

Organ Donation

Opt out?

Neil MacLachlan

ONE OF THESE TWO WILL
GET YOUR ORGANS.
YOU DECIDE.



Neil MacLachlan

Family experience 2006

The
Love
Hearts
Appeal



Great
Ormond
Street
Hospital
Charity

Ever thankful to the donor and their family

- Transfer from Jersey to London Easter 2006
- Transplant June 16th 2006
- Back at school September 2006
- Durham University
- Love Hearts Appeal 2102





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Some interesting facts

- **The first living organ donor in a successful transplant was Ronald Lee Herrick (1931–2010), who donated a kidney to his identical twin brother in 1954. The lead surgeon, Joseph Murray, won the Nobel Prize in Physiology or Medicine in 1990 for advances in organ transplantation.**
- **The youngest organ donor was a baby with anencephaly, 2015, who lived for 100 minutes and donated kidneys to adult in renal failure.**
- **The oldest known organ donor was 107 years Scottish woman whose corneas were donated after death in 2016. The oldest known organ donor for internal organ was 92 year old Texan man whose family agreed to donate his liver after he die of stroke.**
- **The oldest altruistic living organ donor was an 85-year-old woman in Britain, who donated her kidney to a stranger in 2014 after hearing how many people needed to receive a transplant.**

A rare situation

Although over half a million people die every year in the UK, fewer than 5,000 people will die in circumstances where they can become an organ donor.

You are more likely to be in a situation whereby you need an organ to survive than be in a situation where you can donate your organs on death.

Waiting is not easy

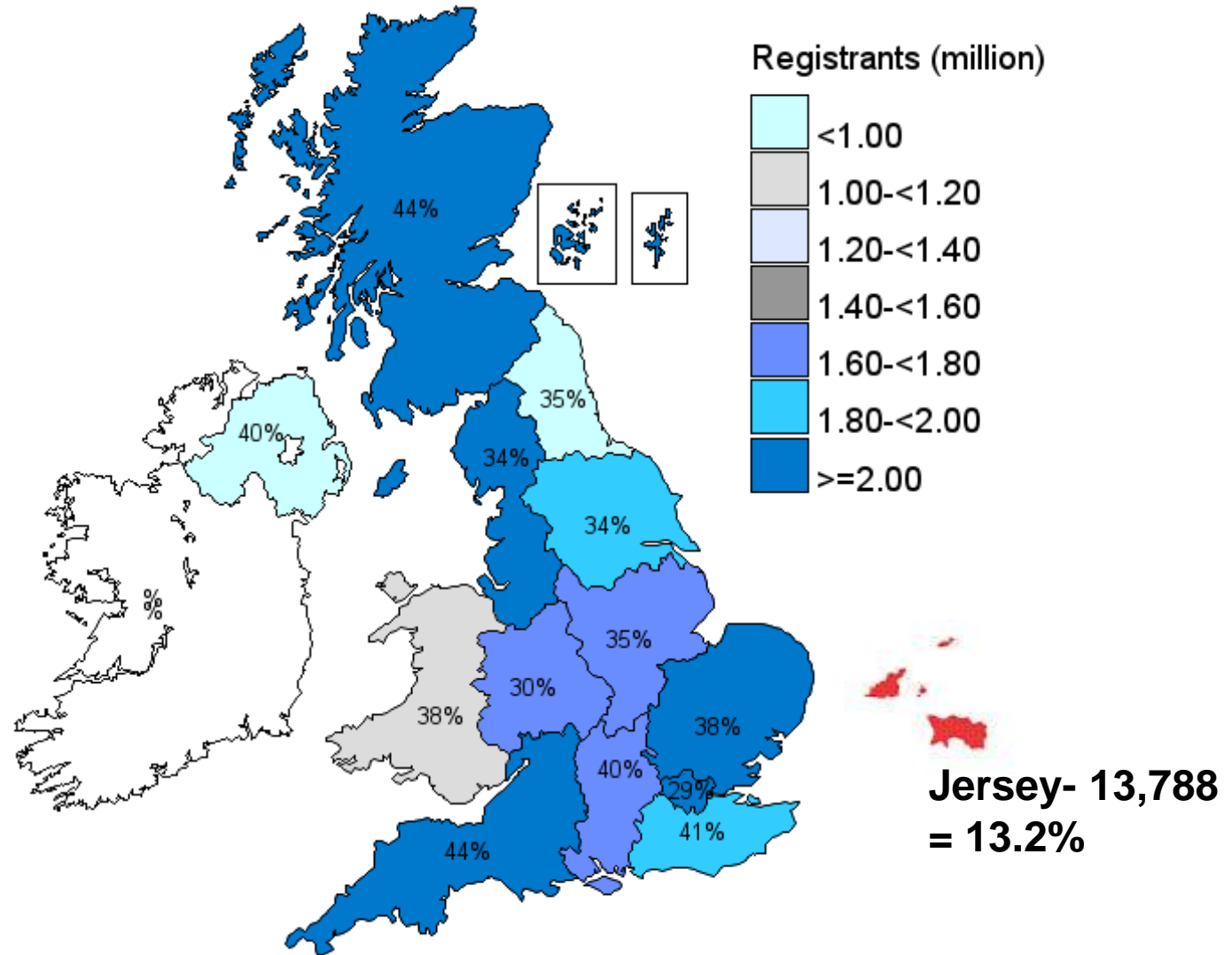
- Last year, 457 people died waiting for a transplant, including 14 children. There are currently 6,414 people on the transplant waiting list including 176 children. 3/day die waiting.





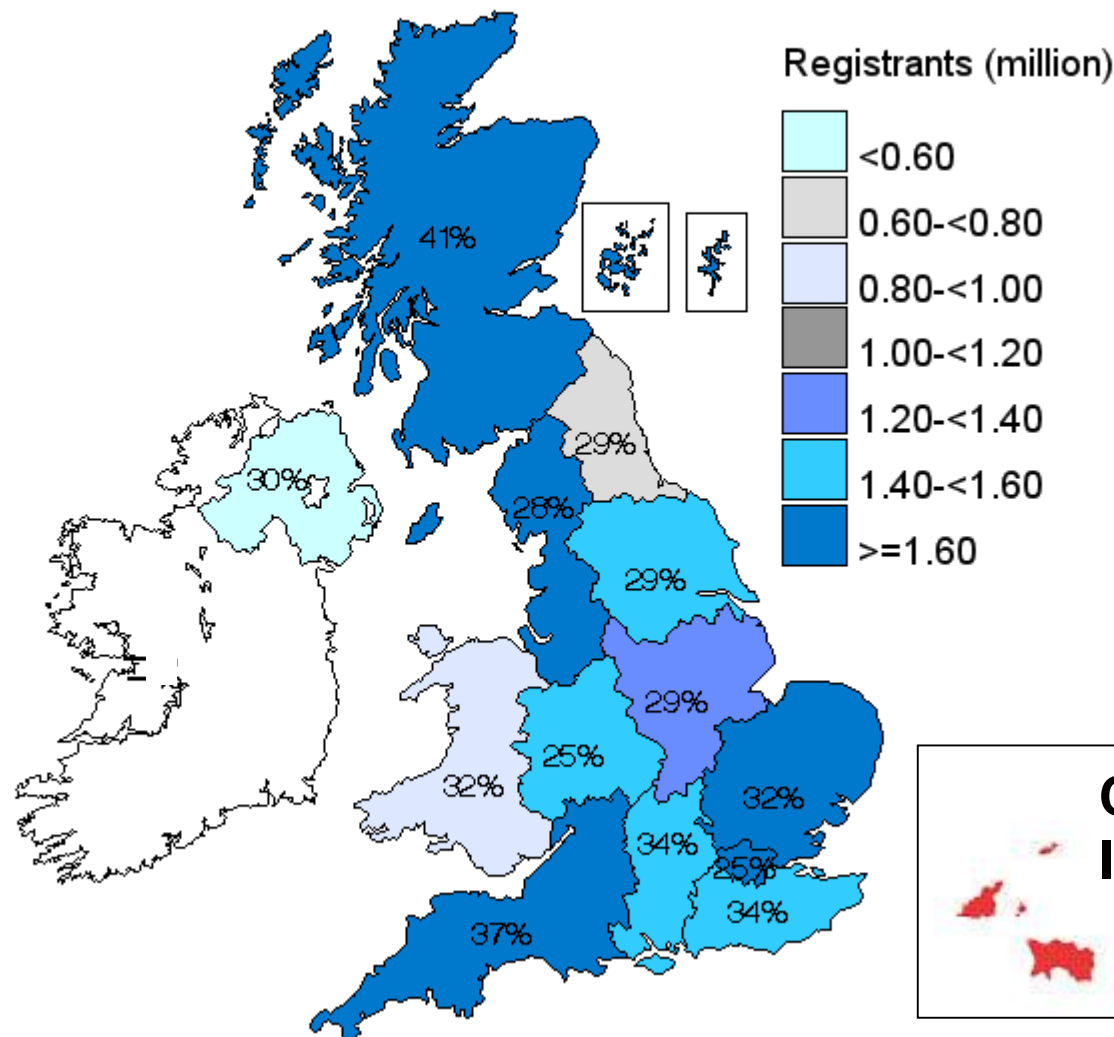
Jemima Layzel – 8 people saved

Proportion of people who opted-in on the NHS Organ Donor Register by 31 March 2017, by Strategic Health Authority



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



Guernsey,
6080/59,000=
10.3%

March 2017

Jersey- 13,788 =
13.2%

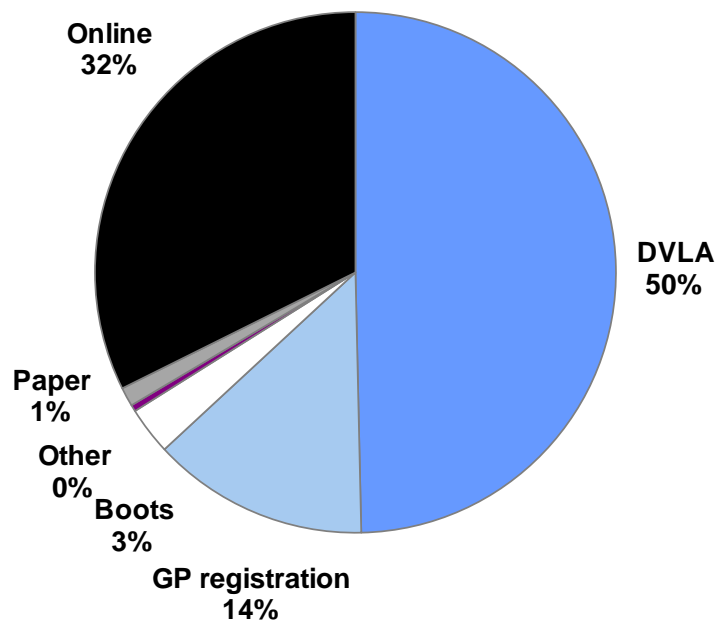
July 2013, 9304,
9% Jersey

Channel Islands

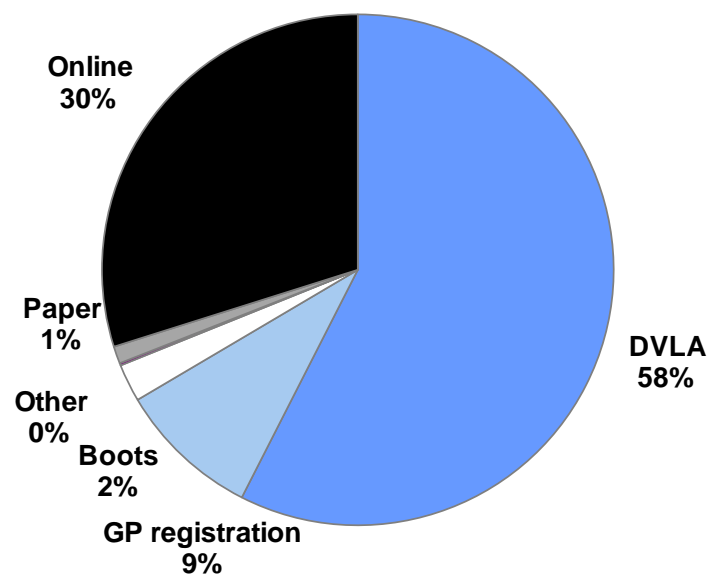
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Source of applications for opt-in registration¹ on the NHS Organ Donor Register, 1 April 2015 - 31 March 2017

2015-2016



2016-2017



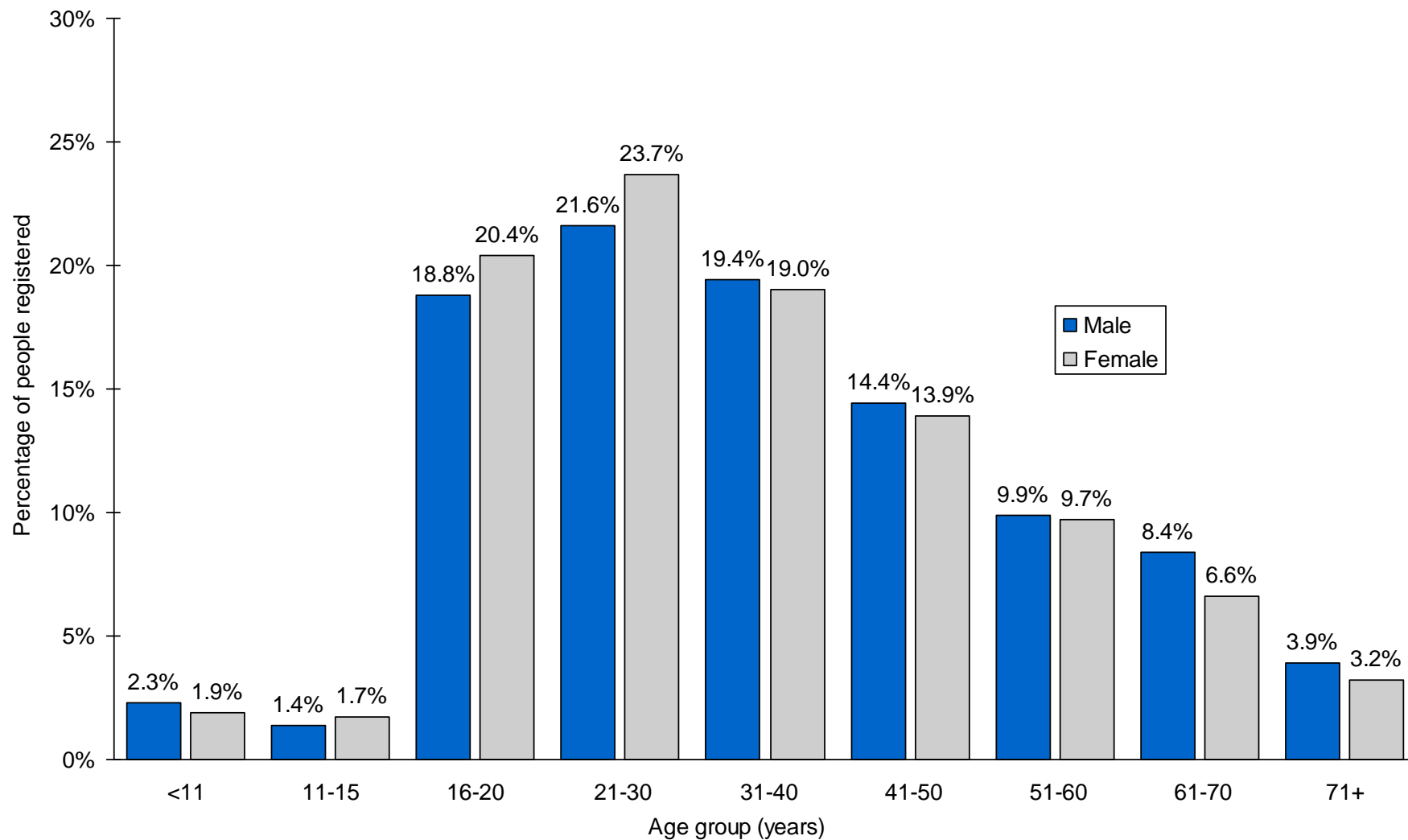
¹ Please note that a back-log of registration activity made via the UK GP Services is not accounted for in these figures. These registrations will be uploaded in due course and reflected in future reports

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www.organdonation.nhs.uk

- 95% people would accept an organ if necessary
- 13% on organ donation register in Jersey
- 36% on register in UK
- One register for all
- 3 people die every day waiting for organ
- 1000 die / year
- Every person has equal right of receiving organ
- 46% family refusal rate

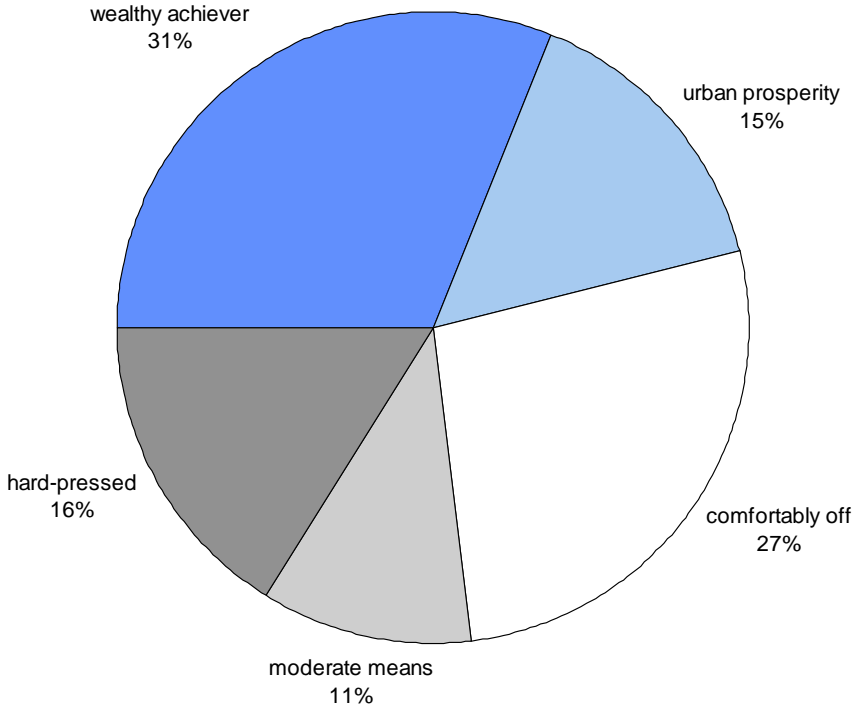
Age and gender of people registered on the NHS Organ Donor Register by 31 March 2012



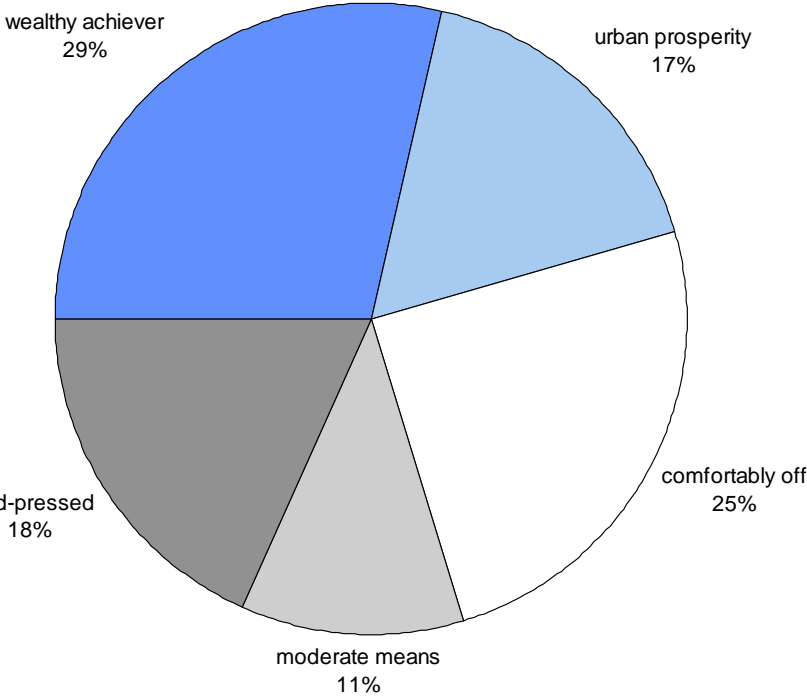
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Registrants on the NHS Organ Donor Register, 1 April 2011 - 31 March 2012, and the general population, by socio-economic group

ODR registrants



UK population



New strategy

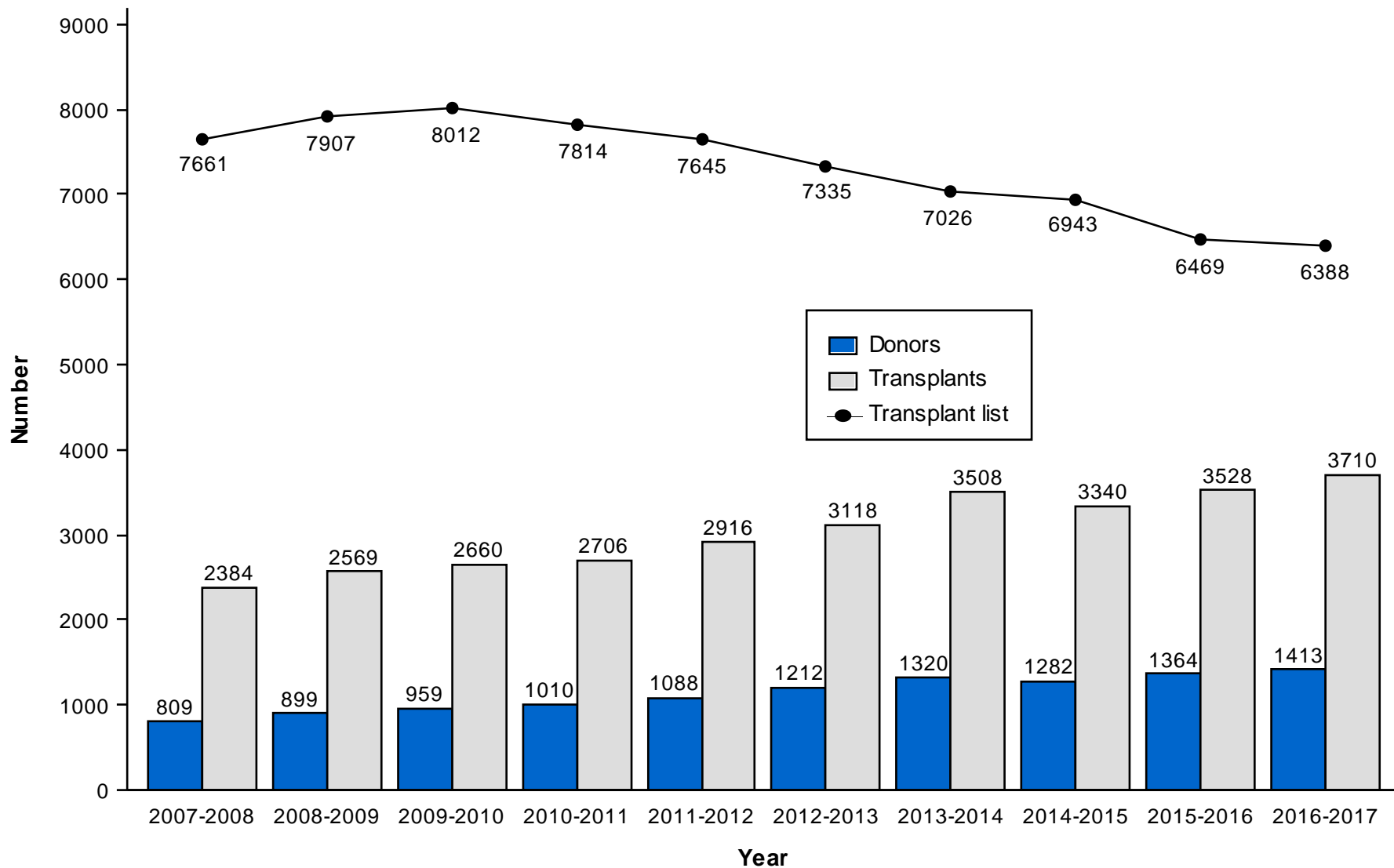
- NHSBT is working with stakeholders to develop **a strategy to ensure that as many people as possible in the UK receive the transplant they need.**
- We aim to increase the number of people having a transplant and this means increasing both the number and quality of donors/organs.

Organ Donation and Transplantation

Strategic Objectives to 2016/17

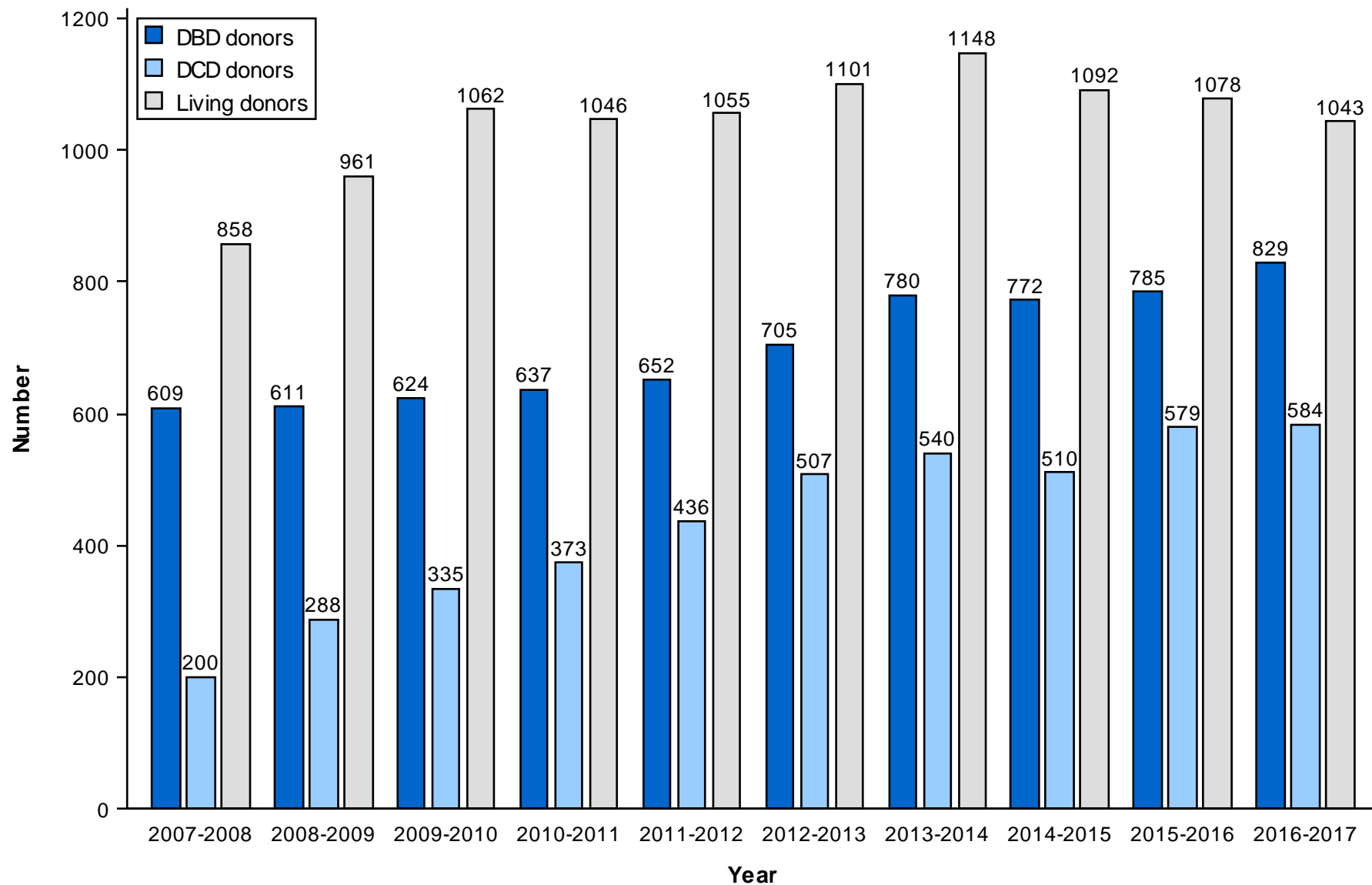
Portfolio of evidence

Number of deceased donors and transplants in the UK, 1 April 2007 - 31 March 2017, and patients on the active transplant list at 31 March



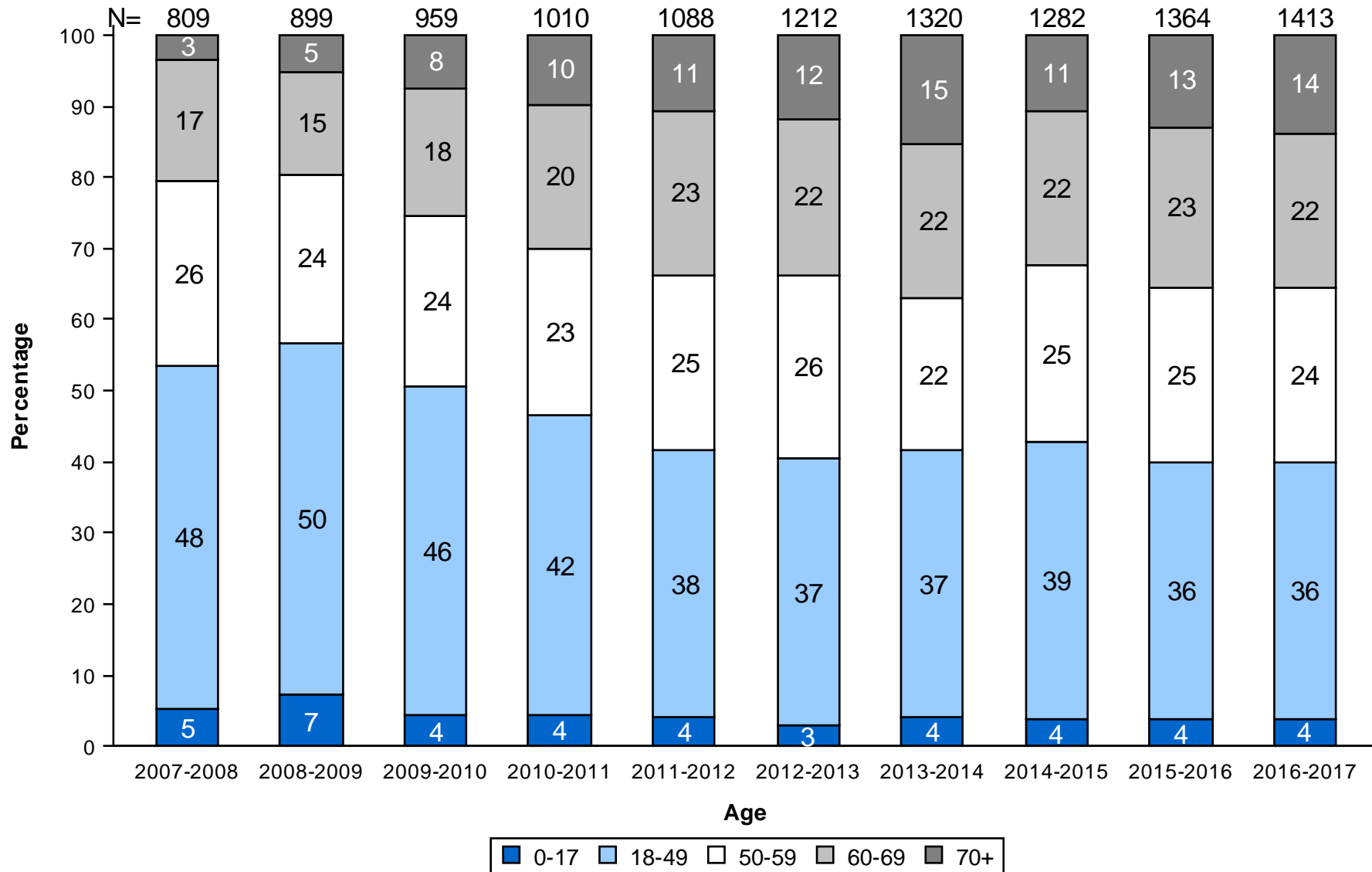
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Number of deceased and living donors in the UK, 1 April 2007 - 31 March 2017



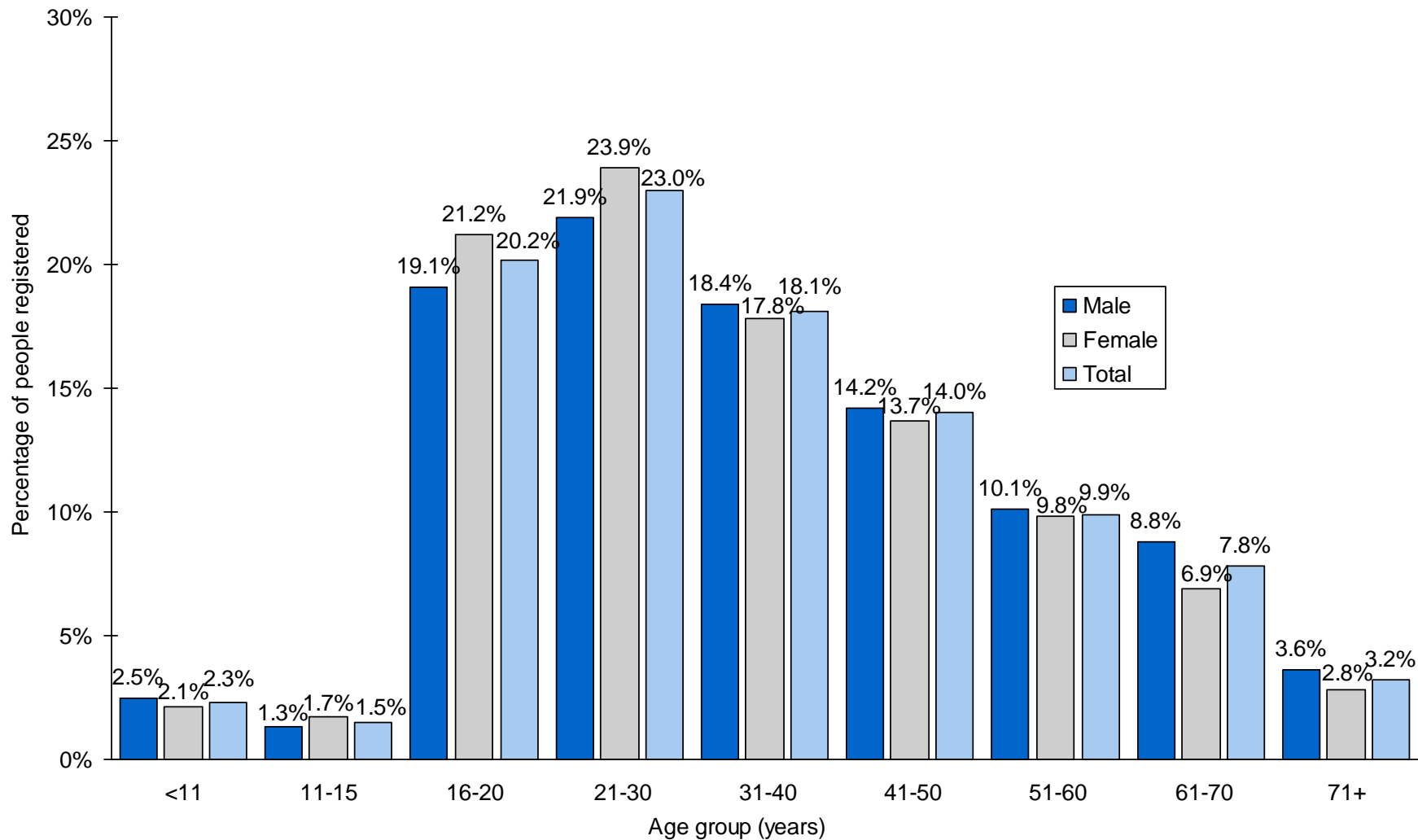
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Age of deceased donors in the UK, 1 April 2007 - 31 March 2017



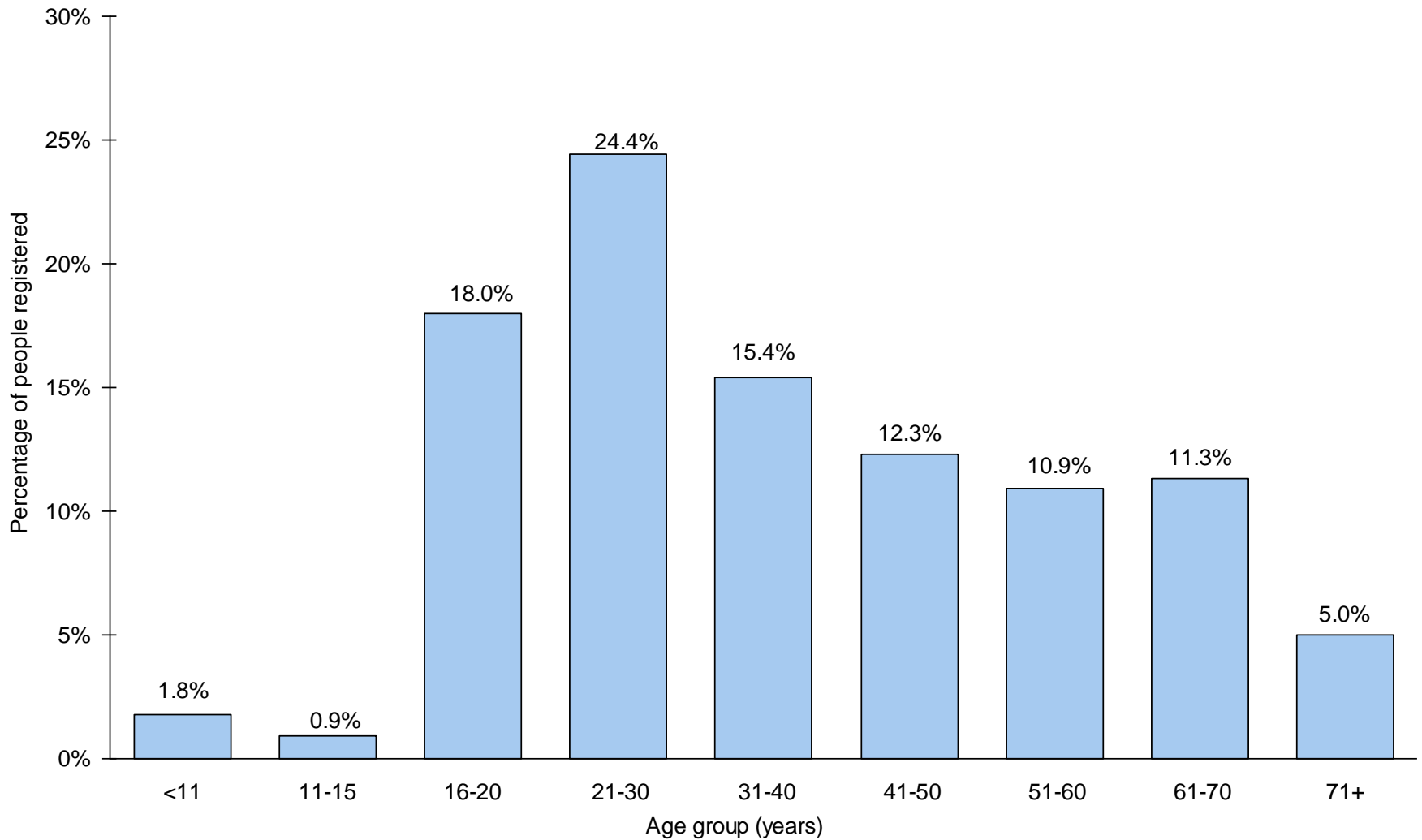
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Age and gender of total people registered as opt-in on the NHS Organ Donor Register by 31 March 2017



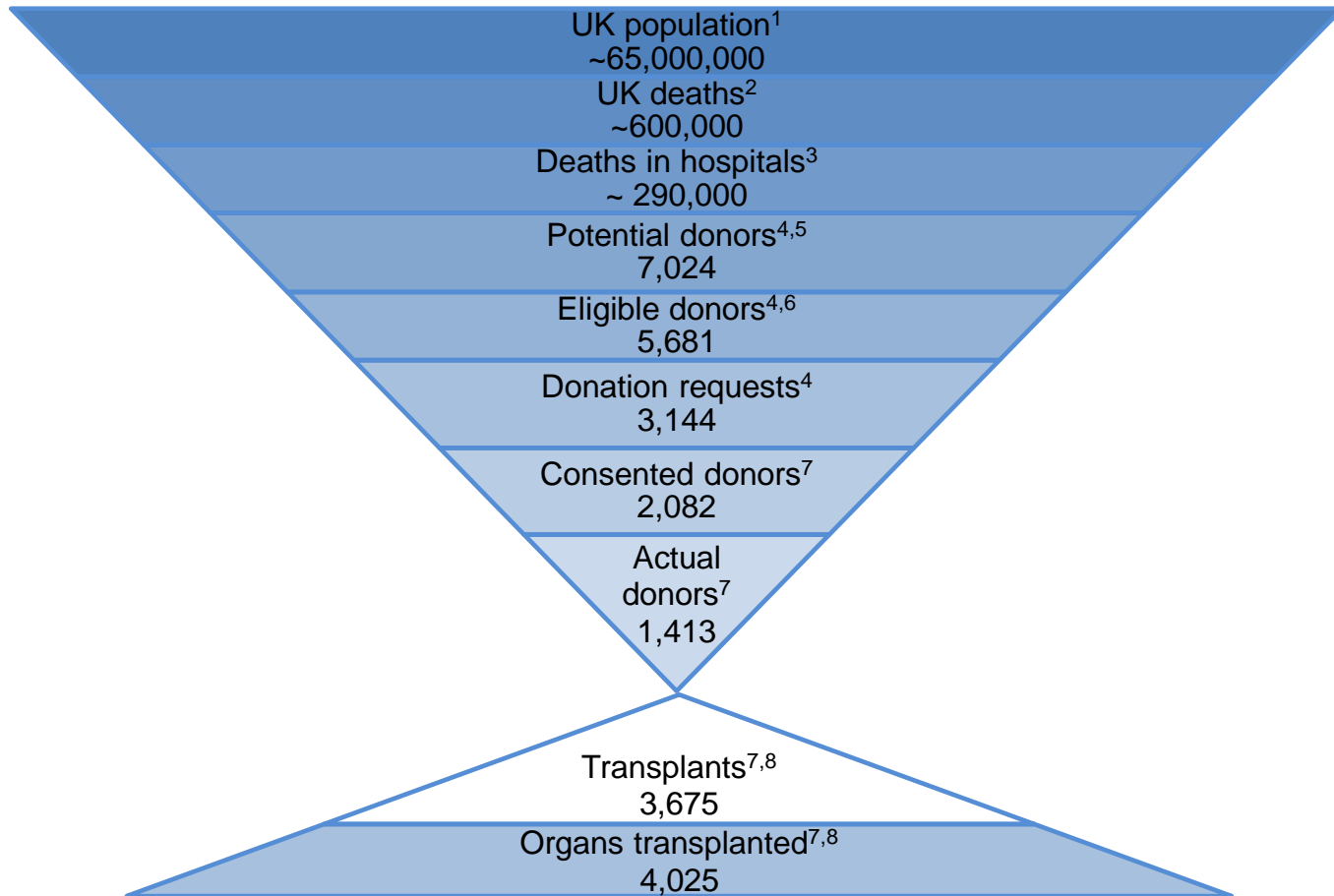
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Age of people registered as opt-in on the NHS Organ Donor Register between 1 April 2016 and 31 March 2017



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UK potential deceased organ donor population, 1 April 2016 – 31 March 2017



¹ Mid 2015 estimates: www.ons.gov.uk

² 2015 data: England & Wales www.ons.gov.uk; Scotland www.gro-scotland.gov.uk; Northern Ireland www.nisra.gov.uk

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⁴ 2016/2017 data: NHSBT, Potential Donor Audit

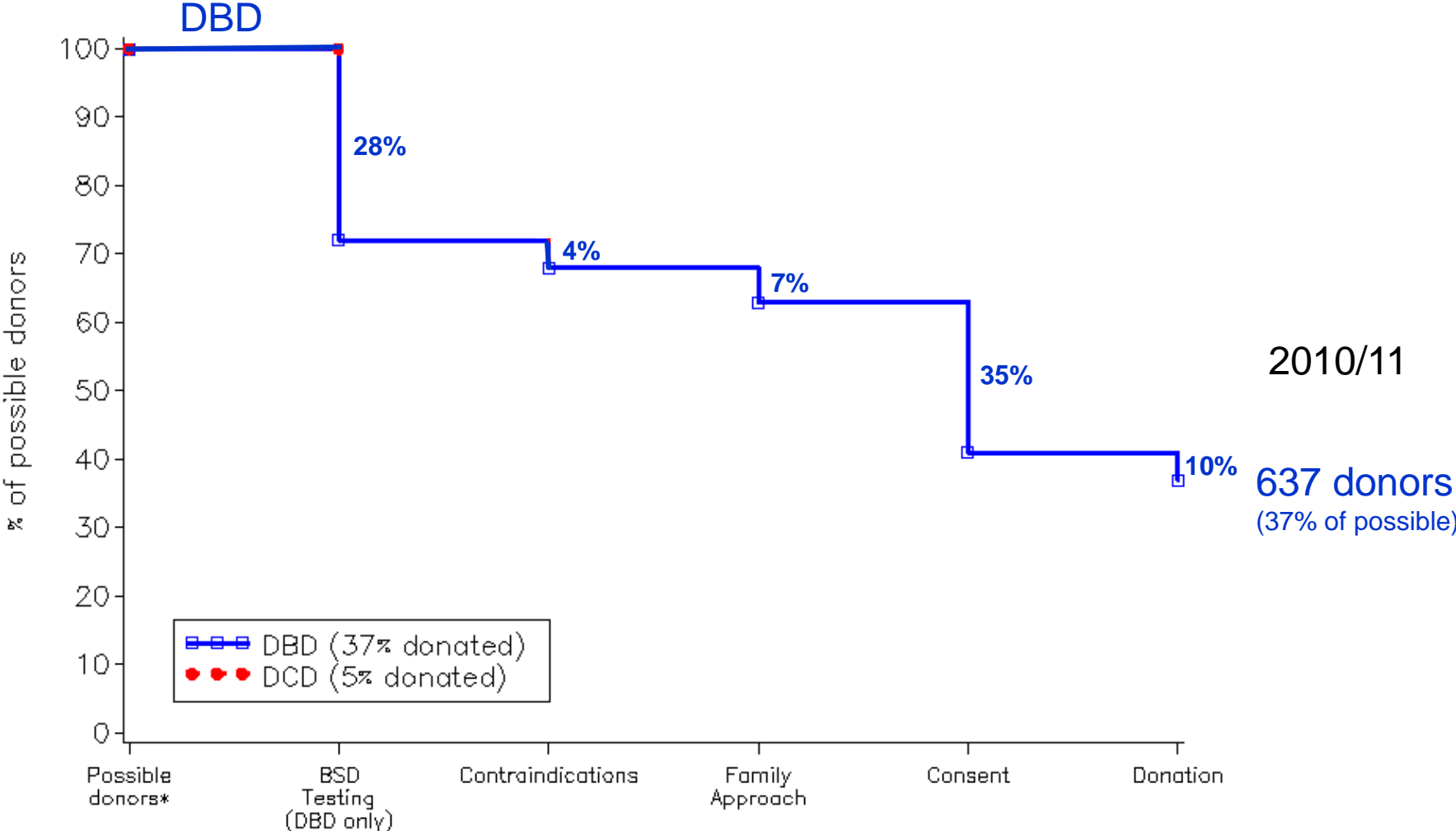
⁵ Potential donor - patients for whom death was confirmed following neurological tests or patients who had treatment withdrawn and death was anticipated within four hours

⁶ Eligible donor - Potential donor with no absolute medical contraindications to solid organ donation

⁷ 2016/2017 deceased donor data: NHSBT, UK Transplant Registry

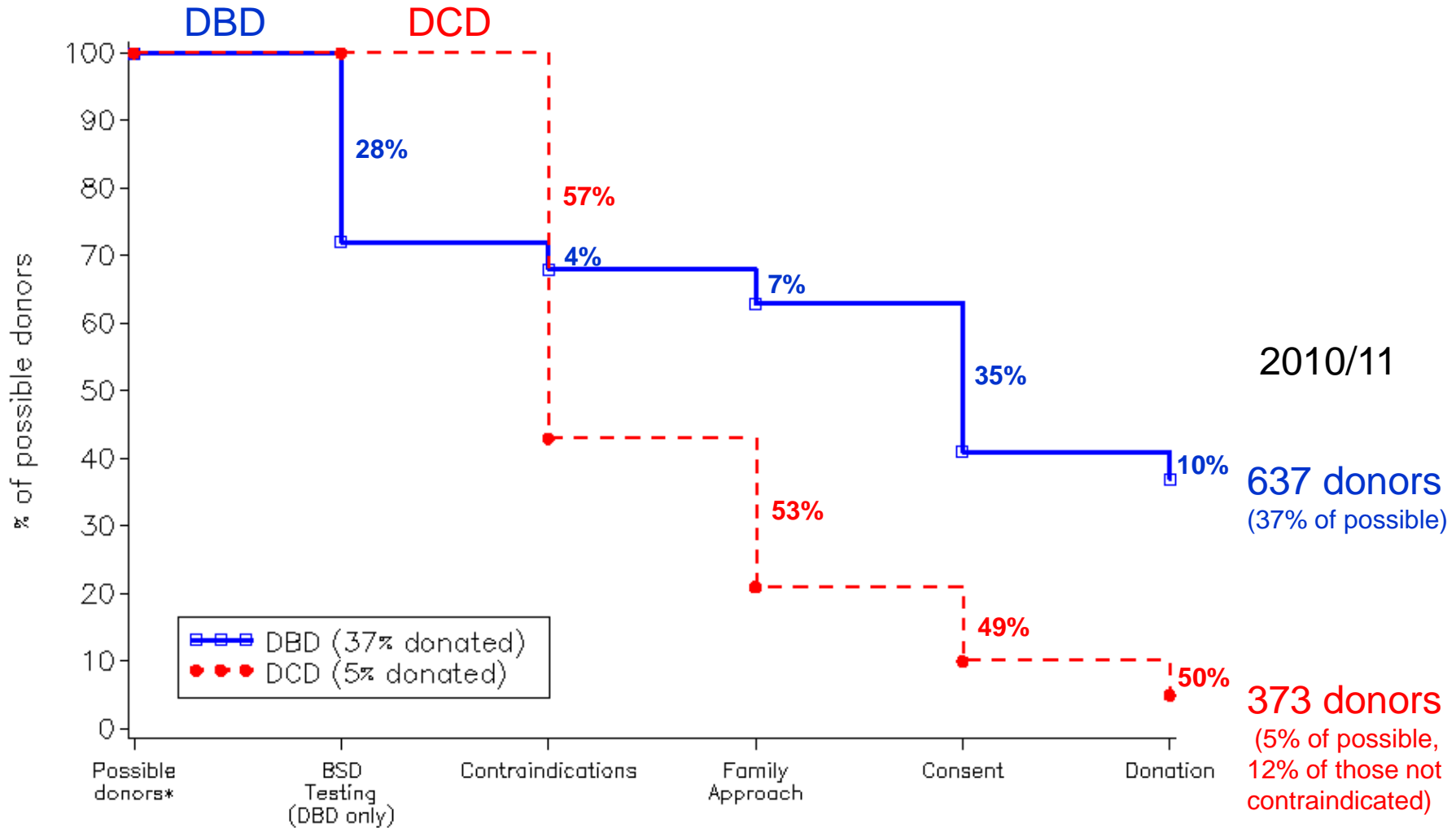
⁸ Using organs from actual donors in the UK

Where are opportunities lost pre-donation?



* DBD – possible donors meeting criteria for neurological testing
DCD – possible donors not confirmed dead by neurological criteria where imminent death anticipated and treatment withdrawn

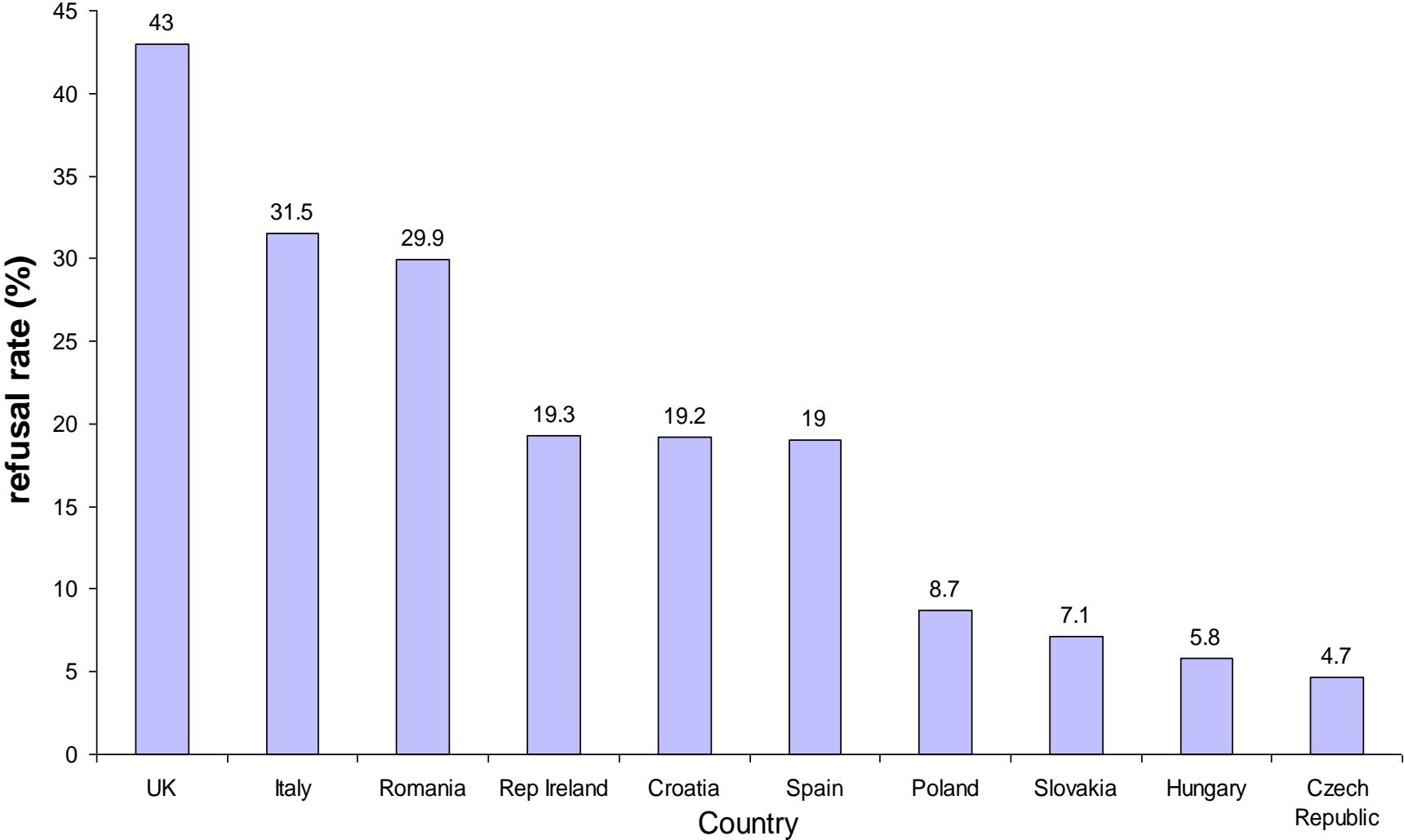
Where are opportunities lost pre-donation?



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Family refusal rates, 2010



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Note – limited international data available on family refusal rates

The deceased rights?

- **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).**

Knowing helps

- 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.**
- 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%.**
- This fact is the crux behind the proposed resolution.

The family input

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

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)

Family members can stop deceased people becoming donors even if they had registered their wishes to donate. 115 families did this last year.

How do we make organ donation a normal part of Jersey / UK culture?

Donor behaviour change

IDEAS

- HSSD/NHS staff to lead the way
- Partnerships with big employers
- Big campaigns every year eg Love Hearts
- Local publicity stories
- **Change consent system**
- Make it part of your will
- **Standard part of the education curriculum**
- Targeted engagement programme with BME communities and the councils where they live
- More information about living and altruistic donation

How do we make sure every eligible donor is given the opportunity to donate?

Perfect practice every time

IDEAS

- No refusal without a detailed conversation with a trained expert
- Allow all families to consider donation over a longer period
- Develop an ICU reimbursement tariff which reflects and rewards perfect practice
- A plan for efficient donor testing
- Dedicated bed in busy units

What should we do to increase the pool of appropriate potential donors?

Total hospital approach

IDEAS

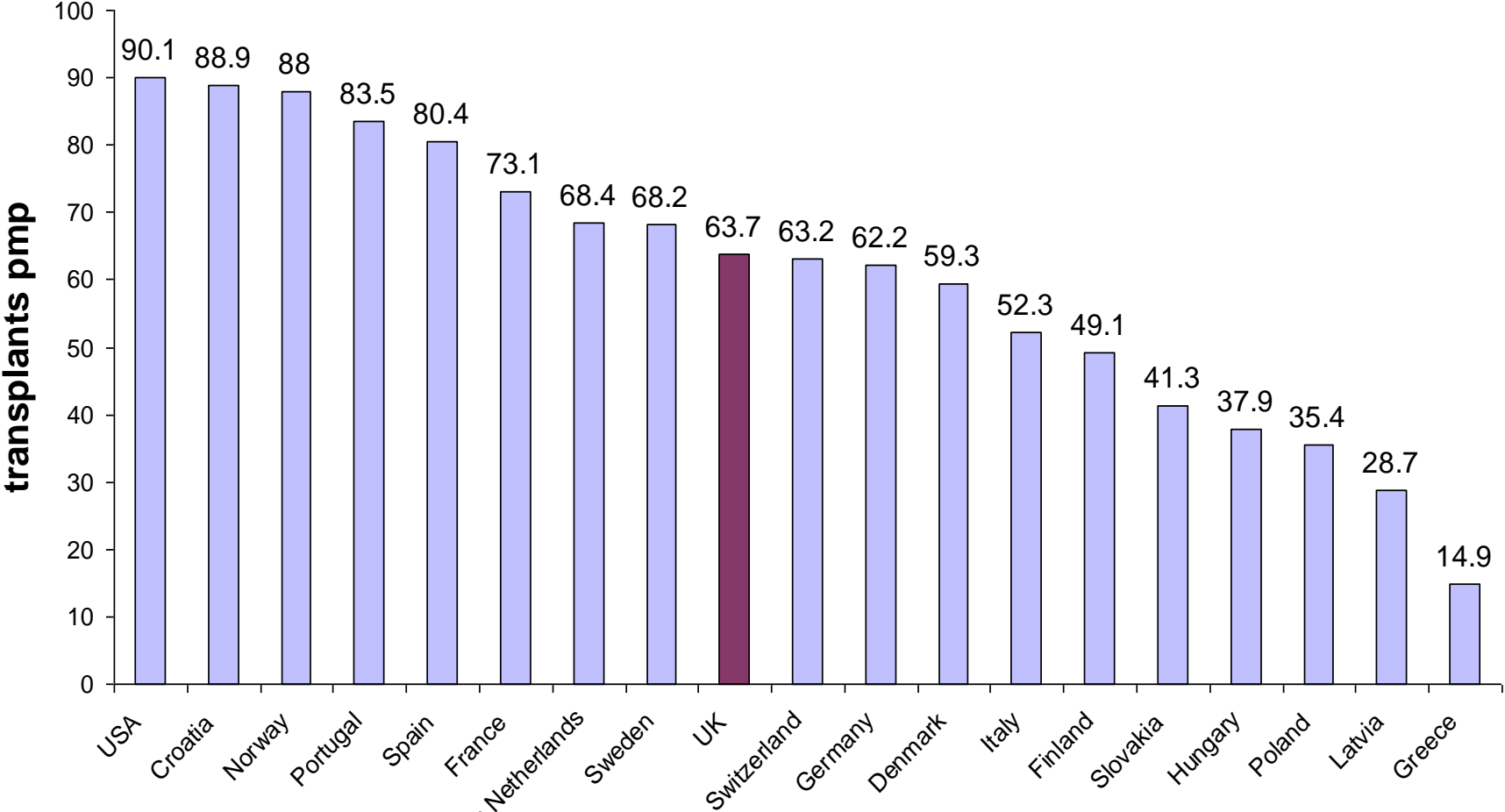
- Donors from outside ICU & ED
- Uncontrolled DCD donors
- Increase ICU capacity when there is a eligible donor
- 48 hour 'watchful waiting' before treatment withdrawal
- Elective ventilation
- Cardiac Donation after DCD

DCD

- INTERESTING CASE
- Female in their twenties with Idiopathic pulmonary fibrosis + awaiting lung transplant.
- She had contracted H1N1 and her respiratory failure progressed rapidly over the course of 4 days; she was admitted to ICU for non-invasive ventilation only (NIV).
- There was further deterioration over the next 2 days despite NIV and a decision was made with the patient that the priority was to keep her comfortable and to withdraw treatment.
- She was registered on the Organ Donor Register and despite intermittent confusion due to hypoxia, she directly expressed a wish to be a donor to the consultant during conversations about end of life care.
- Her family supported this decision and gave consent for solid organ donation.
- Donation after circulatory death occurred and both kidneys were successfully transplanted.

Total transplant rates

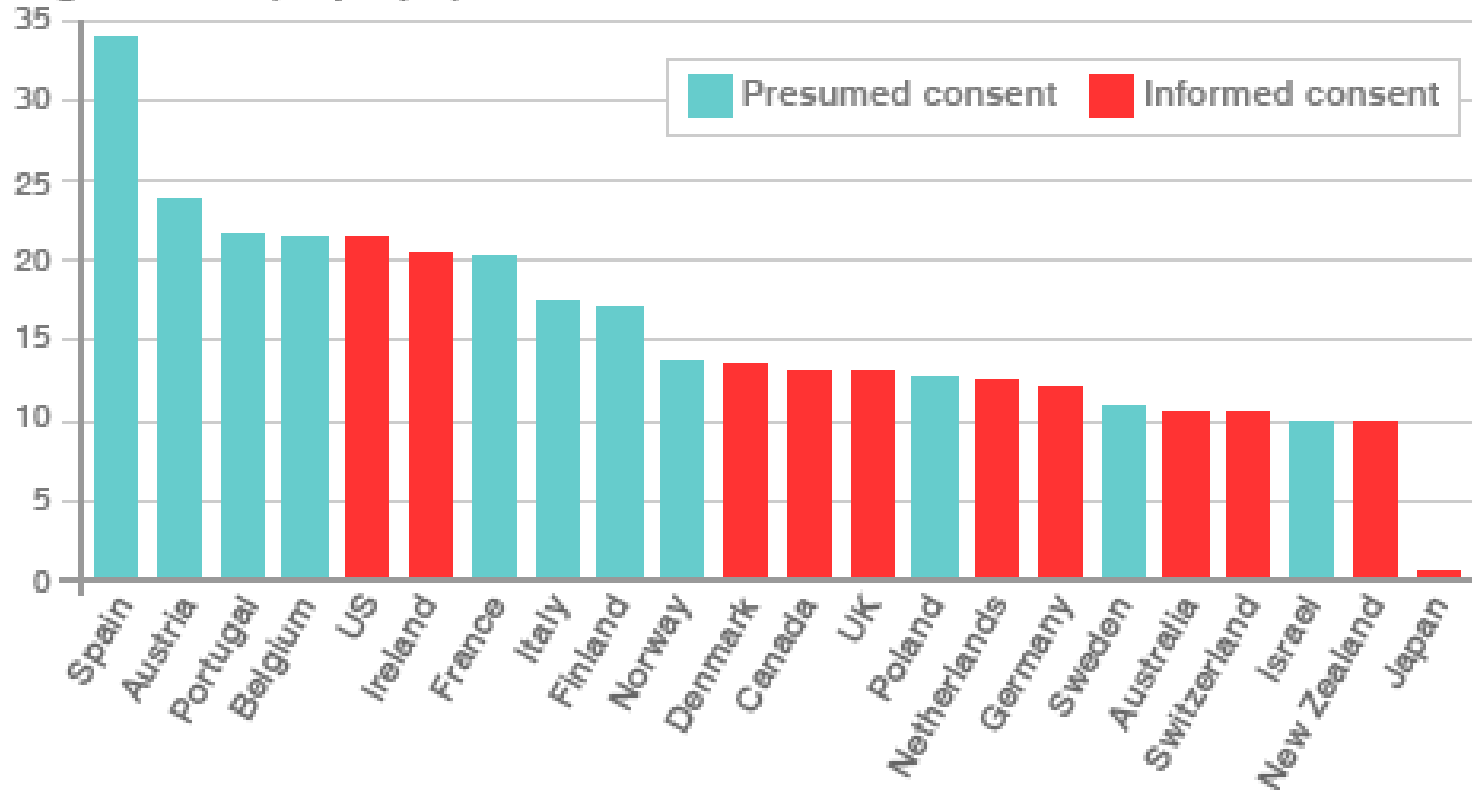
Total transplant rates from deceased and living donors for Europe and the USA, 2010



Consent by country

ORGAN DONATIONS AROUND THE WORLD (2002)

Organ donors (/m people)



SOURCE: Journal of Health Economics

Wales 2015

- spent more than £3.4m on a publicity campaign that has seen every household in Wales receiving a leaflet through their door, as well as TV adverts, supermarket roadshows and flashmobs at Cardiff train station.



Is Opt out necessarily best way?

- In the English system there are two groups of people: those who have opted in and registered their wish to be a donor, and those who have done nothing whose families will be asked to decide.
- In Wales there are now effectively three groups of people: those who have opted in and so registered their wish to be a donor; those who have done nothing for whom it is assumed they are happy to donate their organs, but it is still ultimately for their family to decide; and a third group who have opted out and so expressly registered their wish not to be a donor.
- As it currently stands, 6% of the Welsh population has opted out of organ donation. This is a group of people who in an opt-in system were still potential donors, depending on their families' wishes - they may not have ended up donating organs, but we just don't know.

Other factors important

- **There is correlation between countries having opt-out schemes and having a higher number of organ donors.**
- **But the countries which have the most donors per head combined the introduction of their opt-out schemes with other changes, like better infrastructure, more funding for transplant programmes and more staff working to identify and build relationships with potential donors before their death.**
- **Spain is often touted as an opt-out scheme success story.**
- **So-called "presumed consent" legislation was passed in 1979 but donor rates only began to go up 10 years later when a new National Transplant Organisation (ONT) was founded which coordinates the whole donation and transplantation process.**

Hard Opt out?

- **In both Spain and Wales, families of potential organ donors are always given the chance to refuse. But this is not universal - Austria and Singapore both have "hard opt-out" systems where those who have not opted out are presumed to have consented to organ donation regardless of their families' wishes.**
- **And there are other differences, for example in Israel a priority incentive scheme means those who have agreed to donate their own or a deceased family member's organs are given priority on transplant lists should they themselves need an organ in the future.**
- **In "hard opt-out" systems there were increases in the organ donor rate of up to 25%.**

Jersey – need to do more

- **Awareness – primary health care, schools, work place**
- **States of Jersey – driving license**
- **End of Life Care**
- **SN-OD local (specialist nurses)**
- **DCD – introduce in line with UK**
- **Increase ICU capability**

Problems encountered

- **Primary Health Care – GPs want payment for time spent discussing subject?**
- **Driving License – transfer data from Jersey to UK has been a problem**
- **High bed occupancy and theatre space limited in JGH.**
- **Public lack information**

- Because there are problems with the 2 main routes of signing the OD register in Jersey, and because we have by far the lowest registration rates (next to Guernsey) in the UK, then moving to an opt out system is sensible – but with this must come investment in other areas as happened in the Spanish ONT - eg.education, medical organisation.



**Organ donation.
The gift of life.**