



**UPDATE FROM THE WELSH GOVERNMENT**

**Welsh Transplantation Clinical Reference Group - (Formerly WTAG)  
Background:**

Llywodraeth Cymru  
Welsh Government

The Wales data constitutes of the South Wales Organ Donation Team and 1 Health Board in North Wales, covered by the Northwest Organ Donation Team.

**Activity/performance (April 2024 – June 2024):**

- 8 proceeding deceased donors YTD.
- Consistently high referral rates (98%) and good engagement observed from all units across Wales for deceased donation.
- Consent rates remain a challenge and focus, specifically in the application of deemed legislation and ODR overrides. Combined consent rate for deceased donation is 44% (against a national target 63% and lower when compared to England, Scotland and NI). The consent rate is 67% for DBD but only 23% for DCD YTD.
- The Opt Out legislation has been implemented into Wales for 10 years now and is established, with observed higher opt out rates than other nations. When consent rates are manually adjusted to remove the known opt out registered decisions consent rates are significantly improved. The teams recognise the need for tailored regional promotion, targeting Welsh residents and available in Welsh language.
- SN presence stands out as low in comparison to England, Scotland and NI however Welsh law differs in that families cannot be widely probed about last known decision. In the circumstance of a patient registering an OPT OUT families in Wales are often notified by a consultant unless a SN is available on site, resulting in a lower collaborative approach rate.
- Numbers are small which can cause fluctuations in perceived performance.
- 11 proceeding living donors YTD in South Wales (on course to achieve highest ever number of live donor transplants this year).

**Priorities:**

- Transition to NHS Executive from previous WTAG, first meeting in new structure occurred on 22<sup>nd</sup> May virtually. Future meetings will focus on the delivery of the Welsh Plan 2022-2026 priorities.

<https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/26918/donation-and-transplantation-plan-for-wales-june-2022.pdf>

**Priority 1: Increasing deceased organ donation**

- Consent initiatives: including focus on ODR overrides and deemed decisions.
- Progressing with commissioning an independent marketing company to develop a media campaign and strategy specifically with the intention to improve consent rates.

- Introduction of a Regional Education Clinical Lead Organ Donation (REd CLOD) role/s is underway, with significant opportunity to share practice across Wales and the network.
- A project is in progress to create a bilingual version of the current NHSBT consent form and where possible in situations of Welsh speaking families a Welsh speaking SN is offered.

### **Priority 2: Increasing tissue and eye donation**

- University Hospital Wales is in the process of setting up a funded eye retrieval scheme (ERS) with anticipated commencement Autumn 2024.
- Regional Tissue Donation Nurse Specialist establishing partnerships with hospices.

### **Priority 3: Increasing living donation and transplantation**

- The Wales Transplant Clinical Reference Group (previously the Wales Transplant Advisory Group) has been expanded to include colleagues from the living donation teams from across Wales.
- Living Donor Assessment pathways have been reviewed and streamlined and the trend is towards increased numbers of donors.
- Team have continued to grow the live donor programme year on year due to cross team collaboration and working closely with colleagues in Swansea Bay UHB, who are a referral centre for the programme.
- Challenges are the unpredictable nature of live donor programme and operational capacity constraints.

### **Priority 4: Increasing access to transplantation**

- Working with The Welsh Kidney Network to ensure decisions around transplantation are recorded.
- Pilot of a 'prehab' programme for renal patients in SE with goal of improving fitness and addressing psychosocial barriers to transplantation.

### **Priority 5: Improving transplant outcomes**

- University Hospital Wales National Organ Retrieval Service supports the provision of NRP novel technologies to increase organs available for transplant.
- The transplant centre has a successful Hep C transplant programme with positive outcomes.

### **Priority 6: Ensuring a sustainable, supported and diverse workforce**

- Welsh language and requirement for bilingual resources has been added to the NHSBT Equality Diversity and Inclusion plan.
- Recruitment considerations in promotion and support of Welsh speaking applicants.
- Recent recruitment moves made to stabilise specialist nurse organ donation team.

### **Priorities**

- Public engagement and promotion to raise the profile of organ and tissue donation is essential in view of challenges with consent in Wales, currently

exploring utilising funds for some national media and exploration of a Wales focussed media/communications role.

- Introduction of a Regional Education Clinical Lead Organ Donation (REd CLOD) role/s in underway, with significant opportunity to share practice across Wales and the network.
- Target attentions for areas to influence practice, such as ODR overrides and deemed decisions.
- Donor recognition reimbursement is now held centrally by the SWa and NWe OD teams, this has provided the teams with access to funds to support a number of brilliant initiatives, raise the profile of organ donation and provide exceptional end of life care for patients and support of their families, examples such as bereavement resources, memorial services and promotion to raise awareness.
- UHW is in the process of setting up a funded eye retrieval scheme (ERS) with anticipated commencement Autumn 2024.
- Welsh language and requirement for bilingual resources is to be added to the NHSBT Equality Diversity and Inclusion plan, as is consideration in recruitment.
- A project in progress to create a bilingual version of the current NHSBT consent form and where possible in situations of Welsh speaking families a Welsh speaking SN is offered.
- Regional Collaborative events have taken place with multidisciplinary attendance. These are always really positive opportunities for sharing practice, engagement and networking.
- Order of St John donor recognition events have been held to honour and remember those patients who have given the gift of organ donation.
- South Wales have commenced in a pilot focussing on donor suitability assessment in DCD patients, emphasising the importance of thorough multidisciplinary neurological assessment.

#### **Future events:**

- Rhondda Cynon Taf National Eisteddfod 3<sup>rd</sup> – 10<sup>th</sup> August (approx. 170,000 people attend over 8 days. A promotional hut has been secured and obtained a CTMUHB specific QR code to sign the register to enable audit of the effectiveness of presence at this event) [Our Festival | Eisteddfod](#)
- South Wales and South West Paediatric and Neonatal Organ Donation Study Day 17<sup>th</sup> September Cardiff.
- Snowdon and Pen Y Fan summits on 27<sup>th</sup> September as part of the “Turn the Peaks Pink” an initiative which was born from the North Wales team who have for some years been walking Snowdon in Organ Donation week with donor families.
- Joint Organ Donation Week (University Hospital Wales Transplant team and South Wales Organ Donation team) and Race for Recipients.
- Autumn Regional Collaboratives 13<sup>th</sup> November Swansea.
- Donor memorial events and Order of St John Memorial events

#### **Welsh Blood Service (WBS) Update**

- We have set up an Infected Blood Inquiry: Next Steps for Wales Group, chaired by our new Deputy Chief Medical Officer Dr Push Mangat. It met for the first time on 17 June. It will work with health boards, the Welsh Blood Service, Public Health Wales and WG policy officials to ensure we look at the wrongs of the past and work together to ensure this can never happen again.

- We are in the process of setting up our subgroups to undertake the work as directed in the recommendations.
- We will continue to work with the UK Government and the other devolved administrations to respond to the IBI Report.
- We continue to work with WBS on our Plasma for Medicines Project (awaiting finance clearance).