The Organ Donation Taskforce Report
Development and implementation

Dr Paul Murphy
National Clinical Lead for Organ Donation
NHS Blood and Transplant
UK
### Deceased donors and transplant waiting lists, 2006

<table>
<thead>
<tr>
<th>Year</th>
<th>Number</th>
<th>Deceased donors</th>
<th>Deceased donor transplants</th>
<th>Active transplant list</th>
</tr>
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<tbody>
<tr>
<td>1999</td>
<td>5396</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>5487</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2001</td>
<td>5518</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2002</td>
<td>5665</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>5837</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2004</td>
<td>6024</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>6543</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>7102</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The graph shows the increase in the number of deceased donors, deceased donor transplants, and the active transplant list from 1999 to 2006.
Deceased donation, 2006

- 1994: Organ Donor Register
  - Opt-in legislation
- 2001: Non heartbeating organ donation programmes
  - Controlled
  - Uncontrolled
- 2003
  - Potential Donor Audit
  - Donor liaison clinicians and in house coordinators

A series of ineffective interventions
Deceased donation, 2006

- Diagnosis of brain-stem death
- Identification and referral of potential donors
- Donation after circulatory death
- Family consent / authorisation rates

The UK: an unenviable leader in family refusals
Counting the cost

- 1000 deaths annually on active transplant waiting list
- Restricted access to many waiting lists
- Only 25% of dialysis patients considered for transplantation
- Active promotion of living donation programmes
  - More living donors than deceased donors
- 50% mortality on lung transplant waiting lists

Mary Hand, cystic fibrosis sufferer. Died aged 22
How could the rates of organ donation be so much higher in so many other countries........?
The UK Organ Donation Taskforce

Terms of Reference

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

http://www.odt.nhs.uk/donation/deceased-donation/organ-donation-taskforce/
Is there a Solution?

What are the barriers in hospitals?

- Uncommon
- Poorly understood
- Disruptive
  - ICU / Emergency Medicine
  - operating theatres
- Not ‘core business’
  - no local benefit
- Uncertain ethical and legal boundaries
  - extending the potential donor pool

Why are the rates of deceased donation in the UK so low?
Professional barriers to donation

- Admission to critical care for donation
- Continued ventilation in a patient close to brain-stem death
- Stabilisation for neurological determination of death
- Approaching all families
- Early involvement of trained requestors
- Donation after circulatory death

Wrong place of death
Wrong kind of death
Unknown wishes
The Taskforce Report

- 14 recommendations
  - Donor identification and referral
  - Coordination
  - Retrieval
- Accepted in full by all four health departments
- 50% increase in deceased donation by 2013
- Comprehensive UK-wide framework for donation and retrieval

http://www.odt.nhs.uk/donation/deceased-donation/organ-donation-taskforce/
Local Donation Champions

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 be part of all end-of-life care when appropriate. Each Trust should have an identified clinical donation champion and a Trust donation committee to help achieve this.

Recommendation 4

Donation should not be viewed as something to be inflicted upon patients and families after end of life care.

Rather, it should be considered to be a fundamental component of end of life care and not denied to patients because they are dying in the wrong place or in the wrong way.
The UK framework for donation

NHS Blood and Transplant

- National ODO
- Employment of coordinators
- Commissioning of retrieval
- Audit
- Public engagement
- Education and training

Clinical leads
Embedded coordinators
Donation Committees

Acute hospitals

More patients having their wishes to donate recognised, fulfilled and maximised

Departments of Health

- Funding
- Resolution of ethical and legal obstacles
- Regulation
- Public recognition

The Organ Donation Taskforce Report
Professional Development

Recommendation 11

All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation.

There should also be regular update training.

“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.”

Rafael Matesanz
Director
National Donation and Transplant Organisation
Spain
Framework of Practice

Recommendation 3

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

Wrong place of death
Wrong kind of death
Unknown wishes
Implementation of the UK framework
A managed programme of change

1. Increase urgency (professional and patient pressure)
2. Build the guiding team (Organ Donation Taskforce)
3. Get the right vision (Taskforce Report)
4. Communicate for buy-in (Regional Roadshows)
5. Empower action (Professional Development Programme)
6. Create short term wins (DCD)
7. Don’t let up (Regional Donation Collaboratives)
8. Make it stick (Business relationship with NHS BT)

INFORM
Develop and publish the ODTF recommendations

INVOLVE
Engage, develop and empower local donation committees

INSPIRE
Make donation usual in all hospitals
Phase 1: inform

The Organ Donation Taskforce Report

Organ Donation Roadshows

Increase urgency (professional and patient pressure)
Build the guiding team (Organ Donation Taskforce)
Get the right vision (Taskforce Report)
Communicate for buy-in (Regional Roadshows)
Empower action (Professional Development Programme)
Create short term wins (DCD)
Don't let up (Regional Donation Collaboratives)
Make it stick (Business relationship with NHS BT)
Phase 1: inform

An undeniable case for change
Phase 2: involve

INFORM
Develop and publish the ODTF recommendations

INVOKE
Engage, develop and empower local donation committees

1. Increase urgency (professional and patient pressure)
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INSPIRE
Make donation usual in all hospitals

Sharing the vision
The six big wins

- Consent / authorisation
- Brain-stem death testing
- Donation after circulatory death
- Donation from Emergency Medicine
- Donor identification and referral
- Donor optimisation
Overcoming the obstacles
Donation after Circulatory Death

http://www.odt.nhs.uk/donation/deceased-donation/
Overcoming the obstacles
Donor identification and family approach

http://www.odt.nhs.uk/donation/deceased-donation/
13. If an adult patient lacks capacity to decide, the decisions you or others make on the patient’s behalf must be based on whether treatment would be of overall benefit to the patient and which option (including the option not to treat) would be least restrictive of the patient’s future choices. You must consult with those close to the patient who lacks capacity, to help you reach a view.
81. If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility.

82. You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator.
The UK framework for donation

NHS Blood and Transplant

- National ODO
- Employment of coordinators
- Commissioning of retrieval
- Audit
- Public engagement
- **Education and training**

Clinical leads
Embedded coordinators
Donation Committees

Acute hospitals

- More patients having their wishes to donate recognised, fulfilled and maximised

Departments of Health and Professional Societies

- Funding
- **Resolution of ethical and legal obstacles**
- Regulation
- Public recognition

The Organ Donation Taskforce Report
Deceased organ donors in the UK 2007-12

<table>
<thead>
<tr>
<th>Year</th>
<th>DBD</th>
<th>DCD</th>
<th>Total</th>
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<tbody>
<tr>
<td>2007-8</td>
<td>609</td>
<td>200</td>
<td>809</td>
</tr>
<tr>
<td>2008-9</td>
<td>611</td>
<td>288</td>
<td>899</td>
</tr>
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<td>2009-10</td>
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<td>1010</td>
</tr>
<tr>
<td>2011-12</td>
<td>652</td>
<td>436</td>
<td>1088</td>
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<td>2012-13</td>
<td>705</td>
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Deceased organ donors in the UK 2007-12

The Organ Donation Taskforce Report
Deceased donation and kidney transplantation, 2007-12

The Organ Donation Taskforce Report
Deceased donors up to 2013-14

<table>
<thead>
<tr>
<th>Year</th>
<th>DBD</th>
<th>DCD</th>
<th>Total</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>2007-8</td>
<td>609</td>
<td>200</td>
<td>809</td>
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<tr>
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<td>624</td>
<td>335</td>
<td>959</td>
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<td>637</td>
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<td>2011-12</td>
<td>652</td>
<td>436</td>
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<td>34.0%</td>
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<td>2012-13</td>
<td>705</td>
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<tr>
<td>2013-14</td>
<td>780</td>
<td>540</td>
<td>1320</td>
<td>40.0%</td>
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Total Deceased Donors up to 2013-14: 1320

Percentage: 63.1%
Progress against PDA metrics

Referral

Brain-stem death testing

Consent / authorisation
Deceased donors in the UK up to 2012-13

- Expansion of Maastricht III DCD programmes
- Donor identification and referral from Emergency Departments
- Clinical leads, specialist nurses and hospital donation committees
- Improved relationships between national agencies and donor hospitals
- Resolution of professional, ethical and legal obstacles
Deceased donors, transplants and the transplant waiting list 2003-2014

<table>
<thead>
<tr>
<th>Year</th>
<th>Donors</th>
<th>Transplants</th>
<th>Transplant Waiting List</th>
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<td>5673</td>
<td>2396</td>
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<td>2004-05</td>
<td>6142</td>
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<td>6698</td>
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<td>2381</td>
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<td>7288</td>
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<td>1212</td>
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<tr>
<td>2013-14</td>
<td>7026</td>
<td>3514</td>
<td>1320</td>
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Renal replacement therapies in UK
Monthly donor numbers, 2007-2014

- DBD
- DCD
- total

The Organ Donation Taskforce Report
Running 12-monthly donor numbers

- DBD
- DCD
- Total

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<tr>
<th>Month</th>
<th>Number</th>
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<td>Nov-08</td>
<td>600</td>
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<td>Mar-09</td>
<td>800</td>
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<td>Jul-09</td>
<td>1000</td>
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<tr>
<td>Nov-09</td>
<td>1200</td>
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<td>Mar-10</td>
<td>1400</td>
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<tr>
<td>Jul-10</td>
<td>1600</td>
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<td>Nov-10</td>
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<td>Mar-11</td>
<td>2000</td>
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<td>Jul-11</td>
<td>2200</td>
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<td>Mar-12</td>
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<tr>
<td>Jul-12</td>
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<td>Mar-13</td>
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<td>Jul-13</td>
<td>3400</td>
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<tr>
<td>Nov-13</td>
<td>3600</td>
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<td>Mar-14</td>
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### Potential for DBD in UK

<table>
<thead>
<tr>
<th>Country</th>
<th>Potential DBD pool</th>
<th>Actual DBD donors</th>
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<tbody>
<tr>
<td>Spain</td>
<td>≈ 50</td>
<td>32</td>
</tr>
<tr>
<td>UK</td>
<td>19.9 (26.1)</td>
<td>12.5</td>
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per million population, 2013

How can the potential for DBD vary so much?
Family consent

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