

National Federation of Women's Institutes

2014 Annual Meeting Resolution briefing

Overview

The NFWI Public Affairs Department has compiled these notes to facilitate members' discussions on the resolution that will be voted on at the 2014 AM.

The notes outline the key issues addressed in the resolution, the current status and policy environment on the issues raised, and the main groups already working on the subject.

Please use the notes to inform your further research.

2014 Resolution

Increasing organ donation

The NFWI notes that three people die every day whilst waiting for an organ transplant. We call on every member of the WI to make their wishes regarding organ donation known, and to encourage their families and friends, and members of their local communities to do likewise.

Standon & Cotes Heath WI, Staffordshire Federation

These briefing notes are available online at www.theWI.org.uk/resolutions and on the Moodle. For further information contact:

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Overview

Organ donation is the gift of an organ to help someone who needs a transplant. But there is a shortage of organ donors and three people die every day in the UK while waiting for an organ transplant. People can indicate their wish to be a donor by telling a relative or close friend or joining the NHS Organ Donor Register.

The UK's consent rate is one of the lowest in Europe - last year, four in ten families said no to allowing their loved one's organs to be donated, even in cases when that person was on the Organ Donation Register.¹ The reluctance to discuss organ donation and end of life care has led to the NHS to call for a 'revolution in consent' for organ donation in the UK.

Planned changes to the formal consent system in Wales from 2015 do not change the fact that consent from families is still vital before any transplants in the UK can go ahead. It is the lack of decisions from the thousands of people who die every year, and the subsequent decisions of family members (many of whom may be in a state of distress and quite simply not know the wishes of the deceased) that is the main reason behind low donation rates.

The resolution seeks to encourage WI members to make a choice and make it known (through registering it, or by making sure their closest loved ones know) so that their wishes can be respected upon their death. With surveys finding that around 65% of people are favourable to donating organs upon their death,² the resolution has the potential to add thousands of new would-be donors, each of whom can change nine lives through the gift of organ transplant.

What is organ donation and what is the Organ Donation Register?

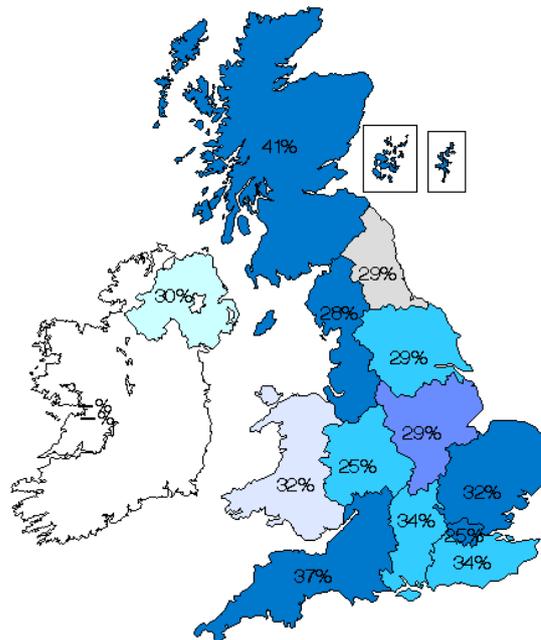
Organ donation is the gift of an organ to help someone who needs a transplant. Kidneys, heart, liver, lungs, pancreas and the small bowel can all be transplanted. Donors can also give their corneas, bone (for use in orthopaedic surgery, for example) and tissue such as skin, heart valves and tendons. One donor can help transform up to nine different peoples' lives.

The Organ Donation Register is a confidential, computerised database which records the wishes of those people who want to donate some or all of their organs and tissue after their death. It also gives legal consent, authorising donation to take place. The register is maintained by NHS Blood and Transplant (NHSBT), the organisation responsible for UK-wide co-ordination of blood and transplant services. The latest statistics from 2012-13 show 3,111 patients benefitted from organs donated after the deaths of 1,212 people, the highest number of transplants ever recorded.³ Last year, almost 942,000 more people joined the Register, bringing the total to 19,532,806 at March 2013.⁴

You can join the Register online, over the phone, by post or when registering with a GP or getting a Boots pharmacy loyalty card. Leaflets to fill out are provided to those applying for a UK passport or the European Health Insurance Card (EHIC). There is no upper or lower age limit to joining - the donor's physical condition (and ability to consent in the case of children) is what is important; organs and tissue from people in their 70s and 80s have been transplanted successfully. The oldest recipient of a cornea transplant in the UK was 104.

The region with the highest proportion of register donors is the South West – but this is still only 37% of the population. The lowest is the West Midlands, at only 25% of people registered.⁵ The Register is important but it is only part of the transplant system. Last year almost 60% of people who donated organs were *not* on the Register.

**Proportion of population registered on the NHS Organ Donor Register by 31 March 2013,
by Strategic Health Authority**



Source: Transplant activity in the UK, 2012-2013, NHS Blood and Transplant

While 25% of the UK population are on the Register, surveys find over 65% of people say they are prepared to donate organs after their death. Further, 90% of people say they would take an organ transplant if they needed one and it was offered to them. However, over two-thirds of families say they would say no to allowing a loved-one's organs being donated for transplantation if they were unaware of their loved one's wishes.⁶

Being a donor

Donors can choose which organs and tissue they'd like to donate, for example, by ticking boxes on the form when joining the Register. Funerals are not delayed as removal of organs and tissue takes place soon after death. NHSBT stress that bodies are not disfigured and incisions are carefully closed and covered by dressings in the usual way. Families are given the opportunity to spend time with their loved one after the operation if they wish.⁷

Generally, donors remain anonymous. But patients and donor families who wish can obtain basic details about donors or recipients, like their age or sex. Some families choose to exchange anonymous letters of thanks or good wishes through NHS transplant co-ordinators and in some instances donor families and recipients have arranged to meet. Various communities around the country have found innovative ways to honour the memory of organ donors through artwork, memorial walls, or gardens, for instance.

The scale of the donor organ shortage

Despite the record number of transplants in this past year, NHS Blood and Transplant still puts the number of people on the waiting list for a transplant at 7,000. The number of people on the register in the UK needs to greatly outstrip the number of people needing a transplant, because while over half a million people die each year in the UK, fewer than five thousand die in circumstances where they can become donors. The pool of potential donors must be very large to increase the chances

that a person dying who is suitable to donate is: a willing donor, has a family that agrees, and will have a blood-type match (etc.) with a recipient. Data from NHSBT shows the number of transplants and donors has remained quite static for ten years while demand for organs continued to increase. Evidence suggests that changes in UK lifestyles and disease prevalence will mean that the need for cardio-thoracic, kidney and liver transplants will continue to increase in the future.

The transplant rate of the UK sits in the middle of the pack of European countries and the United States. In Croatia the transplants per million people figure is 91, the highest rate in Europe. The UK's rate is 49, and Greece's, only 16 (the lowest). Countries' differing forms of consent ('opting-in' to donate vs. 'opting-out' of donating) only partially explains why donation rates and the resulting transplant rates differ so markedly across countries.

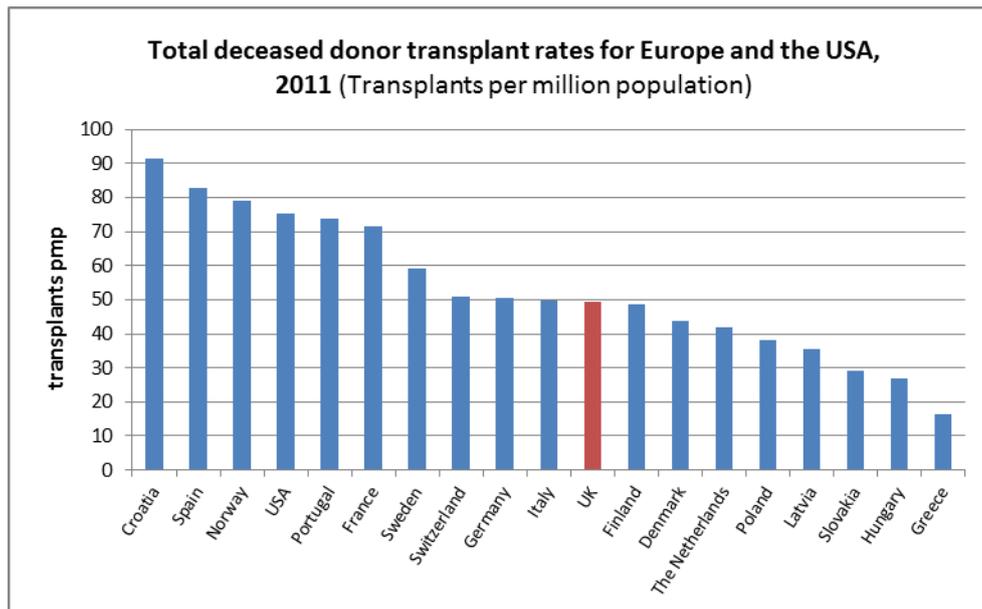


Figure 2: Total deceased donor transplant rates for Europe and the USA.⁸

Giving consent and the role of families

Families are crucial in the transplant system. In 2012/13 more than four out of ten families approached about organ donation refused to donate.⁹ Family refusal rates in the UK are considerably higher than those reported from many parts of mainland Europe and are also substantially higher than might be expected from the reported levels of public support for donation. But most families are only faced with the burden of making a decision about donation at a very distressing time; with a range of factors underpinning any decision about organ donation, the decision is often complex, and the reluctance of many to proceed is understandable. The NHS has worked hard to improve its approach to families and increase the support and information given to them to mitigate the effects of shock and grief upon decision-making.

It is possible for family members to make an organ donation decision on behalf of the deceased, or to overrule the deceased's decision:

1. People can become donors without having officially registered their wishes first if their family gives consent (last year 1,200 people became donors this way)
2. Family members can stop deceased people becoming donors even if they had registered their wishes to donate. 115 families did this last year.

In the case of (1) above, the Organ Donation Taskforce notes that 'unless someone has registered with the Register or carries a donor card, their family and those close to them may not know their views on organ donation when they die'. When their loved one's wishes are unknown, and faced with a decision at a time when they are feeling vulnerable and distressed, 46% of families choose to donate their organs. The remaining 54%, with 'nothing-to-go-on' may feel that the safest course of action for them is to refuse permission for donation.¹⁰ In contrast, when families *know* their loved one wanted to donate - for example either via the NHS Organ Donor Register or via a previous discussion with their loved one about organ donation - their consent rate is 88%.¹¹ This fact is the crux behind the proposed resolution.

In cases of (2), the Human Tissue Act 2004 does *not* provide families with a *legal* right to overrule the wishes expressed by the deceased person. However, the legislation allows 'discretion not to proceed with the donation if doing so would cause deep distress to family members.' This is why family attitudes towards donation remain crucial even if someone is on the Register (and why they will remain crucial in Wales even when people are deemed to have consented by default).

The role of families in donation has prompted NHSBT to call for a 'revolution in consent': 'If the NHS is to save even more lives, more people need to sign up to be a donor, more people need to discuss donation with those close to them and more families need to support donation on behalf of a loved one. Only then will we match the world leaders in the field of organ donation and transplantation.'¹² The Organ Donation Taskforce noted that discussions about donation won't (and don't) happen spontaneously, with people thinking it is morbid or tempting fate. When joining the Register, NHSBT urges anyone registering to speak to their family members about their wishes, 'so that they know what you would like to happen after your death and can confirm to NHS staff what your wishes were.' The Welsh government's 'Have a heart to heart about organ donation' campaign was launched for the same reason.

Recent actions to improve the transplant system

In 2008 a report from the Organ Donation Taskforce called for 14 changes to the UK transplant system. The results have been outstanding; the target to increase organ donation by 50% has been met; there are new guidelines for end-of-life care; more specialist organ donation nurses; and dedicated organ retrieval teams serving the entire UK, 24 hours a day.¹³

Last year NHSBT launched its latest UK-wide Strategy for improving donation rates. It declared that 'Improving consent/authorisation rates is the single most important strategic aim' of the 2013 UK Transplant Strategy, and 'fundamental to the success of the strategy as a whole.'¹⁴ This is an acknowledgment that the NHS must go further than simply increasing the numbers of people the Organ Donation Register. The Strategy states that 'it is naïve to assume that everyone will make a decision and tell their family what they want' and this will also be hampered by families further down the line: 'The UK will never achieve its potential for donation and transplantation when over 40% of families refuse donation, sometimes against the known wishes of the patient.'¹⁵ In short, 'as a society we need to get to a point where we believe it to be normal for families to be asked for consent and normal that they will give it. Secondly, families must be given the best possible support when asked to consider donation on behalf of a loved one.'¹⁶ NHSBT has done its best to address the second part of this point with investment in dedicated donation nurses to be there for bereaved families; the 2013 Strategy and this resolution seeks to achieve the first by asking people to think about their own wishes with the view to having them respected, if ever the question of donation is put to their families.

NHSBT has begun implementing the new Strategy and in October 2013 released new guidelines for NHS staff to help improve the rates of family consent. The guidelines, building upon previous NICE guidance, are based on NHSBT's understanding of the nature of the stress families are often under

when asked to consider donation and how clinicians can do their best to work with families at a crucial time.

Parallel opting-in and opting-out systems in England and Wales from 2015

In 1994 the NFWI passed a mandate calling for the government to consider systems of presumed consent for donation. In 2008 the Organ Donation Taskforce studied the feasibility of introducing an opt-out system in the UK, and advised against it.¹⁷ It concluded that ‘an opt out system has the potential to erode the trust between clinicians and families at a distressing time. The concept of a gift freely given is an important one to both donor families and transplant recipients.’ It ‘found no convincing evidence that [an opt-out system] would deliver significant increases in the number of donated organs.’¹⁸ (Sweden’s switch to opt-out has not increased its donation rates and Spain’s success has been attributed only in part to its opt-out system.¹⁹)

Five years later, the Welsh devolved government has taken a different view from other nations in the UK, and has become the first to introduce an opt-out consent system for organ donation, which will come into force on 1 December 2015. It believes, unlike the Taskforce, that public trust can remain with an opt-out system that it hopes will raise transplant rates by 25%. In 2012/13, only 52 out of 244 potential donors in Wales became actual donors.

Once the legislation comes into effect, Welsh people can:-

- (i) Give express consent to be a donor (opt in); OR
- (ii) make a decision not to be a donor (opt out under a new opt-out register) OR
- (iii) choose not to act and therefore be ‘deemed’ to have given consent.

People who lack capacity to understand that consent could be deemed are excluded from this new system, as are those residing in Wales for less than 12 months.²⁰ Like the current system, people will be able to register a decision to donate all organs and tissues or to select specific organs or tissues. The new consent system in Wales will not change the way that organs and tissues are allocated by NHS Blood and Transplant across the UK. Welsh people waiting for transplants will not be ahead in the queue over anyone else in the UK simply because an organ comes from a Welsh donor.

People in Wales ‘do not need to make any decisions yet’ regarding opting-out and a two year public information campaign has been launched. In the meantime, the Welsh government has encouraged ‘everyone to ensure that people close to them are aware of their wishes regarding donation.’²¹ NHSBT has pledged to work with all UK health departments to alter the organ donation register for the UK so it works for both opt-in and opt-out systems.

During the legislative process, there was opposition from a number of faith groups, patient groups and individuals, and concerns raised about the role of the family. Critics claimed that it would cause extra distress for bereaved families, and could put medical staff in a difficult position. Welsh Health Minister, Mark Drakeford has promised families a ‘clear right of objection’. Where deemed consent applies, ‘the law allows family members to provide information to show the deceased person would not have wished to consent.’ He said that any organs will not be transplanted unless a family member is present. The decision will ultimately rest on clinicians – who still have a duty not to add distress to families of someone who has died.²² Evidence provided to the Welsh government about its decision to introduce an opt-in system concludes:

“The role of the family is crucial under opt-in and opt-out systems of organ donation. Given that relatives’ awareness of the donation wishes of the deceased is one of the most important factors in determining the decision made, campaigns promoting familial discussion about organ donation wishes may be of value.”²³

For people in Wales that have opted out-of donating, their families will not be able to overturn that decision. Consent will also not be deemed for those whose families cannot be contacted or traced. Those who have given their express consent to donate will also have their family consulted, even though it is not legally necessary. Family involvement will remain important to provide information on medical history, mental capacity in some cases, and information about whether the deceased objected to organ donation.²⁴ Figures 3 and 4 below show the role of families in both the current consent process, and the new Welsh process:

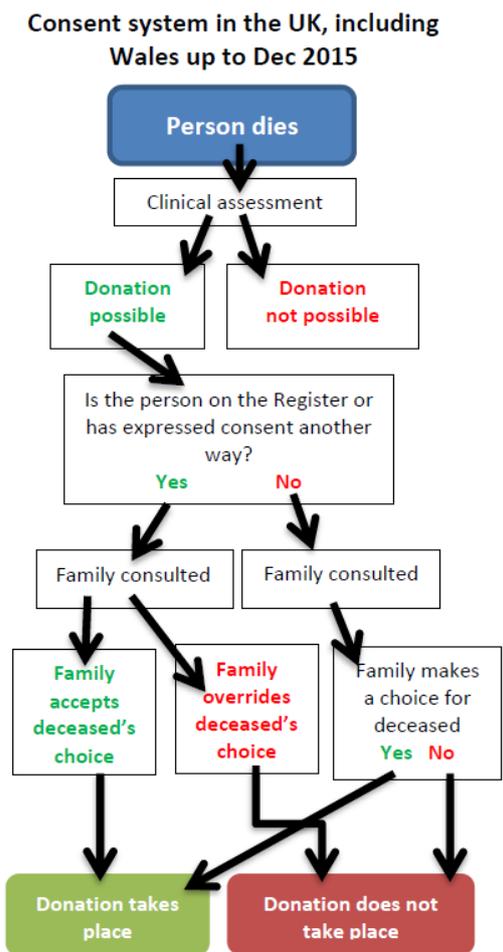


Figure 3: Simplified diagram of the current opt-in system throughout the UK

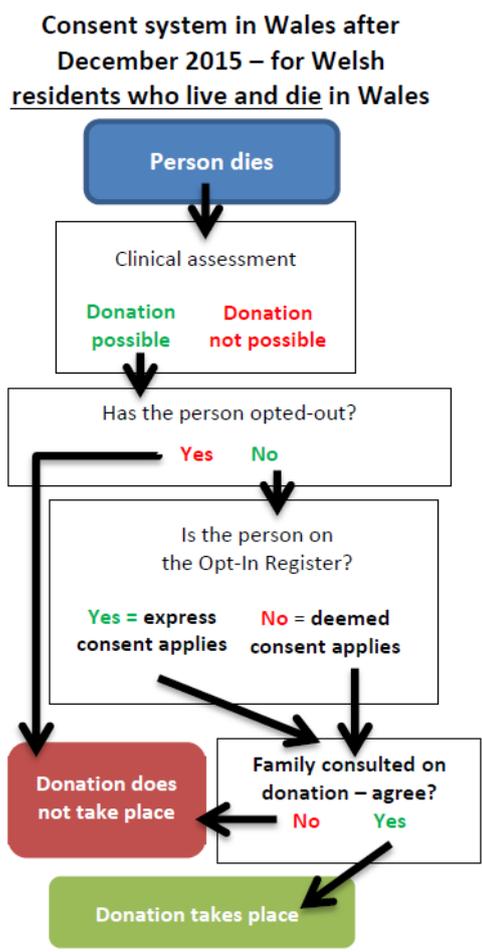


Figure 4: Simplified diagram of opt-out consent system in Wales from December 2015 onwards

The resolution as it stands encourages members to make a decision and make it known (by whatever means they choose), and encourage their family and friends to do so too. After 2015, it will remain important for Welsh members to be encouraged to join the UK-wide opt-in Register, as there is a risk that 'presumed consent' will take away any incentive for people to give express consent.

Welsh people's private, un-Registered wishes *still* can be overruled by their families if consent was 'deemed', as the legislation was purposefully designed to allow this to happen (see figure 4 above). Even with a change to their formal consent system, until there is a 'revolution in consent' Wales still may not overcome the present

situation where many families find it hard to say yes to donation. A potential WI campaign could help make sure presumed consent in Wales is not taken for granted.

Arguments for the resolution

- While most people would take an organ if they needed one, this has been slow to translate into Registration to offer to be a donor. Raising awareness of organ donation, even just amongst WI members, brings the potential of thousands of new donors.
- The current evidence indicates that the crucial aspect to increasing donation rates is getting people to start talking, deciding, and then having their wishes respected.
- The mandate as it stands allows for personal autonomy and choice, a central tenant of the altruistic, gift-based organ donation system that gives such comfort to donors and receivers alike. It also aligns with both forms of consent system in England and Wales.
- Organ donation makes financial sense, and the investment in staff, training and guidelines within the NHS over the last five years has made public attitudes the last piece in the jigsaw puzzle.

Arguments against the resolution

- There are several other high profile public campaigns on this issue, most notably from NHSBT themselves and other medical charities. Is a dedicated WI campaign necessary?
- Members may feel uncomfortable campaigning on an issue that many take as a 'matter of conscience'.

Existing NFWI mandates on the issue

- This meeting urges that the law should be altered to permit people to bequeath their eyes so as to allow surgeons, without obtaining the permission of the executors or next-of-kin, to remove the cornea (front covering of the eye) with adequate safeguard, and in suitable cases, from patients who have died. (1952)
- The meeting urges that improved arrangements should be made for people who wish to donate part of their own body for transplant purposes. (1974)
- To facilitate the donation of organs for transplant and thus reduce the alarming time spent waiting for donors, this meeting urges HM government to consider the systems of presumed consent and required request or other appropriate measures. (1994)

Other campaigns and further information

The Organ Donor Campaign (ODC), part of NHS Blood and Transplant, runs National Transplant Week

NHS Blood and Transplant

Organ Donation and Transplantation Directorate
Fox Den Road
Stoke Gifford
Bristol, BS34 8RR
W:<http://www.organdonation.nhs.uk/campaigns/>.

T: 0117 975 7575
E: enquiries@nhsbt.nhs.uk

Organ Donation Wales

This website features the stories of families who have received and donated organs, as well as information about the changes to the law.

(no postal address or phone number given)
E: organ.donation@wales.gsi.gov.uk
W: www.organdonationwales.org

'Have a Heart to Heart about Organ Donation' – the Welsh government information campaign.
Welsh Government
Cathays Park
Cardiff, CF10 3NQ

W: <http://wales.gov.uk/newsroom/firstminister/2012/121219od/?lang=en>
T: English: 0300 0603300 Welsh: 0300 0604400
E: wag-en@mailuk.custhelp.com

Transplant 2013 – a coalition of patient groups, clinical organisations, and industry representing the organ donation and transplantation community.
One Queen Anne's Gate
London, SW1H 9BT
T: 020 7233 3557
W: www.transplant2013.org.uk

A number of medical charities are interested in this area because of the shortages of organs available for transplant.

Cystic Fibrosis Trust
11 London Road
Bromley
Kent, BR1 1BY
Tel: 020 8464 7211
W: cysticfibrosis.org.uk
E: enquiries@cysticfibrosis.org.uk

The British Lung Foundation
73-75 Goswell Road
London,
EC1V 7ER
W: <http://www.blf.org.uk/Page/Lung-transplantation>
T: 020 7688 5555
E: enquiries@blf.org.uk

British Heart Foundation
Greater London House
180 Hampstead Road
London, NW1 7AW
T: 0300 330 3322
W: <https://www.bhf.org.uk/heart-health/treatment/heart-transplant.aspx>

Speakers

Your nearest acute hospital or transplant unit may be able to assist with speakers. Details for the UK's transplant units are available online: http://www.organdonation.nhs.uk/about_transplants/transplant_units/

Endnotes

¹ NHS Blood and Transplant. 'New Training Tools Launched by NHS Blood and Transplant to Increase Consent Rates for Organ Donation'. Press Release, 9 October 2013.

http://www.organdonation.nhs.uk/newsroom/news_releases/article.asp?releaseld=345

² Organ Donation Taskforce. 'The potential impact of an opt out system for organ donation in the UK: An independent report from the Organ Donation Taskforce'. November 2008.

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalasset_s/@dh/@en/documents/digitalasset/dh_090303.pdf

³ NHS Blood and Transplant (April 2013). 'Organ Donation and Transplantation - Activity figures for the UK as at 12 April 2013' http://www.organdonation.nhs.uk/statistics/downloads/annual_stats.pdf

⁴ NHS Blood and Transplant. 'Statistics'. <http://www.organdonation.nhs.uk/statistics/>

⁵ NHS Blood and Transplant. 'Activity Report 2012/13 Slide Set'.

www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/slide_set_odt_website.ppt

⁶ During May and June 2013, Optimisa Research conducted market research on behalf of NHS Blood and Transplant to measure public awareness, attitudes and behaviour towards organ donation among people living in England. The core sample size was 1,008. There was also a BAME boost sample of 542 people. See NHS Blood and Transplant (14 Jan 2014), 'Partnership urges people to tell their loved ones about their decision to be an organ donor' (press release), http://www.organdonation.nhs.uk/newsroom/news_releases/article.asp?releaseld=357

⁷ NHS Blood and Transplant. 'Organ and tissue donation: your questions answered'. 2009,

http://www.organdonation.nhs.uk/how_to_become_a_donor/questions

⁸ Reproduced from NHS Blood and Transplant. 'Taking Organ Transplantation to 2020: A UK strategy'. 2013,

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

⁹ NHS Blood and Transplant. 'Another record year for organ transplantation - but urgent action needed to save more lives'.

Press Release, 15 August 2013. http://www.organdonation.nhs.uk:8001/newsroom/news_releases/article.asp?releaseld=341

¹⁰ The potential impact of an opt out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. November 2008.

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalasset_s/@dh/@en/documents/digitalasset/dh_090303.pdf.

¹¹ NHS Blood and Transplant. 'Another record year for organ transplantation - but urgent action needed to save more lives'.

Press Release, 15 August 2013. <http://www.nhsbt.nhs.uk/news/2013/newsrelease150813.html>

¹² NHS Blood and Transplant. 'Another record year for organ transplantation - but urgent action needed to save more lives'.

Press Release, 15 August 2013. <http://www.nhsbt.nhs.uk/news/2013/newsrelease150813.html>

¹³ NHS Blood and Transplant. 'Taking Organ Transplantation to 2020: A UK strategy'. 2013,

<http://www.nhsbt.nhs.uk/to2020/the-strategy/summary/#.UgDztcU-PHo>

¹⁴ NHS Blood and Transplant. 'Taking Organ Transplantation to 2020: A UK strategy - Summary'. 2013,

<http://www.nhsbt.nhs.uk/to2020/the-strategy/summary/#.UgDztcU-PHo>

¹⁵ NHS Blood and Transplant. 'Taking Organ Transplantation to 2020: A UK strategy – Improving Donor Conversion Rates'. 2013,

<http://www.nhsbt.nhs.uk/to2020/the-strategy/strategy/improving-donor-conversion-rates/#.UgN8CMU-PHo>

¹⁶ NHS Blood and Transplant. 'Taking Organ Transplantation to 2020: A UK strategy – Improving Donor Conversion Rates'. 2013,

<http://www.nhsbt.nhs.uk/to2020/the-strategy/strategy/improving-donor-conversion-rates/#.UgN8CMU-PHo>

¹⁷ The potential impact of an opt out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. November 2008,

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¹⁸ The potential impact of an opt out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. November 2008,

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalasset_s/@dh/@en/documents/digitalasset/dh_090303.pdf

¹⁹ The potential impact of an opt out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. November 2008,

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalasset_s/@dh/@en/documents/digitalasset/dh_090303.pdf

²⁰ Welsh Government (no date). 'Organ Donation'. <http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/?lang=en>

²¹ Welsh Government (no date). 'Organ Donation'. <http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/?lang=en>

²² Wales Organ Donation opt-out Q&A, 3 July 2013, <http://www.theguardian.com/society/2013/jul/03/wales-organ-donation-opt-out-questions>

²³ Melissa Palmer. 'The role of families in organ donation: International evidence review'. Social research summary no. 45/2012.

Welsh Government, <http://wales.gov.uk/about/aboutresearch/social/latestresearch/familiesorgandonation/?lang=en>

²⁴ Organ Donation Wales (2013). FAQs. <http://organdonationwales.org/FAQs/Organ-donation-from-december-2015/?lang=en>