Best Practice in Organ Donation
An International Perspective

Dr Paul Murphy
National Clinical Lead for Organ Donation
NHS Blood and Transplant
United Kingdom
Outline

- Organ donation in the UK, 2006
- Organ Donation Taskforce Report, 2008
  - Clinical Leads for Organ Donation
  - Resolution of obstacles
- Current status in UK
- ACCORD project
  - Variations in end of life care in EU
Deceased donors and transplant waiting lists, 2006

Year | Deceased donors | Deceased donor transplants | Active transplant list
---|---|---|---
1999 | 745 | 2386 | 5396
2000 | 777 | 2334 | 5487
2001 | 778 | 2339 | 5518
2002 | 770 | 2333 | 5665
2003 | 709 | 2222 | 5837
2004 | 814 | 2454 | 6024
2005 | 753 | 2195 | 6543
2006 | 779 | 2316 | 7102
Deceased donation, 2006

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

A series of ineffective interventions
How could the rates of organ donation be so much higher in so many other countries...........?

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.
What are the barriers?

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

http://www.odt.nhs.uk/donation/deceased-donation/organ-donation-taskforce/
Making a donation happen

- 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
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.

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

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

Acute hospitals
- Clinical leads
- Embedded coordinators
- Donation Committees

More patients having their wishes to donate recognised, fulfilled and maximised
What do doctors know?
Professional Development

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.”
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.
Overcoming the obstacles
Donation after Circulatory Death

http://www.odt.nhs.uk/donation/deceased-donation/
Guidance from the General Medical Council

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.

UK GMC guidance on end of life care, 2010
Overcoming the obstacles

Donor identification

Identify potential donors as early as possible.

Base identification on either of the following criteria, while recognising that clinical situations vary.

- Whichever is the earlier, either:
  - use defined clinical trigger factors in patients who have had a catastrophic brain injury:
    - the absence of one or more cranial nerve reflexes and
    - a Glasgow Coma Scale score of 4 or less that is not explained by sedation unless there is a clear reason why the above clinical triggers are not met and/or
  - a decision is made to perform brainstem death tests.

- The intention to withdraw life-sustaining treatment in patients with a life-threatening or life-limiting condition which will, or is expected to, result in circulatory death.

Initiate discussions with the specialist nurse for organ donation at the time the above criteria are met.

http://www.odt.nhs.uk/donation/deceased-donation/
Deceased organ donors in the UK 2007-15

Year:
- 2007-2008: 609 donors (200 DCD, 409 DBD)
- 2008-2009: 612 donors (288 DCD, 324 DBD)
- 2009-2010: 623 donors (335 DCD, 288 DBD)
- 2010-2011: 637 donors (373 DCD, 264 DBD)
- 2011-2012: 652 donors (436 DCD, 216 DBD)
- 2012-2013: 705 donors (507 DCD, 198 DBD)
- 2013-2014: 780 donors (540 DCD, 240 DBD)
- 2014-2015: 772 donors (510 DCD, 262 DBD)
Deceased donors, transplants and the transplant waiting list 2003-2015
Donor referral and brain death testing

Referral

Brain death testing
European deceased donation rates, 2013

- Spain: 35.1
- Croatia: 35
- Belgium: 29.9
- Portugal: 28.3
- France: 24.7
- Estonia: 24.4
- Slovenia: 24.3
- Italy: 22.2
- United Kingdom: 20.8
- Ireland: 18.8
- Latvia: 17
- Lithuania: 16.7
- Sweden: 16
- Hungary: 15.6
- Netherlands: 15.2
- Germany: 10.9
- Greece: 5.6
International consent rates

Reducing family refusal rates to 20% ≈ 400 donors, 1200 transplants
Consent for DBD

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Unit where referral was made</th>
<th>Nature of patient’s prior donation wish</th>
<th>Timing of formal approach to family</th>
<th>Donation mentioned pre-formal approach</th>
<th>Nature of approach to the family</th>
</tr>
</thead>
<tbody>
<tr>
<td>(p&lt;0.0001)</td>
<td>(p=0.0818)</td>
<td>(p&lt;0.0001)</td>
<td>(p&lt;0.0001)</td>
<td>(p&lt;0.0001)</td>
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</tr>
</tbody>
</table>
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<tr>
<td>(p&lt;0.0001)</td>
<td>(p=0.0848)</td>
<td>(p&lt;0.0001)</td>
<td>(p&lt;0.0001)</td>
<td>(p&lt;0.0001)</td>
<td>(p&lt;0.0001)</td>
</tr>
</tbody>
</table>
1.1.11 A multidisciplinary team (MDT) should be responsible for planning the approach and discussing organ donation with those close to the patient.

1.1.12 The MDT should include:

- the medical and nursing staff involved in the care of the patient, led throughout the process by an identifiable consultant
- the specialist nurse for organ donation
- local faith representative(s) where relevant.

www.odt.nhs.uk/donation/deceased-donation/consent-authorisation
Collaborative requesting in major UK hospitals

- Greater than 99.8% CL
- Between upper 95% CL and upper 99.8% CL
- Between lower 95% CL and upper 99.8% CL
- Between lower 99.8% CL and lower 95% CL
- Less than 99.8% CL

**Trust/Board --- National rate**

- Greater than 99.8% CL
- Between upper 95% CL and upper 99.8% CL
- Between lower 95% CL and upper 99.8% CL
- Between lower 99.8% CL and lower 95% CL
- Less than 99.8% CL
Service improvement methodologies
Overview

Understand the problem and its causes
Define aim and measures
Collect change ideas
Test change idea with PDSA cycles
Implement changes that are improvements

Work with colleagues and value different perspectives
Link frontline changes with strategic objectives
Work towards sustainability as part of implementation
Understanding the problem and its causes

- Stakeholder analysis
  - Identify the people involved
- Process mapping
  - Understand the context
- Root cause analysis
  - What are the real causes

“If I had one hour to save the world, I would spend 59 minutes defining the problem and one minute finding a solution.”

Albert Einstein
Model for Improvement
PDSA cycle

The PDSA cycle is a controlled test of a change idea that should provide a quick assessment of whether the idea will be effective or not.

Remember that a change idea is being tested, that not all will work and some might make things worse.
Model for Improvement

PDSA cycle

**Plan:** we will do this, in this location, with this expectation

**Do:** we did this, we made these measurements and observed these unexpected occurrences

**Study:** our data from the pilot compare with baseline data in this way. We also had the following problems

**Act:** as a result of our observations we will now extend the trial, adjust the change idea, trial more widely, implement into practice etc

- **What are we trying to achieve?**
- **How will we know that change is an improvement?**
- **What changes can we make that will result in improvement?**

---

**Model for Improvement

PDSA cycle**

- **Plan**
- **Do**
- **Study**
- **Act**
**Problem:** late referral, resulting in delayed arrival of SN-OD

**Intervention:** inclusion of referral into ICU daily safety briefing

**Measures:**
- referral

SN-OD = specialist nurse – organ donation = donor transplant coordinator
Timeliness of referral

- Referral/identification of potential donors came earlier i.e. post morning ward round.
  - 25% increase in ‘timely’ identification and referral of potential donors was noted.
- No change in family consent rates.
- Outcomes
  - Modification of checklist accepted
  - Further work on quality of collaborative approach
Collaborative requesting

• **Problem:** clinicians reluctant to involve specialist nurse in family approach

• **Intervention:** critical incident report when clinician would not involve SN-OD

• **Measures:**
  – collaborative requesting
  – Consent

• **Outcome:**
  – Practice accepted
  – Further work on DCD

<table>
<thead>
<tr>
<th>Measures</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative requests (%)</td>
<td>DBD 73</td>
<td>87</td>
</tr>
<tr>
<td>DCD</td>
<td>36</td>
<td>69</td>
</tr>
<tr>
<td>Consent rate (%)</td>
<td>DBD 64</td>
<td>80</td>
</tr>
<tr>
<td>DCD</td>
<td>68</td>
<td>56</td>
</tr>
</tbody>
</table>
Family refusal

- **Problem:** high family refusal rate
- **Intervention:** mandatory training focused on collaborative requesting for all ICU staff
- **Measures:**
  - collaborative approaches
  - Consent
- **Outcome:** systematic training programme

<table>
<thead>
<tr>
<th>Measures</th>
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<tr>
<td>Families approached</td>
<td>28</td>
<td>29</td>
</tr>
<tr>
<td>Collaborative requests</td>
<td>18 (64%)</td>
<td>25 (86%)</td>
</tr>
<tr>
<td>Consents</td>
<td>15 (54%)</td>
<td>22 (86%)</td>
</tr>
</tbody>
</table>
Deceased donation in Europe

- Variation in donation pathway?
  - Diagnosis of brain death
  - Identification and referral
  - Donor assessment
  - Family approach
  - Consent

- Variation in the number of potential donors?
## Ethicus study

### End-of-Life Practices in European Intensive Care Units

<table>
<thead>
<tr>
<th>Region</th>
<th>Unsuccessful CPR</th>
<th>Brain death</th>
<th>Treatment limitation</th>
<th>Treatment withdrawal</th>
<th>Active shortening of dying process</th>
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<tbody>
<tr>
<td>Northern</td>
<td>10.2</td>
<td>3.2</td>
<td>38.2</td>
<td>47.4</td>
<td>0.9</td>
</tr>
<tr>
<td>Denmark, Finland, Ireland, Netherlands, Sweden, UK</td>
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<tr>
<td>Central</td>
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<td>6.5</td>
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<tr>
<td>Austria, Belgium, Czechia, Germany, Switzerland</td>
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<td></td>
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<tr>
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</tr>
<tr>
<td>Range between countries</td>
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<td>16 - 70</td>
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End-of-Life Practices in European Intensive Care Units
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**Notes:**
- CPR: Cardiopulmonary Resuscitation
- Brain death
- Treatment limitation
- Treatment withdrawal
- Active shortening of dying process

**Regions:**
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**Ranges:**
- 5 - 48 for Unsuccessful CPR
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- 16 - 70 for Treatment limitation
- 5 - 69 for Treatment withdrawal
- 0 - 19 for Active shortening of dying process
# Ethicus study

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<tr>
<th>End of life Categories (% patients)</th>
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End of life care and organ donation

- Are there variations in the care given to patients who are dying of conditions that are compatible with organ donation?
- Do these variations influence the likelihood of organ donation taking place?
- Can these variations be addressed through more effective collaboration between intensive care staff and donor transplant coordination?
ACCORD: Achieving Comprehensive Coordination in ORgan Donation

- Joint Action approved by the European Commission
  - Approved in 2011
  - Duration May 2012 – November 2015

- Overall aim
  - to strengthen the full potential of Member States in the field of organ donation and transplantation by improving the cooperation between them

- Coordinated by Spanish National Transplant Organisation (ONT)
Analysis of end of life care practices

• EU-wide audit of end-of-life care decision making in consecutive patients < 80 years dying of neurological conditions known to be a cause of brain death
  – what treatments did they receive?
  – were decisions made to limit or withdraw any treatments that had an impact upon both how they died and whether the potential for donation was lost or preserved?
  – how often was donation considered

• 15 participating EU Member States, 67 hospitals, 1670 completed patient questionnaires
Audit of end-of-life care decision making in consecutive patients (2 months to 80 years) dying of neurological conditions known to be a cause of brain death.
Patterns of care

Q1. Which statement best describes the care of the patient during his/her final illness? Please tick one box only:

☐ Full Active treatment on Critical Care until the diagnosis of brain death.

☐ Full Active treatment until unexpected cardiac arrest from which the patient could not be resuscitated.

☐ Admitted to Critical Care in order to incorporate organ donation into end-of-life care.

☐ Full active treatment on Critical Care until the decision of withdrawal or limiting life sustaining therapy was made, with an expected final cardiac arrest without Cardio Pulmonary Resuscitation.

☐ Not admitted, or admitted to Critical Care but subsequently discharged.
Patterns of care

- **A**: Full active treatment on CCU until the diagnosis of BD
- **B**: Full active treatment until unexpected cardiac arrest from which the patient could not be resuscitated
- **C**: Admitted to CCU to incorporate organ donation into end-of-life care
- **D**: Full active treatment on CCU until the decision of withdrawal or limiting life sustaining therapy was made, with an expected final cardiac arrest
- **E**: Not admitted, or admitted to CCU but subsequently discharged
Patterns of care

- CROATIA (66)
- ESTONIA (94)
- FRANCE (87)
- GERMANY (40)
- GREECE (28)
- HUNGARY (56)
- IRELAND (31)
- ITALY (75)
- LATVIA (12)
- LITHUANIA (81)
- PORTUGAL (43)
- SLOVENIA (18)
- SPAIN (413)
- NETHERLANDS (95)
- UK (531)
- ALL MS (1,670)

A: Full active treatment on CCU until the diagnosis of BD
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DBD pathway

? intubated

267 patients were not intubated at time of death / dying
Intubation and ventilation

Was the patient intubated and receiving mechanical ventilation via an endotracheal or tracheostomy tube at the time of death or at the time of the decision to withdraw or limit life sustaining treatment?

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croatia (66)</td>
<td>90%</td>
</tr>
<tr>
<td>Estonia (94)</td>
<td>85%</td>
</tr>
<tr>
<td>France (87)</td>
<td>80%</td>
</tr>
<tr>
<td>Germany (40)</td>
<td>75%</td>
</tr>
<tr>
<td>Greece (28)</td>
<td>70%</td>
</tr>
<tr>
<td>Hungary (56)</td>
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<td>55%</td>
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<td>Latvia (12)</td>
<td>50%</td>
</tr>
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<td>45%</td>
</tr>
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<td>40%</td>
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<td>All MS (1,670)</td>
<td>15%</td>
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- NETHERLANDS (95)
- UK (531)
- ALL MS (1,670)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

- Yes
- No

Blood and Transplant
Intubation and ventilation

The reason given for the patient not being intubated and receiving mechanical ventilation are:

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not appropriate</td>
<td>53</td>
<td>21.5</td>
</tr>
<tr>
<td>Not needed</td>
<td>34</td>
<td>13.8</td>
</tr>
<tr>
<td>Not of overall benefit to the patient due to the severity of the acute event</td>
<td>145</td>
<td>58.9</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>2.0</td>
</tr>
<tr>
<td>Not reported</td>
<td>9</td>
<td>3.7</td>
</tr>
</tbody>
</table>
Brain death tests were not performed on 153 occasions.
### Reasons for not testing

The reasons given for not testing are:

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absolute or relative medical contraindication</td>
<td>30</td>
<td>19.9</td>
</tr>
<tr>
<td>Cardiac arrest before testing could be performed</td>
<td>25</td>
<td>16.6</td>
</tr>
<tr>
<td>Cardiorespiratory instability</td>
<td>34</td>
<td>22.5</td>
</tr>
<tr>
<td>Family declined organ donation</td>
<td>17</td>
<td>11.3</td>
</tr>
<tr>
<td>Family reasons not to test</td>
<td>5</td>
<td>3.3</td>
</tr>
<tr>
<td>Not identified as potentially BD</td>
<td>8</td>
<td>5.3</td>
</tr>
<tr>
<td>Reversible causes of coma and/or apnoea could not be satisfactorily excluded</td>
<td>9</td>
<td>6.0</td>
</tr>
<tr>
<td>Unable to examine all brain stem reflexes or undertake ancillary tests</td>
<td>4</td>
<td>2.6</td>
</tr>
<tr>
<td>Other</td>
<td>19</td>
<td>12.6</td>
</tr>
</tbody>
</table>
DCD pathway

- Not intubated
- Uncontrolled cardiac death
- Brain dead

Donation rate: 3.7%
239 patients did not have the option of DCD made available.
Referral from the Emergency Department

- **Location**: Italian ED
- **Problem**: poor referral rates

**Interventions:**
- Staff training
- Referral poster

**Measures:**
- Referral rates

**Outcomes:**
- huge improvement in referral
- Better staff engagement
Family refusal

Problem: 32% of families refused organ donation.

Intervention: trained clinical psychologist available to support the family.

Outcome: Clinical psychologist not well accepted by families who perceived it as an external presence. The family refusal rate increased during the intervention (40%).
ORGAN DONORS IN SPAIN SINCE THE START OF O.N.T.

2015: THE BIGGEST INCREASE IN ORGAN DONATION IN SPAIN (+169: +10%)
DCD DONORS IN SPAIN -2015
17% OF TOTAL DONORS
Best practice in organ donation

Possible organ donor

- routine referral
- clinical triggers for identification
- accurate donor assessment
- systematic brain death testing
- goal-directed donor optimization
- best practice in family approach

Actual organ donor
Best practice in organ donation

- Education and training
- Audit and performance management

Possible organ donor
- routine referral
- clinical triggers for identification
- accurate donor assessment
- systematic brain death testing
- goal-directed donor optimization
- best practice in family approach

Actual organ donor

- Clinical leadership
Best practice in organ donation

Organ donation as part of end-of-life care

- Education and training
- Audit and performance management

Possible organ donor

- Routine referral
- Clinical triggers for identification
- Accurate donor assessment
- Systematic brain death testing
- Goal-directed donor optimization
- Best practice in family approach

Actual organ donor

- Clinical leadership
These issues should not be particularly difficult, or even that costly to resolve. Overcoming them will require leadership, boldness and willingness to change established practice. The prize for doing so is considerable.
My Dad Gary died last year on the 9th March 2012. He was the best Dad in the world, he was funny, caring, loving and brave. My Dad had a bald head. When I was 2 I asked Santa to give my dad some hair...

My Dad put a wig on to make my wish come true but I didn’t like it and cried so much Dad took it off and made me laugh. Then I realised he was perfect just the way he was. My Gary Boldy Biscuit always put other people before himself. He always helped people. My Dad Gary isn’t here to watch me and my brothers grow up but he gave all his organs to other people so now others people will get to see their children grow up. I miss my Dad every day but I’m so proud I was his daughter. Please put your name on the organ donation list so you can save lives just like my Dad.