



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. This shortage has led to concerns that below-standard organs, which would have otherwise been rejected, are being used.^{1,2}

As the nation's heart charity, the BHF has a role to play in 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

The BHF supports measures to improve the UK's rate of organ donation. These measures include consistent national promotion coupled with a strong infrastructure of organ retrieval and professional training.

Whilst such measures will go a long way to improving donor organ availability, we believe that an opt out system (presumed consent) should underpin organ transplantation in the UK. This change in legislation, in and of itself, should help increase public support for organ donation.

However, an opt out system will only gain public confidence if it is sufficiently robust to ensure that everyone who wishes to opt out has an opportunity to do so and there are safeguards to ensure that an individual's wish to opt out is respected and honoured. Furthermore, even in the absence of an explicit opt-out statement, close relatives should still be able to refuse permission at the time of request.

¹ Daily Telegraph, Rebecca Smith, Medical Editor: 'Organs from drug addicts 'being used in transplants' 10 December 2008.

² BBC Online: 'Organ transplants using 'risky donors' rising', 24 November 2009.

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 March 2009, 105 people were on the active waiting list for a new heart or a new heart and lung in the UK, whilst between 2008-09 130 heart or heart and lung transplant operations were carried out, of which 34 were undertaken on young people under the age of 16.³ 20 people on the transplant list died before the transplant could be arranged. 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.⁴ Doctors don't want to add to the anxiety of a terminal illness.

Public support

Although 90% of the UK public supports organ donation, just 27% of the UK population are on the NHS Organ Donor Register (ODR).⁵ Around 65% of the public indicate that they are prepared to donate an organ after their death, suggesting that nearly 40% of the UK population fail to register their wishes to donate on the ODR.³ This highlights a significant inadequacy of the current system to capture current donation preferences on the ODR. To rectify this, campaigners have begun to appeal for a change to the law – calling for the introduction of a presumed consent system for organ donation.

In 2003, a Department of Health consultation 'Human Bodies, Human Choices' did not find clear public support for a presumed consent scheme.⁶ But 2007 saw an upturn of activity and publicity in support of an opt out system. Following a recommendation by England's Chief Medical Officer Liam Donaldson, Health Secretary Alan Johnson asked the Organ Donation Taskforce to explore whether all adults should be automatically added to the Organ Donation Register.⁷ This was in addition to the original remit of the taskforce to identify barriers to organ donation and recommend action to increase donation levels.

In autumn 2007, the Scottish Chief Medical Officer Dr Harry Burns, having previously opposed presumed consent, said that he was now backing a system similar to that which operates in Spain where consent is presumed unless relatives specifically object, but stressed the importance of public support for any change.⁸ The Scotland on Sunday newspaper has also been supporting calls for a change in the law.⁹

In October 2007 a survey of 2,000 people in England, Scotland and Wales published by the British Medical Association revealed that two thirds supported a move to

³ Transplant Activity in the UK 2008 – 2009, NHS Blood and Transplant, 2009

⁴ Organ Donation Taskforce (2008): The potential impact of an opt out system for organ donation in the UK.

⁵ NHS Blood & Transplant website, February 2010.

⁶ 'Human Bodies, Human Choices: summary of responses to the consultation report', London, April 2003. Department of Health, Clinical Ethics and Human Tissue Branch.

⁷ The Guardian, Sarah Bosely, health editor: 'Minister puts opt-out organ donation on the agenda', 20 September 2007.

⁸ The Scotsman, Kate Foster: 'Chief medic backs our campaign for new organ donor law', 7 October 2007.

⁹ The Scotsman, Richard Elias: 'Heart foundation backs organ fight', 21 October 2007.

presumed consent.¹⁰ Support in Scotland was the highest, with 74% in the same survey in favour of a move to presumed consent.¹¹

Public support

In 2008, Gordon Brown publicly declared his support for a presumed consent system in the media, characterised by Alan Johnson as an attempt at “kicking off a national debate”.¹² Brown’s views were supported by the BMA and others, but were condemned by some organisations including the British Patient’s Association who argued that organ donation should stay a voluntary matter, decided by an individual’s conscience and not by the State.¹³

In **Scotland**, both the First Minister Alex Salmond and Health Secretary Nicola Sturgeon have indicated they support an opt out system in principle.^{14,15} Labour MSP George Foulkes has been pushing for a change to presumed consent, with 36 MSPs signing his members motion calling for a debate.¹⁶

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 Party.¹⁷

There has been consistent support in recent years from the Health Secretary Edwina Hart in **Wales**, who is taking steps towards introducing an opt out system – see overleaf.

Organ Donation Taskforce recommendations

The Taskforce’s first report¹⁸ was released in January 2008. It included 14 recommendations on how to improve the current organ donation system in the UK aimed at increasing the rate of organ donation by 50% within five years. These recommendations included:

- The establishment of a UK-wide Organ Donation Organisation, which should be the responsibility of NHS Blood and Transplant (NHSBT).
- The establishment of a UK-wide network of dedicated organ retrieval teams to ensure timely, high-quality organ removal from all heartbeating and non-heartbeating donors.
- The mandatory training of all clinical staff likely to be involved in the treatment of potential organ donors in the principles of donation, including regular update training.
- The expansion and strengthening of the current network of Donor transplant co-ordinators through central employment by a UK-wide Organ Donation

¹⁰ BBC Online: ‘Most back opt-out organ donation’, 18 October 2007.

¹¹ The Scotsman, Ian Swanson: ‘SNP ‘can lead UK in opt-out organ donation’, 3 November 2007.

¹² The Guardian, Sarah Boseley, health editor: ‘£11m scheme will boost organ donors by 50%, says taskforce’, 17 January 2008.

¹³ The Times, Phillip Webster: ‘Gordon Brown seeks to make everyone an organ donor – with opt-out’, 14 January 2008.

¹⁴ BBC Online: ‘Sympathy for organ donation change’, 13 January 2008.

¹⁵ The Herald, Paul Hutcheon: ‘Salmond to back opt-out organ donations in health shake-up’, 27 October 2007.

¹⁶ Scottish Parliament Members Motion, George Foulkes: ‘Time for a Fresh Debate on Organ Donation’ 14 September 2007 (S3M-00483).

¹⁷ Alliance Party website: ‘Health Minister should examine opt out scheme to boost organ donation’, 20 July 2007.

¹⁸ Organ Donation Taskforce (2008): Organs for Transplants: A report from the Organ Donation Taskforce.

Organisation. This would end varied employment and training practices across the country.

- The development of local organ donation policies and identifying individuals or committees with responsibility for donation.
- The identification and implementation of most effective methods through which organ donation and the 'gift of life' can be promoted to the general public.

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. NHS Blood and Transplant also runs a separate educational programme for schools to promote donation called 'Give and Let Live'.¹⁹

Nicola Sturgeon welcomed the Organ Donation Taskforce report and asked the Scottish Transplant Group to take forward the implementation of the recommendations in Scotland.²⁰

Organ Donation Taskforce recommendations

Moves towards introducing an opt out system for organ donation received a setback in November 2008, as the Taskforce released their report on the potential impact of such a change in the law.²¹ The Taskforce recommended that an opt out system should not be introduced in the UK at the present time, stating that the system could:

- Undermine the concept of donation as a gift.
- Erode trust in NHS professionals and the Government.
- Negatively impact on organ donation numbers.
- Distract attention away from the essential improvements recommended in their first report, including improving public awareness and understanding of the current system.
- Be challenging and costly to implement.

The Taskforce was also not convinced 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 as a direct result of changing to an opt out system.

However, the Taskforce does believe that the issue of an opt out system could be reconsidered if the Taskforce fails to meet the 50% increase in donations by 2013. Both Gordon Brown and Nicola Sturgeon have said that the situation will be reassessed in 2013.²²

Other findings in the report include:

- The systematic review of research evidence commissioned by the Taskforce revealed an apparent correlation between high donation rates and opt out

¹⁹ Give and Let Live website, NHS Blood & Transplant, February 2010.

²⁰ Press release by Scottish Government 'Human organ donation', 16 January 2008.

²¹ Organ Donation Taskforce (2008): The potential impact of an opt out system for organ donation in the UK.

²² BBC Online: 'Presumed consent not ruled out', 17 November 2008.

systems in countries around the world, though opt out alone does not explain the variation in organ donation rates between the different countries.²³

- The majority of the public – around 60% – would support a change to an opt out system, as long as it was properly implemented to ensure that the rights of vulnerable groups were protected and there was sufficient information to back it up.
- There are no fundamental legal or ethical barriers to introducing a ‘soft’ opt out system, in which, as a safeguard, family members would be consulted about donation.

Organ donation reform in Wales

While regulation of organ donation is devolved in Scotland, at present this is not devolved in Wales. In 2008, the Health, Wellbeing and Local Government Committee recommended against introducing presumed consent. Betty McBride, BHF’s Director of Policy and Communications, gave oral evidence during the Committee inquiry arguing the case for an opt out system in Wales.

In December 2009, Health Secretary Edwina Hart announced that she would submit a bid for a Legislative Competence Order from Westminster to enable the law to be changed within Wales to introduce a ‘soft’ opt out system for organ donation. This followed a consultation on possible options for change that Ms Hart launched in May 2009:

“The consultation shows strong public support for pursuing a legislative change that would ensure the default position is changed in favour of organ donation but with appropriate safeguards to ensure that those who do not wish to donate have the opportunity to register their wishes and opt out. On this basis, I will be advising the Assembly Government to propose a legislative change to introduce an opt out organ donation system in Wales.”²⁴

The Organ Donation Taskforce identified that the Human Tissue Act 2004, which covers both England and Wales, would need to be revised by primary legislation to accommodate an opt out system.

Private Members Bill (Westminster)

In January 2009, Lib Dem MP Jeremy Brown introduced a Private Members Bill that sought to change the organ donation system to an opt out system in England and Wales.²⁵ The Bill was debated at 2nd reading, but did not advance further before the Parliamentary session ended.

Debate on opt out systems

It is clear that views on an opt out system remain mixed. Organ recipients report that the origin of the donor organ plays an important role. Knowing that the organ was donated willingly can be crucial in helping the recipient come to terms with the

²³ Health Technology Assessment (2009): ‘A systematic review of presumed consent systems for deceased organ donation’

²⁴ Welsh Assembly Government (2009): ‘Options for Changes to the Organ Donation System in Wales’

²⁵ Organ Donation (Presumed Consent) Bill 2008-09, Jeremy Brown MP, House of Commons.

circumstances of the donation – a reassurance that could be taken away if an opt out system was in place.

However, even with an opt out system organ donation will remain a voluntary matter provided individuals understand the nature of the system and have had an opportunity to opt out. This could be a big issue for some individuals, such as those with mental illness or non English speaking immigrants. The British Organ Donation 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.²⁶

The BMA have consistently promoted a legislative change on organ donation, and have included this within their 2010 election manifesto. They call for the introduction of an opt out system following an informed public debate and with appropriate safeguards.²⁷

Supporters of opt out systems often cite the high organ donation rates in countries such as Spain, where a 'soft' opt out system– when health care professionals still ask the family for consent – is in operation. However, high donation rates in Spain cannot primarily be attributed to an opt out system, but are due to a number of other reasons, such as a good system of transplant co-ordination, specific training for intensive care staff on approaching relatives – and making sure this is always done – as well as the high number of traffic accidents in the country.^{28,29} A leading Spanish doctor was quoted as saying “many countries try to increase organ donation through legislation. But a change to presumed consent doesn’t improve the donation rate.”³⁰ The doctor who set up the Spanish system explained further that in practice families are always asked for consent.

An American study analysed the impact of opt out legislation on donation rates by evaluating datasets on organ donation rates and potential factors affecting organ donation for 22 countries over a 10-year period. The study concludes that “presumed consent legislation has a positive and sizeable effect on organ donation rates”.³¹

While legislating to introduce an opt out system won’t be a magic bullet to increase donor rates, a change in the law can help shift social norms and increase support for organ donation.³² Social norms often precede laws but these are then supported, maintained and extended by laws. We have seen a similar experience in tobacco control where the recent legislation outlawing smoking in enclosed public places has helped change the public’s view of the acceptability of smoking around non-smokers.³³ A legislative change on organ donation could have the same effect.

²⁶ Healthy Magazine, Hannah Fox: ‘Should we have an opt-out organ donation system?’

²⁷ British Medical Association (2009) ‘Standing up for doctors, Standing up for health: The BMA Manifesto’

²⁸ Gimbel R.W. et al. (2003), “Presumed consent and other predictors of cadaveric organ donation in Europe,” *Progress in transplantation* 13(1):17-23.

²⁹ Martinez, J et al (2001): Organ donation and family decision-making within the Spanish donation system. In: *Social Science & Medicine* 53 (2001), 405-421

³⁰ Branwen, Jeffreys: How the Spanish donor system works (BBC News, 13 January 2008)

³¹ Abadie, A and Gay, S (2006): The Impact of presumed consent legislation on cadaveric organ donation: A cross-country study. In: *Journal of Health Economics*, 25 (4), 599-620

³² Thaler, R.H., Sunstein, C.R., (2003): Libertarian paternalism. In: *American Economic Review (Papers and Proceedings)* (93), 2, 175-179.

³³ Tang, H et al (2003): Changes of attitudes and patronage behaviour in response to a smoke-free bar law. In: *American Journal of Public Health*, 93 (4), 611-617

“At an intuitive level, informed consent laws allow individuals with strong preferences for donation to separate. As a result, families in informed consent countries infer that non-registered individuals had weak preferences for donation on average and do not consent...In contrast, in presumed consent countries, individuals with a strong aversion to donation are allowed to separate. Families in presumed consent countries infer that non-registered individuals had strong preference for donation on average and consent to donation.”³⁴

Opt out systems also have the support of many transplant professionals. An international survey found that 39% of transplant professionals believed presumed consent legislation was the most effective measure to increase organ donation rates with improved public education being a distant second.³⁵

³⁴ Oz, M.C. et al (2003): How to improve organ donation: results of the ISHLT/FACT poll. In: The Journal of Heart and Lung Transplantation (22) 2, 389-410.

³⁵ Ibid