

Organ Donation and Transplants



Transplants are the most effective treatment for organ failure. There is a need to increase the number of organs donated. The Human Transplantation (Wales) Bill passed by the National Assembly for Wales revises the current opt-in consent procedure for donations to deemed consent. A new UK strategy sets out policy intended to improve organ transplant rates. This POSTnote examines this and other policies to increase the availability of donor organs in the UK.

Background

Transplants save lives, improve quality of life and are cost effective, but not enough organs are available. Table 1 shows some key statistics of organ donation, transplantation and demand in the UK. Although deceased donor numbers have risen by 50% since 2008 it is estimated that 1,000 people a year are dying in the UK while waiting for a transplant.¹ The organ shortage is most acute for Black, Asian and Minority Ethnic (BAME) patients who wait longer (one year on average) for an organ (Box 1). The NHS Organ Donor Register (ODR) is a database holding the details of people who would like to donate their organs after death. A donor can donate more than one organ thus the number of transplants is greater than the number of donors.

Few people die in circumstances that make organ donation possible, such as in intensive care. There are over half a million deaths in the UK each year but fewer than five thousand people die in circumstances where organs can be donated (1%). There were 1,212 deceased donors in 2012/13.² The gap between potential and actual donors is because some people's organs are unsuitable to transplant or because their family did not give consent. The rate of transplantation using organs from deceased donors in the

Overview

- The demand for organs for transplant in the UK outstrips supply. The organ shortage is most acute for Black, Asian and minority ethnic groups.
- Implementation of recommendations made by the Organ Donation Taskforce in 2008 increased the number of deceased donations by around 50%.
- The rise in donations is primarily due to more donors being identified and consequently more families being asked to consider donation. Families refuse to consent to donating their loved ones' organs in around 40% of cases where the person's wishes are unknown.
- The National Assembly for Wales has passed a Bill intended to increase organ availability by adopting deemed consent, an opt-out system.

UK is lower than countries such as Croatia, Portugal, Spain, Norway, and France. In 2011, Spain had a rate of 82.8 per million population (pmp) compared with 49.5 pmp in the UK.

	UK	England	Scotland	Wales	NI
% Population on ODR	31	30	41	32	31
Deceased Donors	1,212	1,026	94	52	53
Living Donors	1,095	929	71	42	53
Total Organ Transplants	4,210	3,517	359	211	123
People Remaining on Waiting List	7,336	6,255	625	226	190

Table 1. Organ Transplants across the UK (April 2012- March 2013)

Demand for Organs

Organ failure can be caused by congenital conditions. For example people with cystic fibrosis often need a lung transplant. However the demand for organs is likely to continue to rise because of an ageing population and the increasing prevalence of obesity and diseases such as diabetes, Hepatitis C, hypertension and those related to alcohol. These conditions also contribute to a decline in the

Box 1. Black, Asian and Minority Ethnic (BAME) donation

Transplant patients are more likely to find a match from donors from the same ethnic background. People from BAME communities are Three to four times more likely than white people to need an organ because of higher rates of conditions such as diabetes and high blood pressure. However BAME patients are less likely to find a suitable organ and spend longer on transplant waiting lists, since:

- BAME groups are under-represented on the ODR. While 10.8% of the UK population is BAME, only 3.5% of people on the ODR are BAME.
- The BAME family consent rate is less than half that of families of white potential donors. This rate has not changed since 2009.

Reasons for this increased gap include cultural and religious barriers. For example, discussing death may be taboo for some groups. The National BAME Transplant Alliance is raising the profile of donation by training key community figures. It is also advocating for more BAME Specialist Nurses in Organ Donation since evidence suggests that BAME families are approached less often, possibly due to language barriers.³ Only one of 250 the specialist nurses is from a BAME group.

quality of organs available for transplant. The number of people with organ failure is larger than the number of people registered on the transplant waiting list. To be placed on the waiting list for transplantation a patient would have irreversible organ failure, yet be well enough to undergo the surgery, meaning that some will not be put on the list.

Cost Effectiveness

The entire transplant programme delivers an annual cost saving of £316m to the NHS according to NHS Blood and Transplant (NHSBT). Having a successful transplant often allows patients to return to work and reduces the number of hospital visits. For example the average annual cost of dialysis for a patient with kidney failure is £30,800. A successful kidney transplant operation costs £17,000.¹ The annual cost thereafter is estimated to be £5,000. The NHSBT predicts that for every year a kidney transplant remains functional, the NHS saves £24,100 per patient. . The success rate for a kidney transplant using an organ from a deceased donor is 93%.¹ Transplanted organs may not last for the rest of the life of the recipient, so some patients return to the waiting list if their organ fails. One in five kidney transplants are re-transplants.

Organ Donors and Transplants

The most commonly transplanted organs are the kidney, liver, lung, pancreas and heart. The small bowel and cornea can also be transplanted. Face and limb transplants are possible but uncommon, are not listed on the ODR⁴ and require special consent. Transplant organs come from deceased or living donors.

Deceased Donors

There are two types of deceased donors depending on how an individual died:

- **Donor after brain death (DBD).** Death is confirmed after the brain stem has died, even though the heart may continue to beat for a short while afterwards. These patients are on life support in intensive care and death is diagnosed by two doctors using a set of tests performed twice. The brain-stem controls essential functions that

keep a person alive, such as the ability to breathe and to regulate the heart and blood pressure.³ Brain-stem death is irreversible. 43% of all transplant organ donations came from these patients in 2012/13.

- **Donor after circulatory death (DCD).** The heart stops and cannot be restarted, depriving the brain of oxygen leading to death. DCDs usually come from controlled deaths that occur once life support has been removed if it is considered not to be in the patient's best interests. DCDs donate fewer organs per person than DBDs due to organ damage sustained during death. DCD made up 31% of all donations in 2012/13.

In either case any decision to remove treatment is only taken if it is in the best interest of the patient, regardless of their potential to become a donor. Clinical staff managing these patients and diagnosing their death are not part of the organ retrieval team to avoid perceived conflict of interest.

Living Donors

Living donation accounted for 26% of UK transplants in 2012/2013.⁵ The kidney is the organ most commonly given by living donors but it is also possible to donate part of the liver or more rarely a lung lobe, whilst alive. The Human Tissue Authority (HTA) is responsible for assessing all applications for living organ donation in the UK. In order for the HTA to approve a living organ donation, it must be satisfied that the donor is giving consent freely and that there is no reward attached to the donation. The risk of death from donating a kidney is 1 in 3,000. Compared with Europe and the US, the UK ranked 6th for living kidney donation in 2010 with a rate of 16.6 pmp. The Netherlands ranked highest (28.5 pmp) and the US second (19.8 pmp). If a patient has a friend or family member who is willing to give them a kidney, but cannot because they are not a suitable blood or tissue match, the UK has a system to match these to others in the same situation to maximise the number of transplants (see Box 2). While living donations are usually from family members or friends, the number of donations made to strangers is increasing.

Non-Directed Altruistic Donation

Non-directed altruistic donation is where a person donates an organ to a complete stranger on the NHS waiting list. The first such transplant (a kidney) from a living donor took place in 2007. In 2012-13 there were 76 non-directed kidney donations in the UK. This figure surpassed expectations as original estimates predicted 10 a year. In 2012 the first non-directed liver donation took place in the UK. Non-directed altruistic donations can be used to kick-start a chain of paired or pooled donation (Box 2). Donors are given the option to join the paired/pooled schemes and the spare organ from this is given to a patient on the national transplant list. There have been over 10 of these chains since they started in 2012.

Directed Altruistic Donation

Directed altruistic donations are where the donor chooses to give to an individual patient even though they had no

Box 2. Paired and Pooled Donations**Paired Donations**

If a patient has a person willing to donate to them but they are not compatible by blood group or tissue match (Box 3), they can be paired with another donor and recipient in the same situation to maximise the number of transplants. This has been performed in the UK since 2007, with 51 paired donations in 2011/2012.

Pooled Donations

Pooled donations work in the same way but involve more than 2 donor-recipient pairs. For example if Patient A has a willing donor A they can be matched with another two pairs, say B and C, so that Donor A gives a kidney to Patient B, Donor B gives to Patient C and Donor C gives to Patient A completing the pool. In the UK paired and pooled operations happen at the same time to reduce the risk of all of the transplants in an exchange not being able to go ahead.

previous relationship with the person. Donors may come forward after hearing an individual's story in the media, or donate to estranged family members who have not been in contact for many years. Initial concerns were raised about the fairness of this type of donation. According to the Department of Health (DH) potential donors from the UK alone are considered unless there is a familial connection. Clinical compatibility tests are expensive so many hospitals limit the number of people they will test for one patient.

Consenting to Donation

Before organs are taken consent must be given by the individual, such as signing the ODR. In Scotland the concept of authorisation rather than consent is used. If an individual has not given this in life then consent is needed from someone with a qualifying relationship. Families have no legal veto to override the deceased's wishes about organ donation if they are known, but donation is unlikely to go ahead if opposed by the family as clinicians do not want to cause additional distress or risk bad publicity that could jeopardise the donation programme. According to NHS Blood and Transplant (NHSBT) 96% of the population believe donating organs is the right thing to do. When a person is on the ODR the family will usually support donation. In 2010, less than 1% of families refused to donate at least a kidney where the deceased person was on the ODR, although up to 10% refused to donate additional organs such as the heart.⁶ However, if the deceased's wishes were unknown the refusal rate is much higher, with only 57% of families agreeing to donation.

Allocating Organs for Transplant

The NHSBT conducts organ allocation. It differs depending on organ type, but includes the following considerations:

- those in the greatest clinical need
- on the basis of best tissue match (see Box 3)
- age matching of recipient and donor
- length of time on the waiting list.

Reciprocal arrangements with some European countries mean that organs not matched to NHS patients are offered elsewhere to minimise organ waste. In 2012/13, 11 organs from UK donors went to non-UK hospitals. In the same year 30 transplants were conducted in the UK with organs from other EU countries. The arrangements are limited to Europe

due to the short amount of time organs can endure outside the body. Very rarely, where there is no suitable NHS or EU recipient, organs can be offered to foreign nationals who pay to be treated privately. This has raised ethical concerns and generated media stories that may erode public trust. An independent report commissioned by DH recommended that private practice in this area stops.⁷

Life after Transplantation

Transplant patients require lifelong immunosuppressant drugs to stop their immune system from attacking the donated organ. Their immune system is therefore less able to fight infections and the risk of skin and lymph node cancers is increased. New technologies are being developed to reduce the need for immunosuppressant drugs.⁸ Transplanted organs often do not last for the lifetime of the recipient. 71% of kidneys from DBD, 60% from DCD and 80% from living donors still work 10 years after transplantation.⁹ Once a transplanted organ fails, the patient will need another transplant. Patients who have already had a transplant may be more difficult to match with a new donor due to the increased levels of special antibodies (see Box 3) in their blood.

UK Policy

Legislation governs the removal, storage, use and disposal of human organs and tissue¹⁰ and is regulated by the HTA. In 2008, recommendations made by the Organ Donation Taskforce (ODT) were implemented by the DH, NHSBT and devolved administrations. These were modelled on national and international best practice including the Spanish system which has one of the highest rates of donation in Europe. In 2008 the ODT considered an opt-out system. It advised that it should not be introduced in the UK but that this should be reviewed in 2013 if the 50% target to increase donation was not met. Changes based on the recommendations led to a 50% increase in the number of donors in the last 5 years (2007-08 to 2012-13). The number of deceased donors increased from 809 to 1,212.⁵ However, this did not translate into the predicted number of transplants since the

Box 3. Matching Donors and Recipients**Tissue Matching**

The closer the tissue match between the donor and the recipient the lower the chance of rejection. There are slight differences depending on the organ involved. Tissue matching is more important for kidneys than for heart and lungs. Organs have markers (Human Leukocyte Antigens [HLAs]) that allow the immune system to distinguish cells as being "self" (part of the body) or non-self. Finding a donor with exactly the same HLAs as the recipient is rare, but it is more likely between closely related people. However, successful transplants are possible between people that do not match perfectly. There is a greater chance of finding a close match within the same ethnic group.

Cross Matching

Individuals do not have antibodies against their own HLAs in their blood, but may have antibodies against other HLAs if they have had a blood transfusion, been pregnant or have already had a transplant. The presence of antibodies means that a patient's immune system is primed to attack those HLA types. Thus cross-matching checks if antibodies in a patient's blood react with the donor's cells. If they do, a transplant cannot be performed as the organ will be rejected.

main increase in donors came from DCD, who on average donate fewer organs than DBD. There was only a small increase in DBD numbers. The NHSBT's new strategy for the UK build on the work of the now disbanded ODT. The strategy works within the current legislative framework (with Wales the only country due to implement an opt-out consent system). Key points are highlighted in Box 4.

Changing Policy on Consent

The family consent rate has not changed since 2008. The UK has one of the highest family refusal rates in the western world at 57%.² The recent increase in organ donation resulted from more families being asked. Making donation a normal part of end of life care (as in Spain which has a family refusal rate of less than 20%) is key to raising donor numbers. To improve consent rates, especially in BAME groups, the new strategy proposes a review of the UK consent system. This would include investigating the possibility of preventing families from overriding a person's wishes if they had signed the ODR. The strategy also proposes debates to gauge public attitudes to other approaches. For example they raise the possibility of whether those registered on the ODR should receive higher priority if they need a transplant.

Reviewing Policy on Consent (Wales)

The National Assembly for Wales passed the Human Transplantation (Wales) Bill in July 2013. From 2015, over 18s ordinarily resident in Wales for over 12 months will be deemed to have consented to organ donation unless they have opted-out. The key points are:

- This will be a soft opt-out system. Families will be consulted about the person's wishes.
- The Bill covers standard organs and thus excludes novel techniques such as face transplants.
- People under 18 and those who lack the capacity to understand that consent could be deemed are excluded. However these groups can still give express consent.
- People who do not live in Wales voluntarily, such as prisoners, are excluded from deemed consent.
- The Welsh Government is required to run a campaign informing the public of this consent policy and to report annual outcomes to the National Assembly for Wales. It will work with the ODR. Residents in Wales can sign the ODR in case they die elsewhere in the UK, or wish to become a donor but do not want consent deemed.

At present, 30% of organs donated in Wales are transplanted there and this is not expected to change. It is estimated that deemed consent could increase the number of organs by 25-30% which would be allocated across the UK. However some think this is optimistic. The Welsh Bill was opposed by some groups who believe that opt-out undermines the gift of donation. There have also been concerns raised about the cost involved, lack of public understanding and the potential perception that the state would be taking organs without consent. The evidence surrounding opt-out is not clear cut. For example Spain's increase in donor numbers followed improvements to their

Box 4. Taking Organ Transplantation to 2020

The 2013 transplant strategy sets outcomes to reach by 2020 and a detailed strategy to meet the key aims:

- increase the consent rate from 57% to 80%
- increase the rate of deceased donation from 19.1 pmp to 26 pmp
- transplant 5% more of the organs offered by donors and families.

The strategy details plans to streamline the donation process. For example if variation between different regions was minimised, with all hospitals performing at the higher end of the scale it is estimated that there would be 500 more donors a year. If the strategy meets its aims, donations will increase. The strategy also highlights the importance of a co-ordinated research programme on improving transplantation.⁸

donation infrastructure, several years after opt-out consent was introduced. Organisations that support the move include the British Medical Association, the British Heart Foundation and Kidney Research UK. It is expected that England, Scotland and Northern Ireland will monitor the impact of the Welsh Bill on consent and donation rates.

Changing Public Attitudes to Donation

The UK strategy calls for education and publicity to highlight the importance of organ donation. The rate of family consent and the percentage of the population on the ODR is higher in Scotland than the rest of the UK (Table 1). This is attributed to hard-hitting advertising campaigns and education about organ donation in schools. The DH does not have a budget to promote organ donation in England. The new UK strategy includes building a new ODR for people to record their wishes in a range of ways.

Reviewing Clinical Practice

The UK has lower numbers of DBD donors than other countries. This has been attributed to clinical decisions to withdraw treatment to patients with non-survivable brain damage before brain stem death has occurred or can be tested for, which is not done to the same degree in countries such as Spain, which has more intensive care beds. Withdrawing treatment before brain death can be tested means that some patients forfeit the opportunity to donate, thus reducing donor numbers. Even where brain stem death is confirmed, only 63% of potential donors are referred for donation. The 2013 strategy outlines that brain stem death testing should be a normal part of end-of-life-care (where appropriate) and all potential donors should be referred to the donation team. A pilot project in Scotland is seeking to expand the pool of potential donors to include those who have undergone cardiac arrest in an uncontrolled manner (not as a result of life support removal). If successful, this will be considered at other centres.

Endnotes

- 1 www.organdonation.nhs.uk/
- 2 Taking Organ Transplantation to 2020: A UK strategy, NHSBT, 2013
- 3 NBTA Report on BAME Organ Donation and Transplantation Data, 2012
- 4 A Code of Practice for the Diagnosis and Confirmation of Death, Academy of Medical Royal Colleges
- 5 www.organdonation.nhs.uk/statistics/downloads/united_kingdom_april13.pdf
- 6 Human Bodies: Donation for Medicine and Research, Nuffield Council on Bioethics, 2010
- 7 Allocation of Organs to Non-UK EU Residents, E. Buggins, 2009
- 8 See POSTbox on Organ Transplant Research for more information.
- 9 NHSBT Organ Donation and Transplantation Activity Report, 2011-12
- 10 Human Tissue Act (2004) in England, Wales and Northern Ireland. Human Tissue (Scotland) Act (2006)