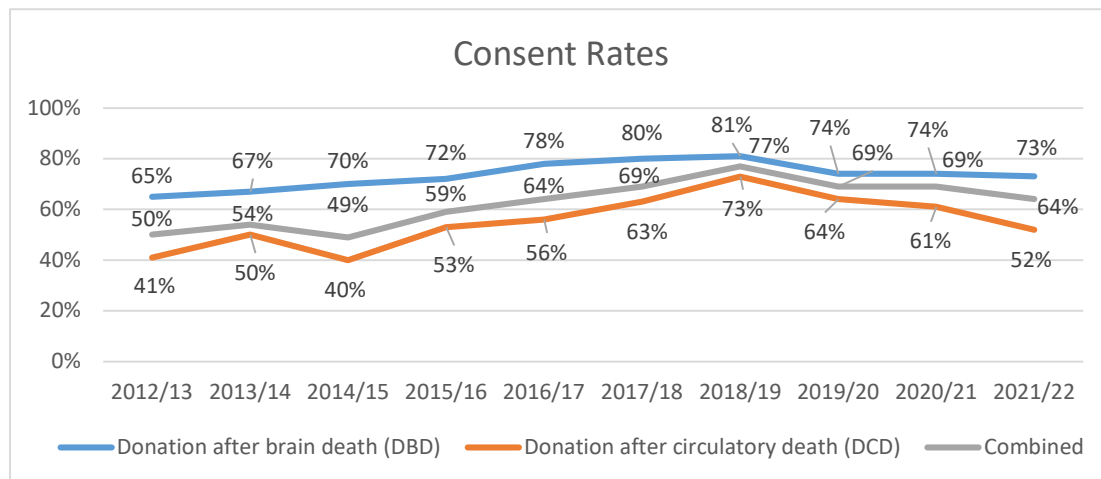
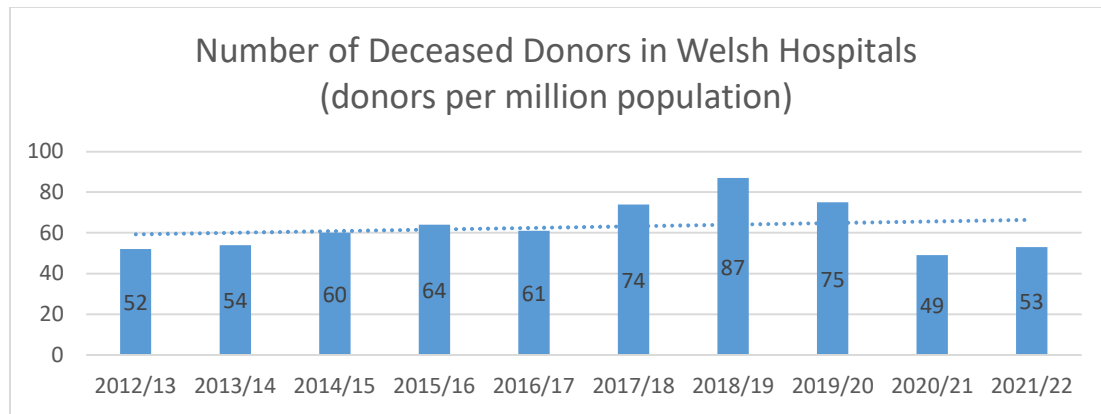
We have continued to see a steady rise in the number of people who have expressed an organ donation decision. Research has shown the majority of the Welsh population are supportive of organ donation but this does not necessarily translate into a willingness to donate. The graph below highlights the number 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.



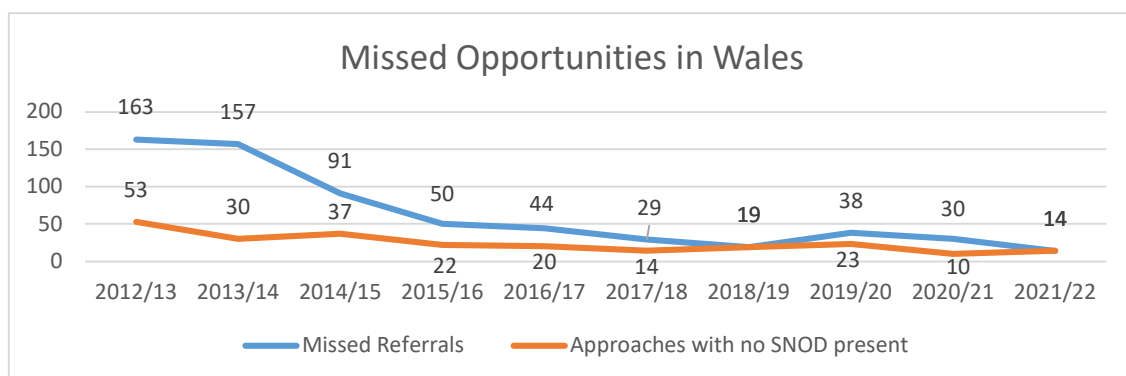
It should be noted that the pandemic, which started in March 2020 had a significant impact on both donation and transplantation as you will see demonstrated in the graphs below.

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.

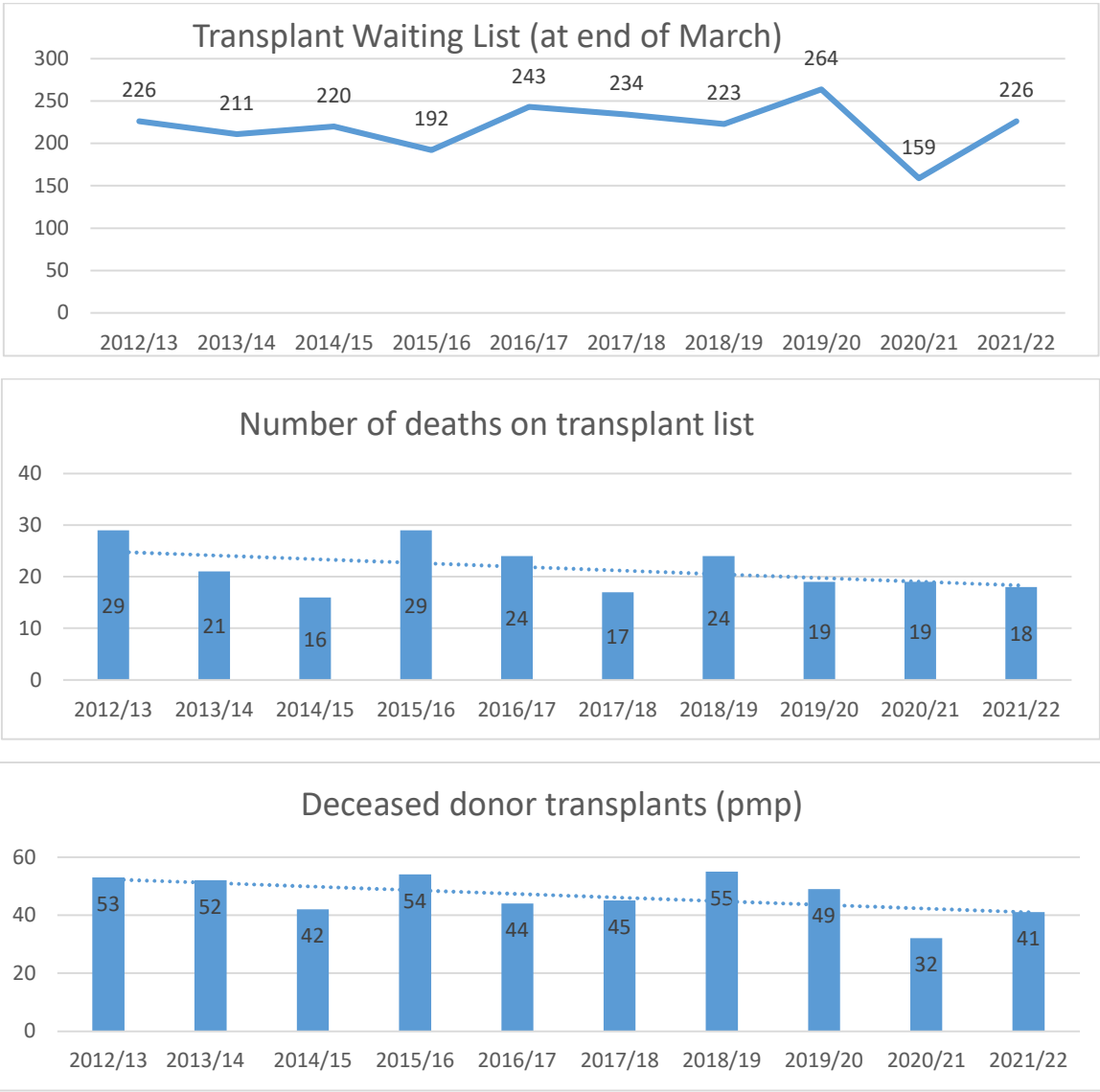




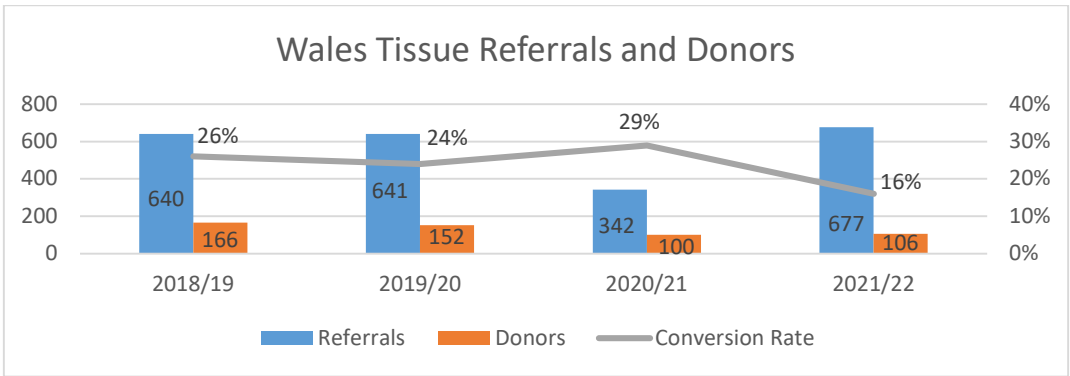
It should be noted that family overrides were calculated differently pre-1 December 2015 (just overrides of an opt in decision), post 2016/17 overrides are expressed decision or deemed consent.



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: <ul style="list-style-type: none"> <li>• any missed opportunity identified</li> <li>• involvement of specialist nurses/requestors and clinical leads</li> <li>• neurological testing is performed in all patients who meet testing criteria, regardless of donor potential</li> </ul>	Ongoing  Health boards/ NHSBT Specialist nurse team/ WTAG
1.2	Public Awareness	Ensure regular public awareness campaigns are undertaken and targeted appropriately	Ongoing  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  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  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  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  Health board Organ Donation Committees/ NHSBT
2.2	Public Awareness	Promote public awareness about the importance of tissue and eye donation	Ongoing  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  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  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  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  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  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  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  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  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  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  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  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  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  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  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  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  Transplant Units/ Commissioners/ DHCW
5.3	Support for patients post-transplant	Provide appropriate psycho-social support for all transplant patients in Wales	Medium Term  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  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  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  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  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  Transplant units/ Health boards/ NHSBT
6.4	Diversity	Utilise cultural diversity within the workforce to help improve public education and engagement	Medium term  Transplant units/ Health boards/ NHSBT