Deceased donation data in the UK

Paul Murphy
National Clinical Lead for Organ Donation
United Kingdom
Deceased donation data in the UK
And the story behind it

Paul Murphy
National Clinical Lead for Organ Donation
United Kingdom
A doctor went to work today and three people died
He never met the people who died
His employers did not notice
He was not censured
Somebody else’s patients
Somebody else’s problem
The aching gap in 2006

Blood and Transplant

Number

<table>
<thead>
<tr>
<th>Year</th>
<th>Deceased donors</th>
<th>Deceased donor transplants</th>
<th>Active transplant list</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>745</td>
<td>2386</td>
<td>7252</td>
</tr>
<tr>
<td>2000</td>
<td>777</td>
<td>2334</td>
<td>7464</td>
</tr>
<tr>
<td>2001</td>
<td>778</td>
<td>2339</td>
<td>7518</td>
</tr>
<tr>
<td>2002</td>
<td>770</td>
<td>2333</td>
<td>7565</td>
</tr>
<tr>
<td>2003</td>
<td>709</td>
<td>2222</td>
<td>6024</td>
</tr>
<tr>
<td>2004</td>
<td>814</td>
<td>2454</td>
<td>6543</td>
</tr>
<tr>
<td>2005</td>
<td>753</td>
<td>2195</td>
<td>1999</td>
</tr>
<tr>
<td>2006</td>
<td>779</td>
<td>2316</td>
<td>2000</td>
</tr>
</tbody>
</table>
The Organ Donation Taskforce

What is the root cause?

How could the rates of organ donation be so much higher in so many other countries........?
Organ donation as part of end of life care

The paradigm shift

Donation should not be viewed as something optional, something to be inflicted upon patients and families after end of life care for the benefit of a third party.
Organ donation as part of end of life care
The paradigm shift

Donation should not be viewed as something optional, something to be inflicted upon patients and families after end of life care for the benefit of a third party.

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.
Local donation champions
Advocates for change

All parts of the National Health Service 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 hospital should have an identified clinical donation champion, an assigned specialist nurse for organ donation and a Trust donation committee to help achieve this.
The UK framework for organ donation

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

Departments of Health and Professional Societies
- Funding
- Resolution of ethical and legal obstacles
- Regulation
- Public recognition

Clinical leads
- Embedded coordinators
- Donation Committees

Acute hospitals

More patients having their wishes to donate recognised, fulfilled and maximised
Increasing Donor Numbers
Donor identification and referral

There were 893 missed DCD referrals in the UK in 2016/17
UK donor numbers, 2007 - 2013

<table>
<thead>
<tr>
<th>Year</th>
<th>Donation after Brain-stem Death</th>
<th>Donation after Circulatory Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007-8</td>
<td>609</td>
<td>200</td>
</tr>
<tr>
<td>2008-9</td>
<td>611</td>
<td>288</td>
</tr>
<tr>
<td>2009-10</td>
<td>624</td>
<td>335</td>
</tr>
<tr>
<td>2010-11</td>
<td>637</td>
<td>373</td>
</tr>
<tr>
<td>2011-12</td>
<td>652</td>
<td>436</td>
</tr>
<tr>
<td>2012-13</td>
<td>705</td>
<td>507</td>
</tr>
</tbody>
</table>

Donation after Brain-stem Death: 609-705
Donation after Circulatory Death: 200-507

Total donation: 49.8%
UK donor numbers, 2007 - 2017

- Donation after Brain-stem Death
- Donation after Circulatory Death

2007-8: 200
2008-9: 288
2009-10: 335
2010-11: 373
2011-12: 436
2012-13: 507
2013-14: 540
2014-15: 510
2015-16: 578
2016-17: 584

Total increase: 74.7%
Age of actual deceased donors

![Bar chart showing the percentage of donors by age group for different years.](chart.png)
Deceased donors, transplants and the transplant waiting list 2007-2017

Cadaveric solid organ transplants in UK
Long term renal replacement therapy in UK

blood and transplant
Long term renal replacement therapy in UK

Figure 3: Additional patient life years — remaining on dialysis versus receiving a transplant (based on age of onset of end-stage kidney disease).
Cadaveric solid organ transplants in UK
Cadaveric solid organ transplants in UK
Cause of death in DBD donors
Implementation of the Taskforce report

- Relevant and persuasive message
- Well planned and resourced communications plan
  - Extensive training programme for hospital donation leads
  - Regular local, regional and national gatherings
  - Series of targeted strategy documents
Implementation of the Taskforce report

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Regional variations in deceased donor numbers, 2016-7 (donors pmp)

<table>
<thead>
<tr>
<th>Country</th>
<th>Deceased donors pmp</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>21.1</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>22.7</td>
</tr>
<tr>
<td>Scotland</td>
<td>25.5</td>
</tr>
<tr>
<td>Wales</td>
<td>21.9</td>
</tr>
<tr>
<td>UK</td>
<td>21.8</td>
</tr>
</tbody>
</table>
Organ donation challenges
Deceased donors pmp, 2015
Organ donation challenges

Deceased donor transplants pmp, 2015

<table>
<thead>
<tr>
<th>Country</th>
<th>DD transplants per million population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>91.6</td>
</tr>
<tr>
<td>Croatia</td>
<td>91.4</td>
</tr>
<tr>
<td>France</td>
<td>77.1</td>
</tr>
<tr>
<td>USA</td>
<td>74.2</td>
</tr>
<tr>
<td>Norway</td>
<td>70</td>
</tr>
<tr>
<td>Portugal</td>
<td>69.6</td>
</tr>
<tr>
<td>Canada</td>
<td>62.6</td>
</tr>
<tr>
<td>Sweden</td>
<td>60</td>
</tr>
<tr>
<td>Switzerland</td>
<td>53.5</td>
</tr>
<tr>
<td>UK</td>
<td>53</td>
</tr>
<tr>
<td>Australia</td>
<td>51.7</td>
</tr>
<tr>
<td>Italy</td>
<td>50.2</td>
</tr>
<tr>
<td>Finland</td>
<td>48.3</td>
</tr>
<tr>
<td>Denmark</td>
<td>47.9</td>
</tr>
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<td>Hungary</td>
<td>44.4</td>
</tr>
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<td>The Netherlands</td>
<td>44.1</td>
</tr>
<tr>
<td>Slovakia</td>
<td>41.9</td>
</tr>
<tr>
<td>Poland</td>
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</tr>
<tr>
<td>Germany</td>
<td>36.9</td>
</tr>
<tr>
<td>Latvia</td>
<td>34</td>
</tr>
<tr>
<td>Greece</td>
<td>8.3</td>
</tr>
</tbody>
</table>
Organ donation challenges
Family consent rates in UK

[Graph showing consent rates from 2005/06 to 2016/17 for DBD and DCD]
International refusal rates

In 2016/17, 1172 / 3144 families said no.

A family refusal rate of 20% → 343 additional donors
Organ donation challenges

Organ utilisation

heart transplants / DBD donor, 2013

Strategic objective: 35%
Are all donation pools the same?

<table>
<thead>
<tr>
<th></th>
<th>Potential DBD pool</th>
<th>Actual DBD donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>≈ 50</td>
<td>31.9</td>
</tr>
<tr>
<td>UK</td>
<td>22.2</td>
<td>12.5</td>
</tr>
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per million population, 2014
Summary

• UK framework introduced in 2008
  – Hospital donation leads, committees
  – Strong principled basis

• Comprehensive portfolio of guidance and professional development

• To date
  – 75% increase in donation
  – 56% increase in transplantation
  – Recognised leader in cDCD

• Challenges
  – Family refusal
  – Organ utilisation
  – Limited donor pool

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per million population, 2014