



Policy statement

Organ donation

Introduction

Heart transplants offer the best chance of long term survival for critically ill heart failure patients. Unfortunately there is a shortage of donor hearts for use in transplantations across the UK, and on average three people die every week whilst waiting for a transplant.¹

As the nation's heart charity, the BHF is committed to increasing the rate of organ donation to make sure that those patients requiring new hearts have the best possible chance of survival. We are also funding research aimed at eliminating the need for heart transplants in the future.

Policy statement

Although nine out of ten people in the UK support organ donation, only three in ten have joined the donor register. We need to change this and make organ donation part of the fabric of our national life.

Promoting organ donation is vital but will not on its own deliver the much needed increase in organs. Even if we meet NHS targets for a 50% increase in donation by 2013, people will still be dying unnecessarily whilst waiting. Our rate of organ donation is low compared to many other European countries.

A soft opt-out system of organ donation, where everyone is considered to want to donate their organs unless they state otherwise, would help increase the number of organs available for donation and better reflect the wishes of the majority of the population. It would also provide people with an option to register their objection to organ donation if they so wish – this is not possible with the current system.

An opt-out system must be sufficiently robust to ensure that everyone who wishes to opt-out has the opportunity to do so, and close relatives must be able to refuse permission at the time of request. Any changes to the system will need to be accompanied by a wide ranging communication strategy to engage with people from a range of communities.

Developments to the organ donation infrastructure, capacity, and training for health care professionals are required to provide essential support for an opt-out system. Increasing the number of critical care beds may help make the most of the system.
Continued

¹ Of all the people on the list, not heart patients alone

We support the Welsh Government's move towards a soft opt-out system, and we are calling on the rest of the UK to follow their lead. The organ donation infrastructure is spread across the UK and a single opt-out system across the four nations would enable a consistent approach to organ donation as well as maximising benefits for people waiting for a heart transplant.

The BHF funds research into regenerative medicine. This may one day enable the heart to repair itself and mean that people will no longer need heart transplants. But until this time transplants remain the best option for critically ill heart failure patients.

Background

Heart transplant is the only effective treatment available for people with end stage heart failure – when the condition cannot be treated effectively with medication – and is extremely successful in carefully selected patients. Heart and lung transplants usually take place in cases of congenital heart disease and severe forms of lung disease such as cystic fibrosis.

In June 2011, 144 people were on the active waiting list for a new heart or a new heart and lung in the UK, 18 of whom were under 18. The list includes 122 people in England, 7 in Wales, 10 in Scotland and 2 in Northern Ireland.

The transplant waiting list would be larger if there were more donor organs available as a lot of people don't get put on the waiting list by their doctor as their chances of receiving a transplant in time are slim.² Doctors don't want to add to the anxiety of a terminal illness.

In 2010/11 134 heart or heart and lung transplant operations were carried out. During this time 18 people on the transplant list died before the transplant could be arranged.³

In 2010/2011 the number of donors increased by 5% in the UK, and cardiothoracic organ transplants increased by 11%. However, the proportion of older and overweight organ donors is increasing, and higher instances of chronic conditions such as heart disease amongst these individuals mean that transplant rates are increasing at a slower rate than donation rates.⁴ For example, donor hearts are not accepted from individuals aged over 65, although other organs may be transplanted. It has also led to concerns that sub-optimal organs, which may otherwise have been rejected, are being used.^{5,6}

In the UK there is a large discrepancy between the number of potential donors and actual donors. Across the UK the total potential donor rate (if *all* potential donors went on to donate) is 45 per million population (pmp), but the actual donor rate is just 16 pmp.⁷ Wales has the highest donor rate of the UK countries at 28 pmp.⁸ There are many reasons why potential donors do not go on to donate their organs, the family

² Organ Donation Taskforce (2008): The potential impact of an opt-out system for organ donation in the UK.

³ Data supplied by NHS Blood and Transplant 2011

⁴ NHS BT Activity Report: Transplant Activity in the UK. 2010/11

⁵ Daily Telegraph, Rebecca Smith, Medical Editor: 'Organs from drug addicts 'being used in transplants' 10 December 2008.

⁶ BBC Online: 'Organ transplants using 'risky donors' rising', 24 November 2009.

⁷ BMA (2012) *Building on Progress: where next for organ donation policy in the UK?* p25.

⁸ BHF and Kidney Wales Foundation (2012) *Opting out in Wales: developing the infrastructure.*

refusing consent is the most common. Currently over 40% of families refuse organ donation because they don't know what their relative's wishes were.⁹

It is important that people talk to their loved ones about their wishes, as well as joining the register, so they understand what decision they would have wanted to make. For potential donors after brain stem death the family refusal rate was 50%, when the individual's wishes were not known, but this dropped to just 6% when the wish to donate was known.¹⁰ Ethnicity is also an important factor, with refusal rates of 29% amongst the white population and 77% amongst the non-white population.¹¹

Becoming an Organ donor in the UK

In order to become an organ donor individuals must sign up to the Organ Donor Register (ODR). The person's family or loved ones are approached to give consent at the time of death, consent is also sought for those individuals not signed up to the register.

Children under-18 can join the register with the consent of their parents or guardians in England, Wales and Northern Ireland, or if they are under-12 in Scotland.

Ways to join the ODR include:

- Calling the NHS donor line
- Registering for a driving licence
- Applying for a Boots Advantage card
- Registering at a GP surgery
- Registering for a European Health Insurance card (EHIC)

Although 90% of the UK public supports organ donation, on average just 30% of the UK population are on the ODR.¹² As of June 2011 the UK breakdown is:

- England 29%
- Wales 30%
- Scotland 36%¹³
- Northern Ireland 28%¹⁴

NICE guidance on organ donation¹⁵ recommends that each hospital should have a protocol that helps ensure that organ donation is a usual part of end of life care and that potential donors are identified as early as possible. It also sets out best practice guidelines for seeking consent and approaching those close to the patient.

A soft opt-out system of organ donation

Several European countries have introduced a soft opt-out system of organ donation, where everyone is considered to want to donate their organs unless they say otherwise. Under such a system close relatives have the option to refuse consent at the time of request.

⁹ NHSBT website <http://www.nhsbt.nhs.uk/news/2012/newsrelease130212.html>

¹⁰ NHS Blood and Transplant (2011) *Potential Donor Audit. Summary report* NHS BT Bristol, p.6.

¹¹ As above

¹² Data supplied by NHSBT (2011)

¹³ The Scottish Government ran a high profile multimedia campaign in 2009-2011

¹⁴ Data supplied by NHSBT

¹⁵ NICE (2011) *Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation*. NICE clinical guideline 135. www.nice.org.uk/cg135

International data shows that an opt-out system is associated with higher donation rates and several studies suggest that it would increase the numbers of organs available for transplantation by up to 30% in the UK.¹⁶ In Belgium the rate of organ donation increased from 19 to 41 pmp three years after the introduction of opt-out legislation.

Evidence suggests combining opt-out with organisational and infrastructure developments can significantly improve rates of donation and transplantation. A report commissioned by the BHF and the Kidney Wales Foundation¹⁷ looked at international examples of opt-out systems of organ donation. Whilst there are difficulties associated with comparing organ donation between countries due to the large number of variables influencing rates of donation – such as infrastructure, religious beliefs, and social norms – our report identifies a number of areas for development that have proved key in maximising the benefits of existing opt-out systems including:

Public awareness and media engagement: Different countries have varied their approach to raising awareness - whereas Belgium has invested heavily in public awareness campaigns, Spain proactively works with the media to provide information about organ donation and transplantation. A public awareness campaign is important in ensuring consistency and impact of message, and it will be important that any campaign engages with people across a spectrum of communities.

- **Training of staff:** All successful international systems have invested heavily in training, particularly for transplant coordinators but also for staff in intensive care and emergency departments.
- **A national agency:** Countries are most successful where there is a national agency with overarching responsibilities for donation and transplantation. In the UK this is led by NHS Blood and Transplant.
- **Transplant co-ordinators:** Appropriately placed and well trained transplant co-ordinators are a crucial part of many successful international examples.
- **Management of donors:** The effective management of donors from identification through to transplant is key. This depends on staff training, and having in place policies, procedures, and standards.
- **Removing financial barriers for hospitals:** A number of successful international models reimburse hospitals for transplant activity. This enables and encourages hospitals, especially smaller ones, to engage with organ donation.
- **Transplant centres and donor hospitals:** The number of transplant centres is the biggest predictive factor in increasing the level of transplants - countries with higher levels of transplant facilities are more likely to be successful.
- **Critical care beds:** Evidence suggests that successful organ donation systems tend to have higher numbers of critical care beds. The UK has one of the lowest rates of critical care beds per head of the population at 6.4 per

¹⁶ For example Abadie A and Gay S (2006) *The Impact of Presumed Consent on Cadaveric Organ Donation: A Cross Journal Study*. Journal of Health Economics 25 (2006) 599-620

¹⁷ BHF and Kidney Wales Foundation (2012) *Opting out in Wales: developing the infrastructure*.

100,000 population, compared to Spain which has 33% more capacity at 8.5 per 100,000 population

Organ donation reform in Wales

Following a period of debate and consultation during 2008 and 2009 the Welsh Government is leading the way in the UK by introducing a soft opt-out system of organ donation. Public debate on the issue has clarified that the majority of people in Wales are in favour of an opt-out system of organ donation.¹⁸ The Welsh Government believe that whilst the Organ Donation Taskforce recommendations will improve the current situation, a significant gap will still remain between the number of donor organs needed and the number available for transplant, and that the move to soft opt-out will normalise donation.

The change means that the current legal framework for organ and tissue donation in the UK - the Human Tissue Act 2004¹⁹ – will need to be amended, and this is currently being considered in light of the new system.

NHS Blood and Transplant are opposed to the change and suggested in their evidence to the Welsh Select Committee in March 2011 that misunderstandings about the opt-out system in other UK countries might lead to fewer people joining the register and giving consent, and therefore reduce the number of organs available across the UK.²⁰

The Human Tissue Agency also opposed the introduction of soft opt-out in Wales, with concerns about public support for the scheme and its potential effect.²¹

Church leaders in Wales have been vocal in their opposition to an opt-out system of organ donation, outlining concerns that it would undermine the concept of donation as a gift.²²

In December 2011 the Welsh Government consulted on a White Paper outlining their proposals for the new system of consent, which is expected to start operating in 2015 following a major public awareness campaign.

The White Paper proposes that the new system will not apply to:

- visitors to Wales
- people who live in Wales but die outside Wales
- people who cannot be identified at death
- those whose family cannot be located
- those without the capacity to make a decision about donation
- children and people under 18 years.

Organ Donation Taskforce recommendations

The Organ Donation Taskforce was established in 2006 by the Labour Government to identify barriers to organ donation and identify actions to increase rates. The taskforce published their first report in 2008, including 14 recommendations on

¹⁸ See <http://wales.gov.uk/consultations/healthsocialcare/organdonation/?lang=en>

¹⁹ This applies in England Wales and Northern Ireland. Scotland is governed by the Human Tissue (Scotland) Act 2006

²⁰ Welsh Affairs Committee written evidence (March 2011) accessed at www.parliament.co.uk

²¹ Welsh affairs committee written evidence (March 2011) accessed at www.parliament.co.uk

²² BBC news online. (2012) *Church Leaders in Wales attack presumed consent*. <http://www.bbc.co.uk/news/uk-wales-16676756>

improving the current organ donation system and increasing the rate of organ donation by 50% within 5 years.²³

The UK Government fully accepted the report's recommendations, and funded a £4.5 million public awareness campaign to boost the rate of organ donation. Nicola Sturgeon, Scotland's Health Secretary, welcomed the report and asked the Scottish Transplant Group to take forward the implementation of the recommendations in Scotland.²⁴

The Taskforce was disbanded by the UK Coalition Government in 2011 and work is now being taken forward by a transitional steering group led by Chris Rudge, who previously worked as the National Clinical Director for Transplantation. It will be the responsibility of NHSBT to drive through further development of donation.

The Taskforce's final report published in December 2011 records progress towards meeting the recommendations and achieving a 50% increase in donation. Good progress has been made and many of the recommendations have been fully implemented:

- **Increase the number of deceased organ donors by 50% within 5 years.** The Taskforce's final report anticipates that the target of a 50% increase by 2013 will be met. However, this will be challenging as current levels suggest an estimated increase of 34% by April 2012.²⁵
- **The establishment of a UK-wide Organ Donation Organisation.** This is now the responsibility of NHS Blood and Transplant (NHSBT) and is delivered through the Organ Donation and Transplantation (ODT) directorate of NHSBT. The ODT maintains the register, provides support to all transplant centres and public raises awareness of the importance of organ donation.
- **Financial disincentives to trusts facilitating donation should be removed.** Trusts are now entitled to claim to cover the cost of managing a potential organ donor, even if donation does not proceed.
- **The establishment of a UK-wide network of dedicated organ retrieval teams** to ensure timely, high-quality organ removal from all donors. The National Organ Retrieval service was established in 2010, with 6 dedicated cardiothoracic retrieval teams.
- **The mandatory training of all clinical staff** likely to be involved in the treatment of potential organ donors, including regular update training. Training is provided for medical and nursing students, and a regional network of organ donation collaboratives is being established to support regional education programmes for clinical staff.
- **Identify and implement the most effective methods through which organ donation and the gift of life can be promoted to the general public, and specifically to the BME population.** NHSBT launched a series of campaigns in 2009-10 and work has been undertaken to engage with BME communities.

²³ Organ Donation Taskforce (2008): *Organs for Transplants: A report from the Organ Donation Taskforce*.

²⁴ Press release by Scottish Government 'Human organ donation', 16 January 2008.

²⁵ NHSBT (2012) *Achieving the 50% increase in organ donation*.

In 2007 the Labour Government asked the Taskforce to undertake a review of opt-out and consider the potential impact of such a system in the UK. The resulting report²⁶ recommended that an opt-out system should not be introduced in the UK at that time.²⁷ The Taskforce concluded that there was no evidence to suggest that an opt-out system would deliver significant increases in the number of donated organs, stating that improved rates in countries such as Spain were not a direct result of changing to an opt-out system.

Political support

In 2008, the then Prime Minister, Gordon Brown publicly declared his support for an opt-out system in the media.²⁸ Conversely, the current Coalition Government favours a non-regulatory approach to increasing the numbers of organ donors, and tasked the Behavioural Insights Team – whose works centres around ‘nudging’ people towards desired behaviour changes – with increasing sign up to the organ donation register.²⁹

The Behavioural Insights Team introduced a mandatory question within the driving licence applications in **England** on a trial basis. Now when applicants apply for a licence and are asked if they would like to join the register they have a choice of three answers –

- yes, would like to register
- I do not wish to answer this question now
- I am already registered on the Organ Donor Register

Information on the impact of this change has not yet been published.

In **Scotland**, both the First Minister Alex Salmond and Health Secretary Nicola Sturgeon have indicated they support an opt-out system in principle.^{30,31} Labour MSP George Foulkes has pushed for a change to presumed consent, with 36 MSPs signing his members motion calling for a debate.³²

The Glasgow Evening Times is campaigning for an opt-out system in Scotland,³³ the ‘Opt for Life’ campaign is supported by a motion in the Scottish Parliament proposed by Humza Yousaf, SNP MSP.

Within **Northern Ireland**, there have been no indications from the Assembly Government that they support an opt-out system, though this has been called for by the Alliance Party³⁴ and Democratic Unionist Party.³⁵ There have been calls for a review of organ donation, led by Jim Wells of the Democratic Unionist Party. In its 2011 programme for government, the Fine Gael and Labour Coalition in the **Republic of Ireland** outlined its intention to legislate for an opt-out system of organ donation to improve the availability of organs.³⁶

²⁶ As above

²⁷ As above

²⁸ The Guardian, Sarah Boseley: ‘£11m scheme will boost organ donors by 50%, says taskforce’, 17 January 2008.

²⁹ Cabinet Office. Behavioural Insight Team (2011) *Applying behavioural insight to health*.

³⁰ BBC Online: ‘Sympathy for organ donation change’, 13 January 2008.

³¹ The Herald, Paul Hutcheon: ‘Salmond to back opt-out organ donations in health shake-up’, 27 October 2007.

³² Scottish Parliament Members Motion, George Foulkes: ‘Time for a Fresh Debate on Organ Donation’ 14 September 2007 (S3M-00483).

³³ Glasgow Evening Times (2011) *Stars back organ donor appeal*. <http://www.eveningtimes.co.uk/news/stars-back-organ-donor-appeal-1.1133061>

³⁴ Alliance Party website: ‘Health Minister should examine opt-out scheme to boost organ donation’ 20 July 2007. Accessed 20 Feb 2012.

³⁵ <http://www.agendani.com/policy-check-up> (2010) accessed Feb 2012.

³⁶ Department of the Taoiseach (2011) Programme for Government 2011

Debate on opt-out systems

In February 2012 the British Medical Association published a report aimed to stimulate discussion on the next steps for increasing donor rates in the UK. The report acknowledges the progress achieved through improvements to the infrastructure as recommended by the Taskforce, but states that whether or not the 50% target increase in organ donation is reached people will still be dying unnecessarily. The report suggests a number of potential actions to increase donation rates, including expanding the types of organs used from circulatory death donors to include hearts, accepting higher risk donors, and elective ventilation with the specific intention of facilitating organ donation. The BMA outlines its preference for a soft opt-out system as a means of increasing rates.

To Transplant and Beyond, a support group for organ recipients and their families, is supportive of an opt-out system.

The British Organ Donor Society, a support group for donor families, believes that the problem of low organ transplant rates is too complex to be addressed simply by introducing an opt-out system, and that there is no evidence that this alone increases organ donation rates.³⁷

BHF activity

We will continue to support the legislative changes in Wales, working alongside the Opt for Life Cymru opt out campaigning alliance, led by Kidney Wales Foundation, and using this as a lever for change across the UK. We will work to ensure the move to an opt-out system is accompanied by the necessary developments to the organ donation infrastructure.

The BHF will continue to work to raise awareness of the importance of organ donation for heart transplants, and to encourage people to sign up to the Organ Donor Register, carry donor cards and make their relatives aware of their wishes.

The BHF supports the charity To Transplant and Beyond, which provides support for transplant recipients and their families, and campaigns on organ donation issues.

We are supporting the 2012 British Transplant Games, this is an opportunity to raise awareness of the organ donor register and our calls for a soft opt-out system.

For more information, contact policy@bhf.org.uk

³⁷ See the British Organ Donor Society website. <http://body.orpheusweb.co.uk/>