

Taking Organ Transplantation to 2020 – Wales Action Plan

A plan up to 2020 for NHS Wales and its Partners
Ensuring every organ donation counts





Printed on recycled paper

Print ISBN 978 1 4734 0527 1
Digital ISBN 978 1 4734 0525 7
© Crown copyright 2013
WG20342

Ministerial Foreword



The Human Transplantation Act 2013 has been the subject of major debate and discussion here in Wales. Yet, the move to deemed consent is only one strand in how we hope to improve donation and transplantation in Wales. Organ Donation and Transplantation is complex and multi-faceted: no single thing will revolutionise donation and transplantation rates – we know this to be true from experience elsewhere in the world. The implementation of the Human Transplantation (Wales) Act 2013 will help deliver a revolution in consent in Wales but we have always been clear it is one part in a series of actions.

Earlier this year, NHS Blood and Transplant, the organisation which manages the NHS organ donor register and the allocation of organs, published on behalf of the UK Administrations 'Taking Organ Transplantation to 2020'. I was pleased to support this over-arching Strategy for organ donation and transplantation. This Action Plan sets out how this will be implemented in Wales as well as adding the Welsh context.

We need simultaneously over the next few years to drive continuous improvement on all aspects of organ donation and transplantation and this plan seeks to do just that. It sets out actions right across the pathway, from ensuring that everybody has the opportunity to make their decision known, whatever that may be, to ensuring that those who receive transplants have the appropriate after-care and follow-up. The Plan commits us to deliver certain outcomes by 2020.

We need to keep in mind the reason why delivering these changes are so important and value every organ donation. Every donor and every donor family deserves our thanks and recognition, and it is our responsibility to ensure that every donation counts. We need to think about the very many lives saved and improved because of somebody else's generosity. It reflects the very best of humanity and society, and the NHS has a duty to do all it can to make every donation count.

We want to have amongst the best organ donation and transplantation rates in the world. These are testing ambitions, but they are achievable. I look forward to reporting real progress over the coming years, and to many more lives being saved and improved.

Mark Drakeford AM
Minister for Health and Social Services

Contents

Overview	5
By 2020, in Wales:	5
Working Together	5
Taking Organ Transplantation to 2020 and how it links to the Wales Action Plan	6
Our journey so far	6
Local plans – local action	6
What we want to achieve?	7
Outcome 1	7
Outcome 2	9
Outcome 3	11
Outcome 4	13
Other areas of action	15
What needs to happen and when	16

Overview

Much has happened since the original UK Organ Donation Taskforce (ODTF) made its recommendations in 2008. In 2013, supported by all the UK Governments, NHSBT published 'Taking Organ Transplantation to 2020', a strategy to improve organ transplantation rates even further than the 50% increase the ODTF called for. This Wales Action Plan sets out what needs to happen in Wales.

In Wales, we have recently passed legislation which brings in **an opt-out system of consent from 2015, which will include a major communication campaign**. More needs to be done across a wider front as consent is only one – albeit critically important – part of the strategy.

For example:

- We know there are circumstances where opportunities for donation are missed due to potential donors not being referred to Specialist Nurses in Organ Donation. This is true even in circumstances where the deceased has recorded a wish to donate (for example, by being on the Register, carrying a donor card or by telling their loved ones of their wishes).
- We know that in some cases, the families of individuals who have expressed a wish to donate do not receive timely information or support from the specialist staff trained in the donation process.
- We know that there is a wide variation in donation rates across the NHS in Wales. While some variation should be expected with small numbers, this may not fully explain the extent of variation seen.

We want Wales to be amongst the best performing countries in the world for donation and transplantation. This plan sets out the actions and outcomes up to 2020 to enable us to achieve this. If the following actions are implemented alongside the Human Transplantation (Wales) Act, we believe that by 2020, donation and transplantation rates in Wales should be comparable with the best performing countries in the world.

By 2020, in Wales, we will have:

- Ensured the public is informed and engaged about organ donation and transplantation
- Increased the number of people in Wales who have made their decision about donation known
- Increased the availability of organs for transplantation
- Made sure that every donation counts
- Ensured all parts of NHS Wales are knowledgeable about and support donation and transplantation

Working Together

NHS Wales are responsible for planning, securing and delivering local services to facilitate organ donation and transplantation.

NHS Blood and Transplant are responsible for managing specialist nurses for organ donation and retrieval services; the NHS organ donor register and the allocation of organs.

Human Tissue Authority is responsible for regulating the use of organs from people in the UK. They also undertake assessments for organ donations from living people.

The **Wales Transplantation Advisory Group** (WTAG) was established in 2012, as a successor to Wales Organ Donation Implementation Group (WODIG), to strengthen leadership and oversight on a broader range of issues. It meets quarterly and provides advice to Welsh Ministers and the NHS in Wales on all issues relating to organ donation, transplantation and tissue donation.

The Group has had a key role in identifying the priorities, and in shaping these into a series of meaningful actions. It also has an important leadership role in the delivery of the outcomes. The Group will be expected to monitor progress against the recommendations made – both in this plan and in the UK-wide Strategy – and report to Ministers on an annual basis.

The **third sector** has an important role to play, in helping to support the implementation and providing service user perspectives to inform the development of improved services.

Taking Organ Transplantation to 2020 and how it links to the Wales Action Plan

The development of a new UK-wide Strategy on organ donation and transplantation has been co-ordinated by NHSBT on behalf of the four UK Health Departments. The UK Strategy is available on the NHSBT website at www.nhsbt.nhs.uk/to2020.

This Welsh Action Plan is very much in line with, and intended to aid, the delivery of the UK Strategy in Wales. Where the UK document sets out general principles and considers those elements of organ donation and transplantation which are managed or can best be addressed across the UK as a whole, the Welsh plan

focuses specifically on the devolved health infrastructure in Wales and those activities which may be unique to Wales or delivered differently. The two documents are inter-related and inter-dependent.

The donation and transplantation of organs is undertaken on a co-ordinated and collaborative basis across the United Kingdom. It is in patients best interests to ensure the best match between donors and recipients and this can be best achieved by matching organs to the largest group of patients. This means we will work closely with the other parts of the UK.

Our journey so far

Like the other UK countries, Wales worked hard to deliver the ODTF recommendations and significant progress was made during the five year period, although fluctuations in 2012/13 meant we did not meet the 50% increase in the number of donors in the final year.

- 2012/13 saw 56 donors in Welsh hospitals compared to 45 in 2007/08.
- 32% of the population had joined the register at the end of 2012/13, compared to the 26% in 2007/8.
- 2012/13 saw 211 organ transplants on Welsh recipients compared to 183 in 2007/08.

Local plans – local action

Local Health Boards are required to develop and publish local plans highlighting how they implement the actions and report annually on progress.

What we want to achieve?

Outcome 1

Action by society and individuals will mean that the UK's organ donation record is amongst the best in the world and people donate when and if they can.

- Develop national strategies to promote a shift in behaviour and increase consent.
- Ensure that it is easy to pledge support for organ donation and once a pledge has been given, honour the individual's wish.
- Increase Black, Asian and Minority Ethnic community awareness of the need to donate, to benefit their own communities and provide better support for people in these communities to donate.
- Learn from the experience of legislative change in Wales and elsewhere.

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Develop national strategies to promote a shift in behaviour and increase consent and test progress with regular public surveys.	Implementation of the Human Transplantation (Wales) Act	Welsh Government/ NHSBT
	Implement NICE and good practice guidelines on family approach Improve communication skills of health professionals to talk to patients and their families Support families to respect the wishes of their loved ones	Local Health Boards/Regional Collaboratives/NHSBT Local Health Boards
	Commission and publish regular public attitudes surveys	Welsh Government
The relevant Government Health Departments should explore with Education Departments the possibility of incorporating donation and transplantation issues into schools curricula.	Maximise opportunities to include organ donation on the education curriculum within Wales	Welsh Government
	Ensure the schools education pack continues to be maintained and updated	Welsh Government working with NHSBT
All Governments should provide regular reports to Parliament/ Assembly on progress in their nation and Health Ministers should have a duty to promote organ donation and transplantation, effectively leading to a significant improvement in public attitudes and consent for organ donation.	Publish an annual report on progress improving organ donation and transplantation	At All Wales level – Welsh Government
	Report performance against specific organ donation and transplant indicators to the All Wales Donation and Transplantation Advisory Group at least annually	At local level – Local Health Board

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
There should be national debates to test public attitudes to radical actions to increase the number of organ donors. For example, whether those on the Organ Donor Register should receive higher priority if they need to be placed on the transplant waiting list.	To be taken forward at a UK level	NHSBT/Welsh Government in conjunction with other UK health departments
Ensure that the introduction of a system of deemed consent to organ and tissue donation in Wales as described by the Human Transplantation (Wales) Bill is as successful as possible and learn from this experience.	Implement programme of work including training, to ensure successful implementation of the Human Transplantation (Wales) Act	Welsh Government/ NHSBT/Local Health Boards
Develop a community volunteer scheme to support Trust/Health Board donation committees to promote the benefits of donation in local communities, particularly amongst groups with little tradition of organ donation.	Explore opportunities to develop community volunteer schemes Work with the Third Sector to ensure effective signposting to sources of information and support.	NHSBT/third sector/Regional Collaboratives/Local Health Boards
Following the experience in the USA, ensure everyone who has made a decision to donate during their life has their wishes honoured if they die in circumstances where donation is possible.	Work to develop this will be taken forward at a UK level and Local Health Boards will seek to implement any change in practice required	NHSBT/Local Health Boards

Outcome 2

Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.

- Increase the number of people who are able to donate following brain death.
- Increase the number of people who are able to donate following circulatory death and learn from the Scottish pilot on donation after failed resuscitation.
- Provide hospital staff with the support, training, resources and information they need to provide an excellent organ donation service.
- Ensure every donor's care, prior to retrieval, boosts organ quality.

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
End-of-life care standards should promote BSD testing as the preferred method of diagnosing death, where this can be achieved and is in the best interests of the patient.	Review Wales Integrated Care Priorities and Quality Markers for End of Life and incorporate action if required	WTAG/Palliative Care Implementation Board
End-of-life care practices should be reviewed to establish whether they might be adjusted so as to promote donation after DBD.	Already implemented in Wales and incorporated into Wales Integrated Care Priorities and Quality Markers for End of Life	Palliative Care Implementation Board
Establish a National Referral Service to improve support to hospitals.	Work to develop this will be taken forward at a UK level and Local Health Boards will seek to implement any change in practice required	NHSBT
Scope the potential for donation following unexpected cardiac arrest in the UK, learning from the pilot programme in Scotland.	Monitor outcome of pilot programme in Scotland and consider potential within Wales	WTAG
Families of potential donors will only be approached by someone who is both specifically trained and competent in the role, training packages and accreditation will be provided to those who wish to develop this competence.	NHS in Wales to work with professional bodies and NHS Blood and Transplant to ensure training and accreditation packages are adopted and families of potential donors will only be approached by someone who is both specifically trained and competent in the role	Local Health Boards/ Professional Bodies in Wales
	Provide information so generalist teams know how to access support to facilitate organ donation, if appropriate	Local Health Boards

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Work collaboratively to reduce instances of objection to organ donation from the Coroner and Procurator Fiscal service and the police.	Joint UK action	WTAG/NHSBT
Publish hospital data to include: brain-stem death testing rates, donor referral rates, family approach rates, Specialist Nurse involvement and other key areas.	Ensure published data is analysed at a local level and any potential service improvements are considered and implemented where necessary	UK level – NHSBT Data published six monthly from September 2013 Local Level – Local Health Boards/ WTAG

Outcome 3

Action by NHS hospitals and staff will mean that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.

- Increase the number of organs that are retrieved from both DBD and DCD donors.
- Increase the number of organs that can be transplanted safely, providing surgeons with the information and guidance to make decisions about organ suitability.
- Improve transplant recipient survival by improving understanding of the donor organ/ recipient compatibility.

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Improve donor management for potential cardiothoracic donors, providing a 24/7 service to assist if pilot schemes prove effective. (SCOUT Pilot)	Monitor outcome of pilot programme and consider potential within Wales	NHSBT/Local Health Boards
Review what pre-mortem interventions could legally and ethically be undertaken to maximise the potential for organ donation (such as the administration of heparin, elective ventilation etc.).	Develop guidance on pre-mortem intervention where consent may be deemed	UK level – UK DEC/ Professional Bodies in conjunction with Welsh Government and other UK health Departments
	Ensure any guidance developed is implemented within the NHS in Wales	Local level – Local Health Boards
Evaluate new techniques and technologies for the preservation of retrieved organs with a view to their use in the UK.	Ensure any guidance developed is implemented within the NHS in Wales	UK level – NHSBT/ Professional Bodies Local Level – Cardiff and Vale UHB/WHSSC
Develop a system of peer review that is underpinned by a set of agreed standards for retrieval/ transplant centres.	Ensure participation and compliance with any system established	UK level – NHSBT/ Professional Bodies in conjunction with WHSSC and other UK commissioners
	Fully participate in and act on the outcome of national clinical audits.	Local level – Cardiff and Vale UHB
Provide guidance on levels of acceptable risk in relation to offered organs, particularly from extended criteria donors, relevant to the individual recipient's needs and wishes.	Ensure any guidance developed is implemented within the NHS in Wales	UK level – NHSBT/ Professional Bodies Local level – Local Health Boards

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Publish centre-specific risk-adjusted patient survival from listing as well as from transplantation.	Ensure published data is analysed at a local level and any potential service improvements are considered and implemented where necessary	UK level – NHSBT Local level – Cardiff and Vale UHB/ WRCN/WHSSC
Ensure clinicians are aware of and follow, best practice to increase patient and graft survival.	Ensure clinicians are aware of and follow best practice Ensure transplant recipients receive the care and support they need	NHSBT/Professional Bodies/WTAG/ Local Health Boards

Outcome 4

Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

- Support Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practice and promote organ donation.
- Review and improve the workforce, IT, systems and processes which operate throughout the donation and transplant pathway.
- Build a sustainable training and development programme to support organ donation and retrieval.

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Develop a workforce strategy for the organ donation service which will tailor the service to the needs of individual hospitals and seek to provide a workforce that is focused on supporting the potentially conflicting demands of providing a service to the donor family, donor management and donor co-ordination. This may be configured in one or more roles as the needs of the service dictate.	Joint UK action	NHSBT/Local Health Boards
Subject to variations in Government policy, agree a formal contract for organ donation with hospitals specifying how hospitals and the NHSBT donation service work together to achieve excellence.	Joint UK action	NHSBT/ Welsh Government/ WHSSC/Local Health Boards
Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practices and in local promotion of donation and transplantation.	Develop and implement a coordinated action plan to drive improvements in organ donation and retrieval across Wales	North Wales and South Wales Regional Collaboratives
	Develop and implement a communication plan for the promotion of organ donation and transplantation	Welsh Government/ WTAG Communications Group
	Promote public awareness of the importance of organ donation and transplantation including Living Donation	Welsh Government/ WTAG Communications Group/Local Health Boards

Taking Organ Donation to 2020 Action	Wales Action	Responsibility
Ensure that transplant centres have the capacity and surgical expertise and other clinical skills to meet the demands for transplantation as donor numbers increase.	For patients receiving transplants within Wales	Cardiff and Vale UHB/ WHSSC/Welsh Renal Clinical Network
	For Welsh residents requiring transplants outside of Wales	WHSSC/Welsh Renal Clinical Network
Develop training programmes to sustain and increase clinicians' organ donation understanding and expertise.	Will be taken forward at a UK level except for training requirements necessary as a result of the Human Transplantation (Wales) Act	NHSBT/Welsh Government
Optimise the processes, timescales, resources and supporting IT at every stage of the pathway from donor identification to long-term survival.	Work with NHSBT to optimise the processes, timescales, resources and supporting IT at every stage of the pathway from donor identification to long-term survival	NHSBT/Local Health Boards
Review the current processes for donor characterisation (especially for microbiology and tissue typing).	Work with NHSBT to review the current processes for donor characterisation (especially for microbiology and tissue typing)	Velindre NHS Trust (Welsh Blood Service)/ NHSBT
Develop and implement a training and accreditation programme for all retrieval surgeons and extend this to supporting post-mortem technologies when these are introduced.	Will be taken forward at a UK level	NHSBT/ Professional Bodies
Investigate the feasibility and implications for the provision of a 24/7 provision of expert histopathology advice.	Work with NHSBT to investigate the feasibility and implications for the provision of a 24/7 provision of expert histopathology advice for Welsh residents	Velindre NHS Trust (Welsh Blood Service)/ NHSBT

Other areas of action

Wales Action	Responsibility
Identify key actions required to improve donation from emergency departments including: <ul style="list-style-type: none"> • 100% referral of potential donors from Emergency Departments • Identify a donation lead in each Emergency Department • Ensure representation from Emergency Department on LHB Donation Committee 	WTAG working with Local Health Boards/Regional Collaboratives
Identify key actions required to deliver an increase in the number of living donation	WTAG working with Local Health Boards/Regional Collaboratives
Identify key actions required to ensure equity of access to both living and deceased organ transplants	WTAG working with Local Health Boards/Regional Collaboratives
Develop a plan to support Local Health Boards to improve tissue retrieval services	WTAG working with Local Health Boards/Regional Collaboratives

What needs to happen and when

Key Action	Responsibility	When
1. Write local plans demonstrating a systematic approach to progressive implementation of this plan	Each Local Health Board, in liaison with Trusts, WHSSC and the third sector	By March 2014
2. Agree a programme of work to address delivery against this Plan covering areas where an All-Wales approach is required	WTAG	By March 2014
3. Report formal progress to Boards and Welsh Government and publish on website a) Completion and outcomes of actions 1 b) Progress in delivering the local action plans	Local Health Boards and Trusts and WTAG	a) By end of March 2014 b) By end of July 2015 and annually thereafter
4. Review and update plans and milestones	Each Local Health Board, in liaison with Trusts, WHSSC and the third sector	At least annually, with first review by March 2015
5. Publish annual All Wales report based on reports at action 3	Local Health Boards and Welsh Government	Following publication of LHB reports in July 2015 and then annually
6. Ensure successful implementation of Human Transplantation Act 2013	Welsh Government/NHSBT	By December 2015