Deceased donor kidney program, 1 April 1998 – 31 March 2008
Number of donors, transplants and patients on the active transplant list at 31 March
Number of deceased donors per million population, 2007:

- Spain
- Belgium
- US
- France
- Portugal
- Austria
- Ireland
- Italy
- Norway
- Finland
- Netherlands
- Germany
- Canada
- Sweden
- UK
- Denmark
- Switzerland
- Australia
- Poland
- New Zealand
- Israel
To identify barriers to donation and transplantation and recommend solutions within existing operational and legal frameworks in England.

To identify barriers to any part of the transplant process and recommend ways to overcome them to support and improve transplant rates.
## Organ Donation Taskforce

### Membership

<table>
<thead>
<tr>
<th>Category</th>
<th>Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical care</td>
<td>Paul Murphy, Martin Smith</td>
</tr>
<tr>
<td>DTCs</td>
<td>Chris Elding, Karen Morgan, Sue Falvey</td>
</tr>
<tr>
<td>Transplantation</td>
<td>Robert Bonser, Simon Bramhall, Chris Watson</td>
</tr>
<tr>
<td>Ethics</td>
<td>Bobbie Farsides</td>
</tr>
<tr>
<td>Trust management</td>
<td>Julie Moore</td>
</tr>
<tr>
<td>Communications</td>
<td>Viv Parry</td>
</tr>
<tr>
<td>Patient group</td>
<td>Bob Dunn (National Kidney Federation)</td>
</tr>
<tr>
<td>Donor family</td>
<td>Michael and Kathryn Lewis</td>
</tr>
</tbody>
</table>

Representatives from NHSBT, 4 Health Departments, NSCAG
## Organ Donation Taskforce

### Work programme

<table>
<thead>
<tr>
<th>Month</th>
<th>Events</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 06</td>
<td>Background; initial scoping</td>
</tr>
<tr>
<td>January 07</td>
<td>American and Spanish models Ethical dilemmas</td>
</tr>
<tr>
<td>February</td>
<td>Economics of transplantation NHBD</td>
</tr>
<tr>
<td>March</td>
<td>DTCs and organ retrieval</td>
</tr>
<tr>
<td>May</td>
<td>Draft report</td>
</tr>
<tr>
<td>July</td>
<td>Emergence of recommendations</td>
</tr>
<tr>
<td>August</td>
<td>Clinical triggers for referral</td>
</tr>
<tr>
<td>September</td>
<td>Consultation with DTCs Report sign off</td>
</tr>
<tr>
<td>January 08</td>
<td>Publication</td>
</tr>
</tbody>
</table>

14 recommendations

.....50% increase in donation over 5 years
Organs for Transplants
A Report from the ODTF

- role of NHS
- review of co-ordination & retrieval
- training
- legal and ethical issues
- public promotion

14 recommendations
......20 donors pmp by 2013
The UK Model!
Organ donation partnership

ICUs / Trusts — NHSBT

Clinical champions
Embedded coordinators
Donation Committees

SHAs
Departments of Health
NHS

Effective coordination and retrieval
Education, training and audit
Public engagement

Funding
Resolution of outstanding ethical, legal and coronial issues
Performance management
Training
Public engagement recognition

Elisabeth Buggins CBE
Chair, ODTF
“The burden of responsibility to raise the question of donation ... falls on medical professionals, few of whom ever receive any specific training for this difficult and delicate task. This is, by far, the target group on which the efforts to improve organ donation must be concentrated.”
The UK Model!

Process mapping

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**NHSBT**

- Effective coordination and retrieval
- Education, training and audit
- Public engagement

**Central administrations**

- Funding
- Resolution of outstanding ethical, legal and coronial issues
- Performance management
- Training
- Public recognition

**ICUs**

**Trusts**

---

**More donors**

**Clinical champions**

**Embedded co-ordinators**

**Donation committees**
Brainstem death testing
Identification of marginal donors
Minimum referral criteria
Improved consent rates
HRT for heart beating donors
Donation from A&E departments
Nationwide DCD program
• BSD, not tested
• 350 missed potential donors
• 172 actual donors
• 619 additional transplanted patients
• extra 2.8 donors pmp
Incidence of diagnosed brainstem death, 2003-8

2003/4
2004/5
2005/6
2006/7
2007/8

number
1000 1050 1100 1150 1200 1250 1300 1350 1400
North Thames ED donation summary activity 2001- current

Year

Number

- Donor referrals
- Donors
- Transplants
Deceased NHB organ donors in the UK 1998 - 2007

Year

Number

1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
NHB donors by DTC team
1 April 2007 – 31 March 2008

<table>
<thead>
<tr>
<th>Year</th>
<th>NHB Donors</th>
<th>Donating ICUs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004-5</td>
<td>87</td>
<td>49</td>
</tr>
<tr>
<td>2005-6</td>
<td>125</td>
<td>54</td>
</tr>
<tr>
<td>2006-7</td>
<td>159</td>
<td>65</td>
</tr>
<tr>
<td>2007-8</td>
<td>200</td>
<td>92</td>
</tr>
</tbody>
</table>
International Consent Rates, 2007

- UK consent rate 61%
- a consent rate of 85%
  - 256 additional donors
  - 921 additional transplanted patients
  - extra 4.1 donors pmp

<table>
<thead>
<tr>
<th>Country</th>
<th>Consent Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greece</td>
<td>54</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>59</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>67</td>
</tr>
<tr>
<td>Norway</td>
<td>67</td>
</tr>
<tr>
<td>France</td>
<td>70</td>
</tr>
<tr>
<td>Italy</td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td></td>
</tr>
<tr>
<td>Estonia</td>
<td>79</td>
</tr>
<tr>
<td>Romania</td>
<td>79</td>
</tr>
<tr>
<td>Latvia</td>
<td>81</td>
</tr>
<tr>
<td>Slovak Republic</td>
<td>83</td>
</tr>
<tr>
<td>Spain</td>
<td>83</td>
</tr>
<tr>
<td>Hungary</td>
<td>91</td>
</tr>
<tr>
<td>Poland</td>
<td>91</td>
</tr>
<tr>
<td>Portugal</td>
<td>94</td>
</tr>
</tbody>
</table>
Government task force to explore presumed consent for organ donation

Health Secretary Alan Johnson has today asked the organ donation taskforce to explore whether all adults should be automatically included on the organ donor register.
“To examine the potential impact on organ donation of introducing an “opt out” or presumed consent system in the UK, having regards to the views of the public and stakeholders on the clinical, ethical, legal and societal issues, and publish its findings”.
Organ Donation Taskforce II

Approach

- Will presumed consent be effective?
- Are there any ethical and legal obstacles?
- Will presumed consent be acceptable to
  - healthcare professionals
  - general public
  - patients and their families
- What are the practicalities?
  - timescales
  - costs
ODTF II
Methodology & evidence

• Working Groups
  – Practical
  – Legal
  – Ethical
  – Clinical
  – Cultural
  – Communications
• Systematic Literature Review

• Costing Analysis
• Public Deliberative Events
• Stakeholder engagement
  – Professional bodies
  – Focus groups
  – 17 faith & culture groups
The bar chart shows the number of deceased donors per million population in 2007 for various countries, comparing presumed consent (blue) and informed consent (light blue) systems. Spain has the highest number of deceased donors under both systems, followed by Belgium and the United States. The chart indicates that countries with presumed consent generally have higher numbers of deceased donors compared to those with informed consent, except for the Netherlands and France, which have similar numbers under both systems.
Presumed Consent in Spain

- In place for a decade without any change in donation rates
- Little operational impact upon how families are approached
- Spanish model applied successfully elsewhere without it
Taskforce members had a wide range of views at the outset. However, after examining the evidence, the Taskforce reached a clear consensus in recommending that an opt out system should not be introduced in the UK at the present time. The Taskforce concluded that such a system has the potential to undermine the concept of donation as a gift, to erode trust in NHS professionals and the Government, and negatively impact on organ donation numbers. It would distract attention away from essential improvements to systems and infrastructure and from the urgent need to improve public awareness and understanding of organ donation. Furthermore, it would be challenging and costly to implement successfully. Most compelling of all, we found no convincing evidence that it would deliver significant increases in the number of donated organs.
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Bridging... ...the gap

- Clinical collaborative
- Long contact model
- Training for requesting
- ODR
- Presumed consent
91% is the consent rate when patient is known to be on ODR on 36% of occasions, the ODR is not used to inform approach to family.
The UK Model!
Process mapping

NHSBT
Effective coordination and retrieval
Education, training and audit
Public engagement

Central administrations
Funding
Resolution of outstanding ethical, legal and coronial issues
Performance management
Training
Public recognition

ICUs
Trusts
More donors

Clinical champions
Embedded co-ordinators
Donation committees
Role of NHS
Donation as part of EOL care

Recommendation 4a
All parts of the NHS must embrace organ donation as a usual, not an unusual event. Local policies, constructed around national guidelines, should be put in place. Discussions about donation should part of all end-of-life care when appropriate.
Recommendation 4b

Each Trust should have an identified clinical donation champion and a Trust donation committee to help achieve this.
Recommendation 9
Additional co-ordinators, embedded within critical care areas, should be employed… There should be a close and defined collaboration between donor co-ordinators, clinical staff and Donation Champions.

Collaborative of embedded donor co-ordinators and clinical champions
Role of NHS
Minimum referral criteria

Recommendation 5
Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis.

early referral is vital

• The DTC should be notified as soon as the decision to perform brainstem death tests has been made.
• The DTC should be notified as soon as the decision to withdraw active treatment has been made.
Role of NHS

Brainstem death testing

Recommendation 7

BSD testing should be carried out in all patients where BSD is a likely diagnosis, even if organ donation is an unlikely outcome.
Recommendation 6

Donation rates in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent for donation should be reported. The Trust Donation Committee should report to the Trust Board and the reports should be part of the assessment of Trusts through the relevant healthcare regulator.

“making donation usual, not unusual”
Ethico-legal Uncertainties
Dying but not yet dead

- donation after cardiac death
- transfer from A&E
- donor stabilisation
- early referral to DTC
- early consultation of ODR
Recommendation 3

Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established.
Recommendation 14

The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.
Programme Delivery Board

- Chair - Sir Bruce Keogh
- Members
  - ODTF
  - Colleges
  - Societies
  - NHS management
  - DH and Devolved admins
  - NHSBT
  - Commissioners
Recommendations 1,2

- Sally Johnson (Executive Director)
- James Neuberger (Medical Director)

Workstreams
- DTCs: Jane Griffiths/Fiona Wellington
- Engaging the NHS: Paul Murphy
- Retrieval: David Mayer
- Gift of life: Henrietta Joy
Establishing the Collaborative Clinical Champions

• Sharing the vision
  – Professional engagement
  – Face to face meetings with SHAs
  – Regional roadshows, May/ June ‘09

• Realising the vision
  – 51 Clinical champions
  – 1st meeting with CCs 23rd Feb 09
  – Professional development to start September 09

“Making donation usual, not unusual”
Establishing the Collaborative Donor Transplant Co-ordinators

- Recruitment of new coordinators
  - 30 new DTCs appointed in 2008/9
  - 85 to be recruited in 2009/10

- Transfer of current DTCs to NHSBT
  - Scotland, London and Yorkshire before end 2008/9
  - Remainder will transfer in 2009/10

- Restructuring and “embedding”
  - Current 18 teams will be restructured into 12 larger regional teams (4 in 2008/9, remainder in 2009/10)
Implementation: central issues

- Resolution of ethical and legal issues
  - UK Ethics Committee
  - Legal opinion
  - Guidelines for Coroners
- Performance management
- Training
- Recognition of donors
Promotion with the Public
A role for us all

Recommendation 13
There is an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public, and specifically to the BME population.
25 million on ODR by 2013

Number on Organ Donor Register

One million additional registrants
≡ 5 extra donors per year
Recommendation 13

- NHSBT
  - £4.5m campaign during 2009/10 and onwards
- DH
  - a Research Coordination Group
  - working with – and funding – 3rd sector (charity) activities
Organ Donation Organisation
Effective coordination and retrieval
Education, training and audit
Public engagement

NHSBT

ICUs

More donors

Central administrations

Funding
Resolution of outstanding ethical, legal and coronial issues
Performance management
Training
Public recognition

Clinical champions
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Donation committees
Organ Donors in Spain
Number & Annual Rate (p.m.p.)

(Population in 2000 was 39.6 million inhabitants, 41.1 in 2001 and 41.8 in 2002)