Organ Donation in the UK
Five years on from the Organ Donation Taskforce

Dr Paul Murphy
National Clinical Lead for Organ Donation
Objectives

- Organ donation in 2006
- Understand the impact of the Organ Donation Taskforce report
  - Donation after circulatory death
- Learn about the landscape of deceased donation in the UK
- Accept the challenge of future interventions
  - Donor identification and referral
  - Donor optimisation
  - Family refusal
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  - Donor identification and referral
  - Diagnosis of brain-stem death
  - Donor optimisation
  - Family refusal
Deceased donors and transplant waiting lists, 2006

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<th>Year</th>
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<td>779</td>
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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

Organ Donation, Past Present and Future
Deceased donation, 2006

The UK: an unenviable leader in family refusals

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

Organ Donation, Past Present and Future
Professional barriers to donation

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
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

Recommendation 4

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

Clinical leads
- Embedded coordinators
- Donation Committees

Acute hospitals

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

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“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.”

**Organ Donation, Past Present and Future**
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

INFORM
Develop and publish the ODTF recommendations

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)

INVOLVE
Engage, develop and empower local donation committees

5. Empower action (Professional Development Programme)
6. Create short term wins (DCD)

INSPIRE
Make donation usual in all hospitals

7. Don’t let up (Regional Donation Collaboratives)
8. Make it stick (Business relationship with NHS BT)
Phase 1: inform

Organ Donation Roadshows

Organ Donation, Past Present and Future
Phase 1: inform

An undeniable case for change

Organ Donation, Past Present and Future
Phase 2: involve

Organ Donation, Past Present and Future
The six big wins

- Consent / authorisation
- Brain-stem death testing
- Donation after circulatory death
- Donation from Emergency Medicine
- Donor identification and referral
- Donor optimisation

Leadership
Change management
Communication skills
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/

Organ Donation, Past Present and Future
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.
Phase 2: involve

A ten fold increase in MC III DCD over a decade

Create early gains
Deceased organ donors in the UK 2007-12

Organ Donation, Past Present and Future
Deceased organ donors in the UK 2007-12

Organ Donation, Past Present and Future
Deceased donation and kidney transplantation, 2007-2012

[Diagram showing the number of donors and kidney transplants from 2007 to 2013, with bars for DCD and DBD donors and a line for kidney transplants.]

Organ Donation, Past Present and Future
Deceased donors, transplants and the transplant waiting list 2007-12

Organ Donation, Past Present and Future
Deceased donation and heart transplantation in the UK 2007-12

Organ Donation, Past Present and Future
Deceased donation, 2012

UK 2012: much improved............ but could do better still
Phase 3: inspire

- Donor identification and referral
- Diagnosis of brain-stem death
- Donor optimisation
- Family refusal

Doing things differently
Brain-stem death testing

- 427 patients not tested (25.7%)
- 220 additional brain-stem dead donors
- 860 additional organ transplants

Potential Donor Audit, 2011-12
Organ utilisation in DBD donors

% possible organs

- Kidney
- Liver
- Pancreas
- Hearts
- Lungs

Organ donors → Meet specific organ criteria → Consent for organ and organ offered → Organ accepted and retrieved → Organ transplanted

Kidney: 100, 90, 80, 70, 60, 50, 40, 30, 20, 10, 0
Liver: 100, 90, 80, 70, 60, 50, 40, 30, 20, 10, 0
Pancreas: 100, 90, 80, 70, 60, 50, 40, 30, 20, 10, 0
Hearts: 100, 90, 80, 70, 60, 50, 40, 30, 20, 10, 0
Lungs: 100, 90, 80, 70, 60, 50, 40, 30, 20, 10, 0

Organ Donation, Past Present and Future
Family refusal rates

The UK will never have a world class donation and transplantation service when 40% of families say ‘no’.
Family refusal rates

If the UK had a 20% family refusal rate
- Additional 120 DBD donors
- Additional 280 DCD donors
- Additional 1200 transplants

The UK will never have a world class donation and transplantation service when 40% of families say ‘no’.

Organ Donation, Past Present and Future
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.

Mary Hand, cystic fibrosis sufferer. Died aged 22

*Organs for Transplants*
A Report from the Organ Donation Taskforce (2008)