



Policy statement

Organ donation

Introduction

Heart transplants offer the best chance of long-term survival for critically ill heart failure patients. There is currently a shortage of donor hearts for use in transplantations across the UK, and on average three people die every day in need of an organ.¹

As the nation's heart charity, the British Heart Foundation (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 around three in ten have joined the donor register. We need to change this and make organ donation part of the fabric of our everyday lives.

Promoting organ donation is vital but will not on its own deliver the much needed increase in organs. People are still dying unnecessarily whilst waiting on the transplant list. We need urgent action to address our low rate of organ donation, which performs poorly compared to many other European countries.

We support changing organ donation to a soft opt-out system, where everyone is considered to want to donate their organs unless they state otherwise. We believe this would help increase the number of organs available for donation and better reflect the wishes of the majority of the population.

A soft opt-out system must be sufficiently robust to ensure that everyone who wishes to opt-out has the opportunity to do so, and close family members should be consulted at the time of organ retrieval. Any changes to the system should be accompanied by a wide-ranging communication strategy to engage with people from a range of communities. It's vitally important that people let their families know their wishes so that these are clear and respected after they die.

Organ donation must become part of the everyday routine within hospital practice.

Continued

Developments to the organ donation infrastructure, capacity, and training for health care professionals are therefore also required to provide essential support for an opt-out system.

We support the Welsh Government's move to a soft opt-out system, and we are calling on the Scottish and UK Government and Northern Ireland Executive to follow their lead and pass legislation. NHS Blood and Transplant look after organ donation and transplantation across the UK and a single soft 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

A 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.

As of 8 August 2014, 269 people were on the active waiting list for a new heart or a heart and lung transplant in the UK, 32 of whom are under 18.² However, in reality the real demand is likely to be much higher as many who could benefit from a transplant sadly never make the waiting list, or die waiting.³ In the UK in between April 2013 and March 2014, 456 patients died while on the active waiting list for their transplant and a further 828 were removed from the transplant list.⁴ Between April 2013-March 2014 216 heart or heart and lung transplant operations were carried out.⁵

Between April 2013- March 2014 the number of donors increased by 9% in the UK, and cardiothoracic organ transplants increased by 24%.⁶ However, the number of people on the waiting list for heart transplants has risen by 132% since 2005.⁷ The proportion of older and overweight organ donors is also 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.⁸ For example, donor hearts are not normally accepted from individuals aged over 65, although exceptions can be made on a case to case basis. This has also led to concerns that sub-optimal organs, which may otherwise have been rejected, are being used.^{9,10,11,12}

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 85 per million population (pmp), but the actual donor rate is just 20.6 pmp.¹³ Northern Ireland has the highest donor rate of the UK countries at 26.4 pmp.¹⁴ There are many reasons why potential donors do not go on to donate their organs, their family refusing consent being the most common. Currently 43% of families refuse organ donation because they don't know what their relative's wishes were.¹⁵

It is therefore crucial that people talk to their loved ones about their wishes, as well as join the Organ Donor Register, so they understand what decision they would have wanted to make. When the deceased wishes were known the refusal rate plummets to 11.6%.¹⁶ Ethnicity is also an important factor, with family refusal rates of 75% amongst the non-white population.¹⁷

BME communities

Black and Minority Ethnic (BME) communities in the UK are more likely to need an organ yet have significantly lower rates of donation than the UK white population. For example people of Black and South Asian communities are three times more likely to need an organ transplant.¹⁸ This group represents 7.8% of the UK population¹⁹ but only make up 2% of the organ donor register.²⁰ Research shows²¹ that there are a number of reasons for this low donation rate:

- **Religious belief** – although none of the major religions in the UK oppose organ donation, there are concerns surrounding donation harming one's body and that donation would hinder the respected quick burial ritual followed in some religions.
- **Lack of conversation** – there is a great reluctance amongst some BME communities to discuss death. This is believed to be inappropriate and tempting fate, and therefore results in many dying without their family knowing their wishes.
- **Anxieties and myths of organ donation** – research has shown that the most common barrier to organ donation in BME communities is lack of information surrounding organ donation including how to become a donor. There is also distrust of doctors to do their best to prolong your life if they know you are on the organ donor register. There is also concern around the process of organ removal and if this would distress families where an open casket funeral was the norm.

Becoming an Organ donor in the UK

Currently, in order to become an organ donor individuals must sign up to the NHS Organ Donor Register (ODR). The person's family or loved ones are approached to confirm their wishes at the time of death, and consent is also sought for those individuals not signed up to the register. It is often important for healthcare professionals to speak to a relative at the time of death for information on their medical and social history that may be important in determining whether they are suitable to be a donor. Family members do not have the legal right to veto or overrule the wishes of someone that indicated they would like to donate their organs when they die.

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:

- Registering online at the NHS Blood and Transplant website or via [BHF website](#)
- Calling the NHS donor line: **0300 123 23 23**
- Registering for a driving licence

- Applying for a Boots Advantage card
- Registering at a GP surgery
- Registering for a European Health Insurance card

Although 90% of the UK public supports organ donation, on average just 32% of the UK population are on the ODR.²² As of March 2014 the UK breakdown is as follows:

- England 31%
- Wales 33%
- Scotland 40%
- Northern Ireland 32%²³

Guidance on organ donation²⁴ produced by the National Institute of Health and Care Excellence 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

There are two main forms of opt-out organ donation system, hard opt-out and soft opt-out. Both are systems of presumed consent, where everyone, over a certain age, is presumed to consent to organ donation, unless they register an objection. By registering an objection to donation, that person will opt-out of being an organ donor. A soft opt-out system is characterised by its involvement of the deceased's family at the point of retrieval. For example, families can object to donation if they believe that the deceased objected to donation, but did not get round to opting-out for some reason. Under hard opt-out systems, there is no family involvement at the point of organ retrieval. The BHF is calling for a soft opt-out system.²⁵ Under some opt-out systems the choice to opt-in remains. For example in Wales, residents who wish to expressly consent to donation will still be able to register their wish to donate.

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.²⁶ In Belgium the rate of organ donation increased from 19 to 41 per million population (pmp) three years after the introduction of opt-out legislation. Croatia has one of the highest rates of donation in the Europe, where a soft opt-out system has operated since 1988.

Evidence suggests combining opt-out with organisational and infrastructure developments can significantly improve rates of donation and transplantation. For example, in Norway an opt-out system has operated since 1973 and has seen significant investment in its infrastructure – with Europe's largest single transplant centre based in Oslo and five transplant co-ordinators to aid retrieval across the country. Norway's rate of donation in 2011 was 24.5 pmp,²⁷ which was well above the European average.²⁸ In comparison, in Sweden, where a system of mandated choice operates there is a low organ donor rate at 15.5 pmp in 2011.²⁹ Research suggests that this is due to lack of investment in the infrastructure and organisation with a lack of intensive care beds³⁰ and insufficient identification of potential donors.³¹ A report commissioned by BHF³² 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, for example Belgium has invested heavily in public awareness campaigns, and 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 co-ordinators and 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 6.6 per 100,000 population, compared to Spain which has 33% more capacity at 9.7 per 100,000 population and Belgium which has an even higher rate of 15.9.³³

Cost benefit argument for soft opt-out system

Although heart transplants are expensive treatments the benefits to be gained by patients who receive transplants are priceless, such as an extension of their life, an improved quality of life and removal from medical management of their condition. Together these provide 'favourable cost effective ratios' for heart transplantation³⁴

A cost-benefit analysis model conducted in Wales as part of the legislation to introduce soft opt-out shows that transplantation under an opt-out system is a cost effective treatment option, and would in effect 'more than pay for itself.'³⁵ This is based on the conservative assumption that a change of system would generate just

one additional donor per year. Across all organs this would see a saving of £3million in the first year set against the costs of implementing the system change. There are a number of projections as to the extent to which rates of organ donation are likely to increase following the introduction of an opt-out system. One study suggests that rates could increase by 25-30%.³⁶ This would mean an approximate increase of 15 donors in Wales per year, offering significant financial benefits. Expanding this model and projection to the UK would see a potential increase of between 330 and 396 donors in the UK as a whole representing large cost savings to the healthcare system.³⁷

For heart transplants this analysis also estimated that over a ten year period – the average survival time for heart transplant patients – there would be a net benefit of £2.4 million per transplant.³⁸ This includes a saving of £50,000 per patient, over ten years as a result of removing the need for medical management.³⁹ This figure also takes into consideration the improvement of life quality each transplant patient would experience, calculated through Quality Assured Life Years (QALY).⁴⁰

The benefits in QALYs from a successful donation are significant; patients who receive donor hearts can see their life expectancy increase from only 1.5 years on medical management, to an average survival time of ten years.⁴¹ For those with critical heart failure, a heart transplant is their only treatment option. There will also be significant psychological gains for patients that no longer have to receive on-going medical management and have the peace of mind of longer term survival.

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.⁴² In July 2013, the Welsh Government passed the Human Transplantation (Wales) Act to introduce a soft opt-out system of donation, which will start operating in 2015. Until then the current system of opt-in will continue to operate. The Bill received Royal Assent in September 2013. The bill outlines the following;

The new system will not apply to:

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

The change means that the current legal framework for organ and tissue donation in the UK – the Human Tissue Act 2004⁴³ – will be amended.

NHS Blood and Transplant (NHSBT) raised concerns around introducing a soft opt-out system in Wales 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.⁴⁴ The Human Tissue Authority also did not support the introduction of soft opt-out in Wales, with concerns about public support for the scheme and its potential effect.⁴⁵

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.^{46,47}

In 2007 the UK Labour Government asked the Organ Donation Taskforce to undertake a review of opt-out and consider the potential impact of such a system in the UK. The resulting report⁴⁸ recommended that an opt-out system should not be introduced in the UK at that time.⁴⁹ 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. There is concern that a move to a soft opt-out system would still not close the yawning gap between those waiting for organs and donations. However, even a small increase in the number of donors, which is expected with a move to soft opt-out would be an improvement on current donation rates.

Organ Donation Taskforce recommendations

The Organ Donation Taskforce was established in 2006 to identify barriers to organ donation and identify actions to increase rates. The Taskforce published their first report in 2008, including 14 recommendations on improving the current organ donation system and increasing the rate of organ donation by 50% within 5 years.⁵⁰

The Taskforce recommendations made in 2008 have now all been achieved or undertaken. A key success included achieving an increase in number of deceased donors by 50% within 5 years which NHSBT met in May 2013; the total transplant rate has also increased by 30% since 2008.⁵¹ Other recommendations included the establishment of a UK-wide Organ Donation Organisation, which is now the responsibility of NHSBT and is delivered through the Organ Donation and Transplantation (ODT) directorate of NHSBT; Removal of financial disincentives to trusts facilitating donation and mandatory training of all clinical staff.

The Taskforce was disbanded by the UK Coalition Government in 2011 and work is now being taken forward by a transitional steering group. It will be the responsibility of NHSBT to drive through further development of donation.

Taking Organ Transplantation to 2020

As a follow up on the previous Organ Donation Taskforce report and building on the achievement of a 50% increase in deceased donors NHSBT published their seven year strategy '*Taking Organ Transplantation to 2020*' in July 2013.⁵² The strategy focuses on reducing high family refusal rates, which at 43% is one of the highest in the western world. NHSBT have set four main ambitious targets to achieve by 2020:

1. Aim for consent/authorisation rate in excess of 80% (currently 57%)
2. Aim for 26 deceased donors pmp (at time of publication 19.1pmp, this has risen to 20.6 in the last financial year⁵³)
3. Aim to transplant 5% more of the organs offered from consented, actual donors (35% of hearts and lungs from DBD donors to be transplanted, currently 30%)
4. Aim for a deceased donor transplant rate of 74pmp (currently 49%)

To achieve these goals NHSBT will consider public opinion on radical changes to the

system - opt-out, however, is not one of these options. Instead the strategy notes it will maintain a watching brief on the success of legislative change in Wales.

Political support across the UK

The current UK 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.⁵⁴

The Behavioural Insights Team introduced a mandatory question within the driving licence application in **England** on a trial basis for applications in 2011. 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 but statistics from 2012-13 show that over half of all new signatories to the organ donor register came from Driver and Vehicle Licensing Agency (DVLA) registrations.⁵⁵

In **Scotland**, both the First Minister Alex Salmond and Deputy First Minister (former Health Secretary) Nicola Sturgeon have previously indicated they support an opt-out system in principle.^{56,57}

BHF Scotland has worked with other stakeholders including the British Medical Association to support a Glasgow Evening Times petition⁵⁸ *Opt for Life* which calls for the introduction of a soft opt-out system for organ donation. In July 2013, the Scottish Government announced they were no longer pursuing a change to the system due to lack of consensus between the Scottish Transplant Group (STG). They will be keeping a watching brief on the success of the Welsh legislation.

However in June 2014, MSP Anne McTaggart launched a Members Bill proposing the introduction of a soft opt-out system of organ donation in Scotland. This is now in the consultation phase, expected to close 25 September 2014. The BHF support this Bill and will be responding to this consultation.

In **Northern Ireland**, BHF Northern Ireland work alongside BMA Northern Ireland, the Northern Ireland Transplant Forum, and is part of the Donate NI alliance which is central to promoting organ donation and encouraging as many people as possible to have a conversation with their loved ones about their wishes.

In April 2013, the Northern Ireland Minister for Health, Edwin Poots MLA announced a commitment to conduct a public attitudes engagement to gauge the Northern Ireland population’s views on organ donation. The Executive also committed to bringing forward a consultation of improving organ donation, of which soft opt-out will feature. The public engagement took place over the summer 2013 and results showed that 84% of Northern Irish public support organ donation. Encouragingly, 56% support the introduction of a soft opt-out system. 54%, however were also in favour of the introduction of a mandatory system. However the survey also showed a high level of misunderstanding and confusion about the current organ donor system, more than a third were not aware that the ODR existed and only 16% identified the ODR when asked unprompted what their understanding of the current system was.⁵⁹

There is some political support for an opt-out system in Northern Ireland. Notably the Alliance Party⁶⁰ and Democratic Unionist Party (DUP)⁶¹, who have both called for an opt-out system to be introduced. Jim Wells of the Democratic Unionist Party has been vocal in calls for a review of organ donation. In July 2013, MLA Jo-Anne Dobson launched a consultation to inform a Private Members Bill on a change to soft opt-out. BHF Northern Ireland supported this consultation and the Private Members Bill should follow in late autumn 2014. This consultation reported an 82% support rate for the introduction of a soft opt-out system.⁶² In October 2013 Alastair Ross MLA of the DUP launched his own Private Members Bill on legislation to introduce a prompted choice system, where those applying for or renewing a driver's license would be asked to make a choice on organ donation.⁶³

Republic of Ireland

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.⁶⁴ The consultation launched in July 2013, with the intention of introducing a soft opt-out system. In March 2014, the Irish Department of Health announced that they will introduce a system of soft opt-out.⁶⁵

Debate on opt-out systems

In February 2012 the British Medical Association (BMA) published a report aimed to stimulate discussion on the next steps for increasing donor rates in the UK.⁶⁶ The report acknowledges the progress achieved through improvements to the infrastructure as recommended by the Organ Donation Taskforce, but stated 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.

Kidney Research UK and Transplant Families UK is supportive of the introduction 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.⁶⁷

BHF activity across the UK

We will continue to support the legislative changes as they are implemented in Wales, working alongside the 'Opt for Life Cymru' alliance, led by Kidney Wales Foundation. We will work to ensure the move to an opt-out system is accompanied by the necessary developments to the organ donation infrastructure.

Using the success in Wales as our lead we will encourage the Scottish, Northern Irish and Westminster Governments to move towards a system of soft opt-out

The BHF will continue to work to raise awareness of the importance of organ donation for heart transplants within the current system, 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 2013 British Transplant Games.

'I thought I was going to die'

Wendy was well until she was 23 but when her son, Josh, was born she was diagnosed with post-partum dilated cardiomyopathy. She was told that she has heart failure and put on medication.



"To be told at 23 years old was absolutely devastating. I thought I'd never get to see my son grow up because I was going to die."

Heart failure had a profound effect on her life. She developed symptoms including breathlessness and exhaustion.

In February 2011, Wendy was assessed for a heart transplant. She was given just weeks to live, placed on the emergency list and received her transplant. The night before the operation she said her goodbyes to her best friend, mother, sister and son because she didn't know if she would wake up again. She spent two months in intensive care.

Now she has a completely new lease of life with her Josh. Last year she did a 25-mile bike ride for BHF and this year is planning to do another BHF 40-mile ride in York.

"I have got a life now; I am not a walking zombie like I was before," she said.

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

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

² NHS Blood and Transplant (2014) 'Weekly Statistics'

http://www.organdonation.nhs.uk/statistics/downloads/weekly_stats.pdf

³ Organ Donation Taskforce (2008) 'The potential impact of an opt-out system for organ donation in the UK.'

⁴ NHS Blood and Transplant (2014) 'Transplant Activity Report 2013/14'

http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf figures for all organs, not just hearts.

⁵ NHS Blood and Transplant (2014) 'Transplant Activity Report 2013/14'

http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf

⁶ Ibid (includes hearts, lungs and heart/lung transplants)

⁷ NHS Blood and Transplant (2014) 'Transplant Activity Report 2013/14'

http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf

⁸ NHS Blood and Transplant. (2012) 'Organ Donation and Transplantation Activity Report 2010/11.'

http://www.organdonation.nhs.uk/statistics/transplant_activity_report/archive_activity_reports/pdf/ukt/activity_report_2010_11.pdf

⁹ Daily Telegraph (10 December 2008) 'Organs from drug addicts 'being used in transplants.'

¹⁰ BBC Online (24 November 2009.) 'Organ transplants using 'risky donors' rising.'

¹¹ The Telegraph (5 December 2012) 'The lungs that Jennifer Wederell was given to save her life brought only agonising death.' <http://www.telegraph.co.uk/health/9747128/The-lungs-that-Jennifer-Wederell-was-given-to-save-her-life-brought-only-agonising-death.html>

¹² The Times (11 July 2013) 'Smokers and Drinkers urged to join organ donor register.'

<http://www.thetimes.co.uk/tto/health/news/article3813489.ece>

¹³ NHS Blood and Transplant (2014) 'Transplant Activity Report 2013/14'

http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf

¹⁴ ibid

¹⁵ NHS Blood and Transplant (2013) 'Taking Transplantation to 2020.'

http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf

- ¹⁶ NHS Blood and Transplant (2013) 'Transplant Activity Report 2012-13' http://www.organdonation.nhs.uk/statistics/transplant_activity_report/archive_activity_reports/pdf/ukt/activity_report_2012_13.pdf
- ¹⁷ Sims, J et al. (2012). 'Overcoming barriers to registering as an organ donor among minority ethnic groups.' *Race Equality Foundation*. <http://www.better-health.org.uk/briefings/overcoming-barriers-registering-organ-donor-among-minority-ethnic-groups>
- ¹⁸ NHS Blood and Transplant (2013) Campaign materials. <https://www3.access-24.co.uk/Stock.aspx?G0=Group1&G1=2733>
- ¹⁹ ACORN Statistics <http://acorn.caci.co.uk/>
- ²⁰ NHSBT Campaign materials
- ²¹ Sims, J et al. (2012). 'Overcoming barriers to registering as an organ donor among minority ethnic groups.' *Race Equality Foundation*. <http://www.better-health.org.uk/briefings/overcoming-barriers-registering-organ-donor-among-minority-ethnic-groups>
- ²² NHS Blood and Transplant (2013) 'Transplant Activity Report' http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2012_13.pdf
- ²³ Ibid
- ²⁴ 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
- ²⁵ Unless otherwise stated when this statement refers to opt-out it means soft opt-out .
- ²⁶ 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
- ²⁷ European Commission (2011) 'Organ Donation and Transplantation Facts and Figures.' http://ec.europa.eu/health/blood_tissues_organs/docs/ev_20121009_facts_figures.pdf
- ²⁸ ibid
- ²⁹ ibid
- ³⁰ Sanner et al (2006) 'Obstacles to organ donation in Swedish intensive care units.' *Intensive Care Medicine* Volume 32, number 5: 700-707.
- ³¹ Persson, NH et al. (2005). 'Potential for organ donation in Sweden. Analysis of five year registration of all ICU deaths in southern Sweden.' *Lakartidningen*. Feb 28.03 102(9) 638-41
- ³² British Heart Foundation (2013) 'Making opt-out a reality: Organ donation in Wales'
- ³³ Rhodes, A et al. (2012) 'The Variability of Critical Care Bed Numbers in Europe.' *Intensive Care Medicine*. 38. Pg. 1651.
- ³⁴ NICE 'Guideline No.5 Chronic Heart Failure: National clinical guideline for diagnosis and management in primary and secondary care.' http://www.nice.org.uk/nicemedia/pdf/Full_HF_Guideline.pdf
- ³⁵ Welsh Government (2012) 'Human Transplantation (Wales) Bill Regulatory Impact Assessment.'
- ³⁶ Abadie A and Gay S (2004) 'The Impact of Presumed Consent Legislation on Cadaveric Organ Donation.'
- ³⁷ BHF estimate based on 1,320 donations as cited in NHS Blood and Transplant (2014) 'Transplant Activity Report 2013/14' http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2013_14.pdf
- ³⁸ Welsh Government (2012). 'Human Transplantation (Wales) Bill: Explanatory Memorandum' <http://www.assemblywales.org/bus-home/bus-business-fourth-assembly-laid-docs/pri-ld9121-em-e.pdf?langoption=3&ttl=PRI-LD9121-EM%20-%20Human%20Transplantation%20%28Wales%29%20Bill%20-%20Explanatory%20Memorandum>
- ³⁹ Welsh Government (2012) 'Human Transplantation (Wales) Bill Regulatory Impact Assessment.'
- ⁴⁰ QALY: A measure of health status in terms of the quality of life associated with a state of health, and the number of years for which that health status is enjoyed. Using the Department of Health's measurement that 1 QALY equates to £60,000. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216003/dh_120108.pdf
- ⁴¹ Welsh Government (2012) 'Human Transplantation (Wales) Bill Explanatory Memorandum.' Pg. 48.
- ⁴² See <http://wales.gov.uk/consultations/healthsocialcare/organdonation/?lang=en>
- ⁴³ This applies in England Wales and Northern Ireland. Scotland is governed by the Human Tissue (Scotland) Act 2006
- ⁴⁴ Welsh Affairs Committee written evidence (March 2011) accessed at www.parliament.co.uk
- ⁴⁵ Welsh affairs committee written evidence (March 2011) accessed at www.parliament.co.uk
- ⁴⁶ BBC News online. (2012) 'Church Leaders in Wales attack presumed consent.' <http://www.bbc.co.uk/news/uk-wales-16676756>
- ⁴⁷ The Guardian (2 July 2013) 'Opt-out Organ Donation in Wales.' <http://www.guardian.co.uk/society/2013/jul/02/opt-out-organ-donation-walesBBC>
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