



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

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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 plan¹ 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.

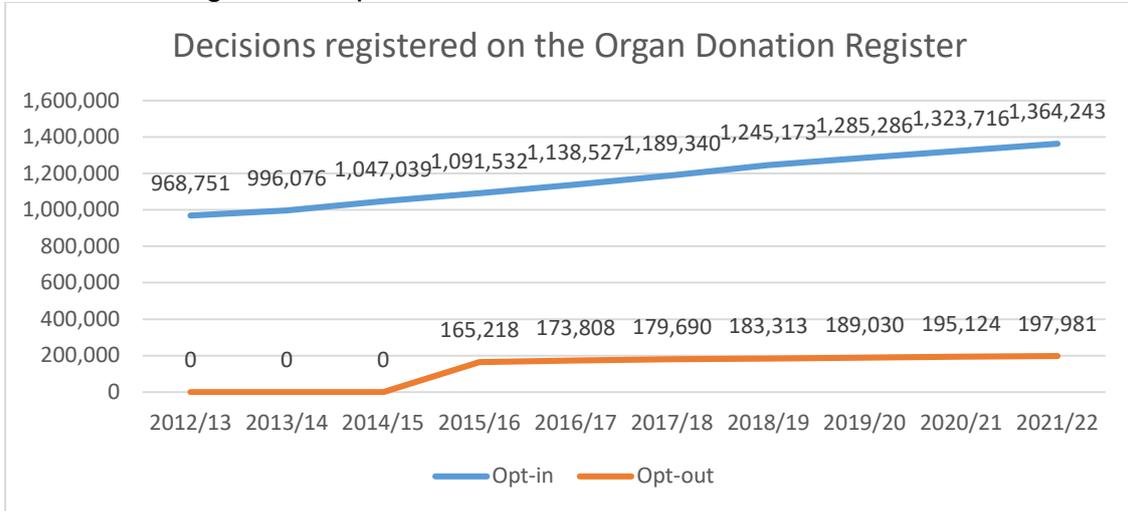
We need to recognise the context in which this plan was developed during the COVID-19 pandemic and the impact this has had on NHS services, the ongoing pressures within the NHS and the necessary changes which have taken place such as video consultations. There is an ongoing need to provide services differently 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/>

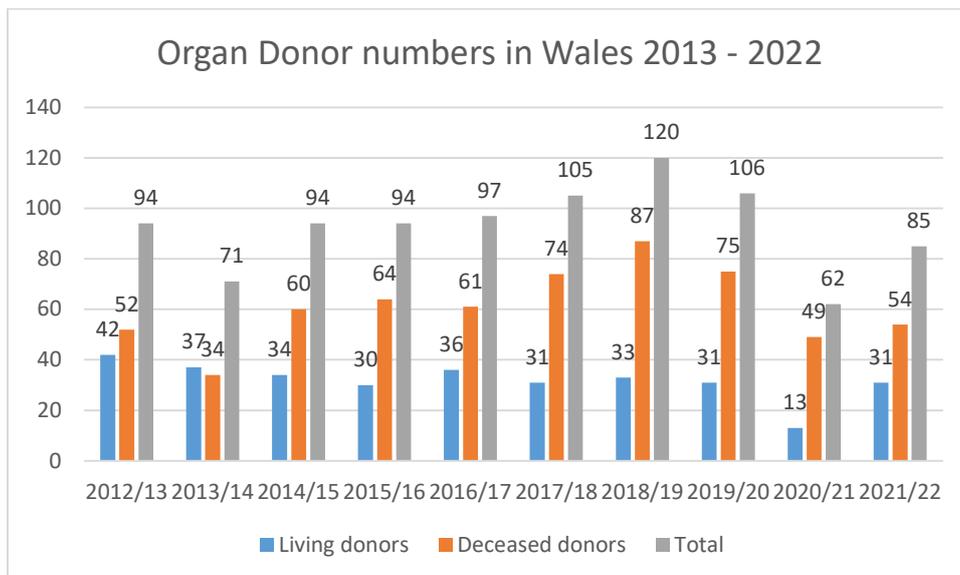
Current position/progress

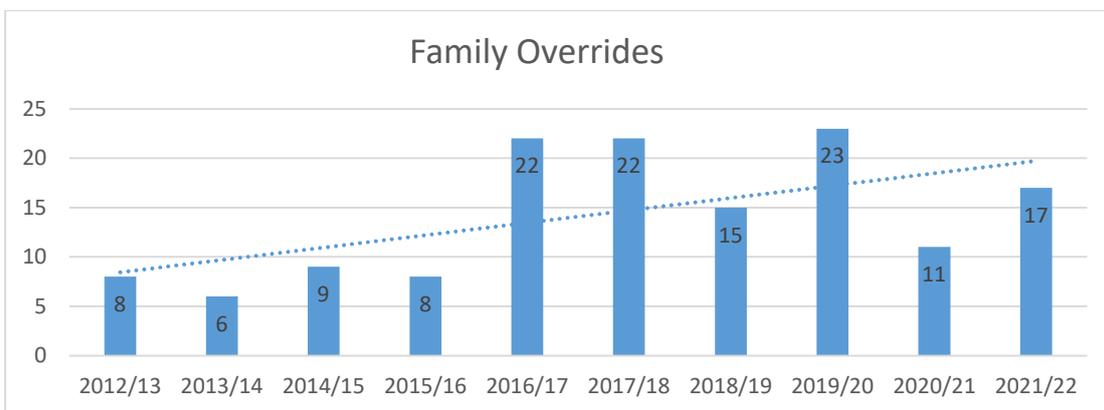
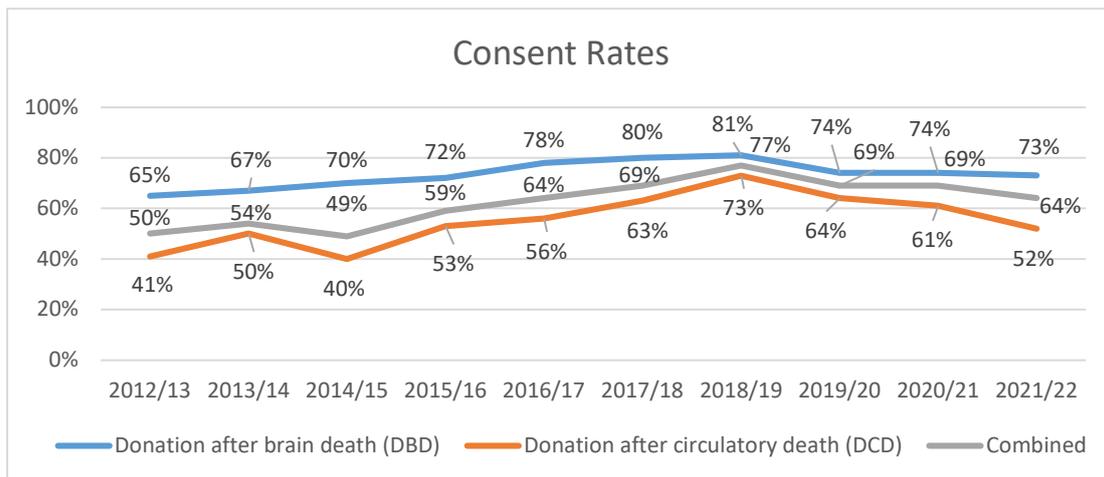
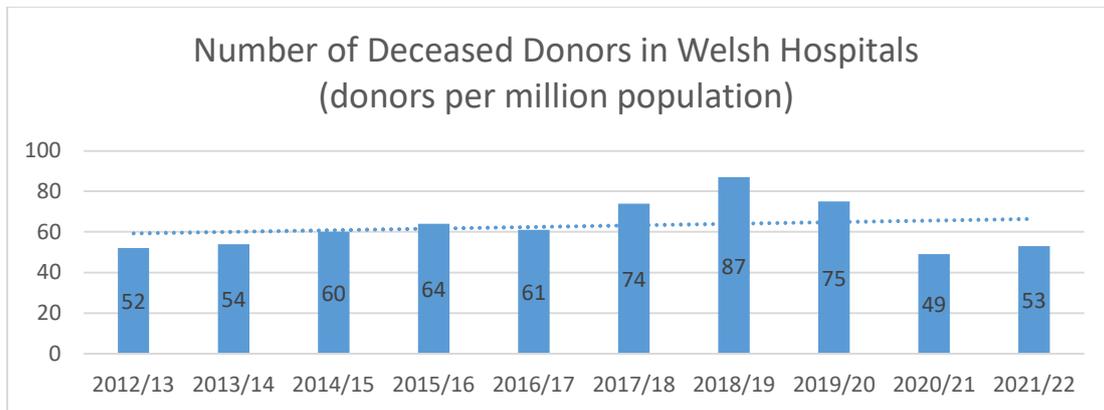
We have continued to see a steady rise in the number of people who have expressed an organ donation decision. Research has shown the majority of the Welsh population are supportive of organ donation but this does not necessarily translate into a willingness to donate. The graph below highlights the number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



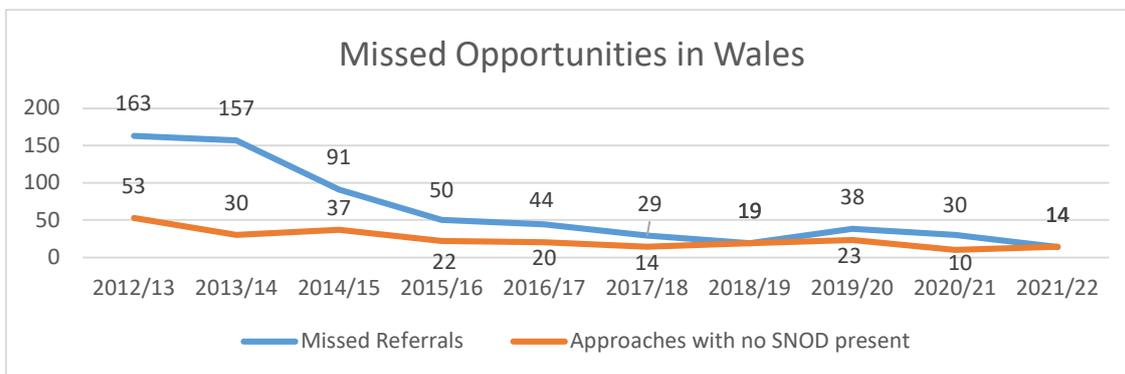
It should be noted that the pandemic, which started in March 2020 had a significant impact on both donation and transplantation as you will see demonstrated in the graphs below.

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.

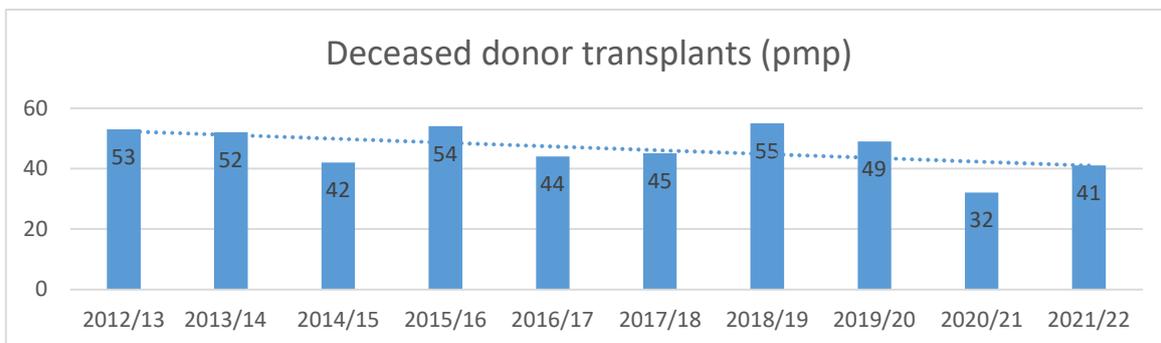
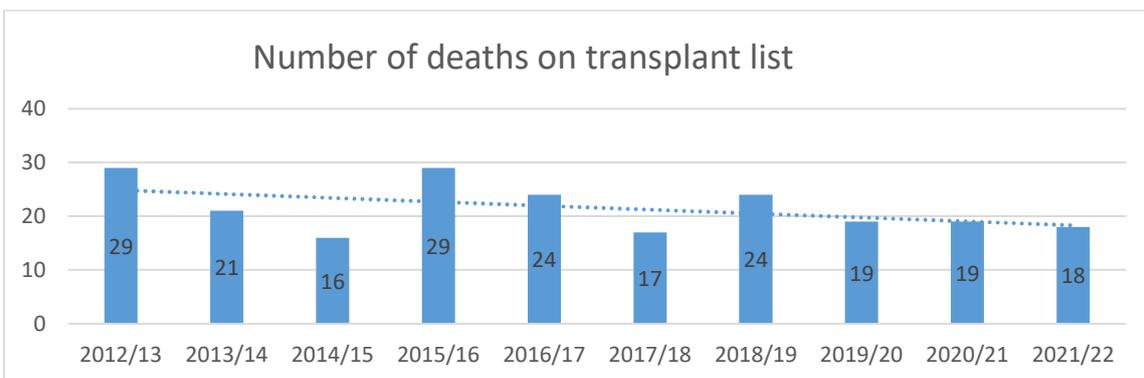
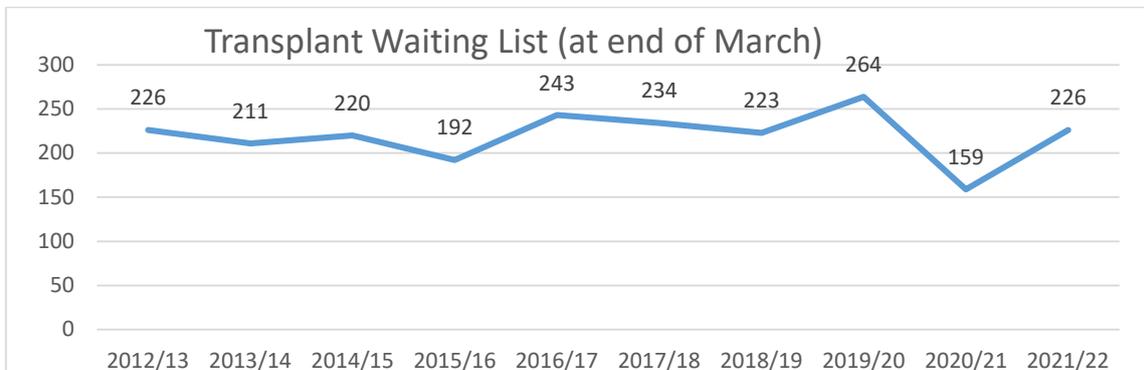




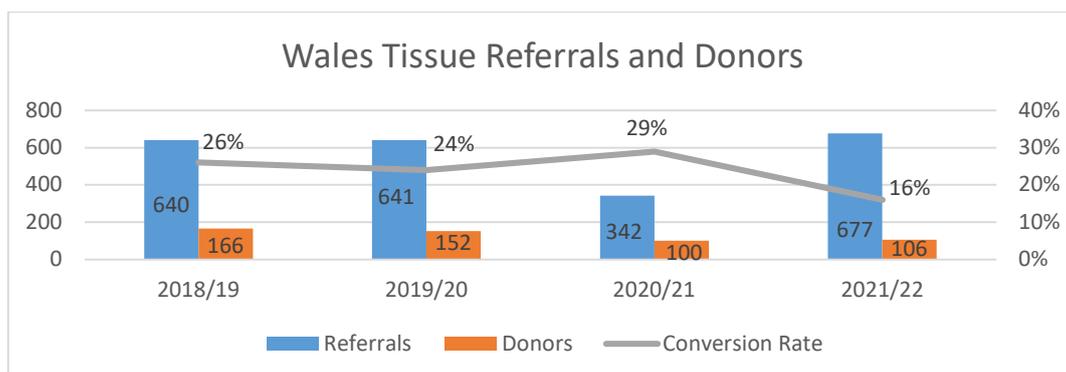
It should be noted that family overrides were calculated differently pre-1 December 2015 (just overrides of an opt in decision), post 2016/17 overrides are expressed decision or deemed consent.



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: <ul style="list-style-type: none"> • any missed opportunity identified • involvement of specialist nurses/requestors and clinical leads • neurological testing is performed in all patients who meet testing criteria, regardless of donor potential | 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 |