

Best Practice in Organ Donation

An International Perspective

Dr Paul Murphy

National Clinical Lead for Organ Donation

NHS Blood and Transplant

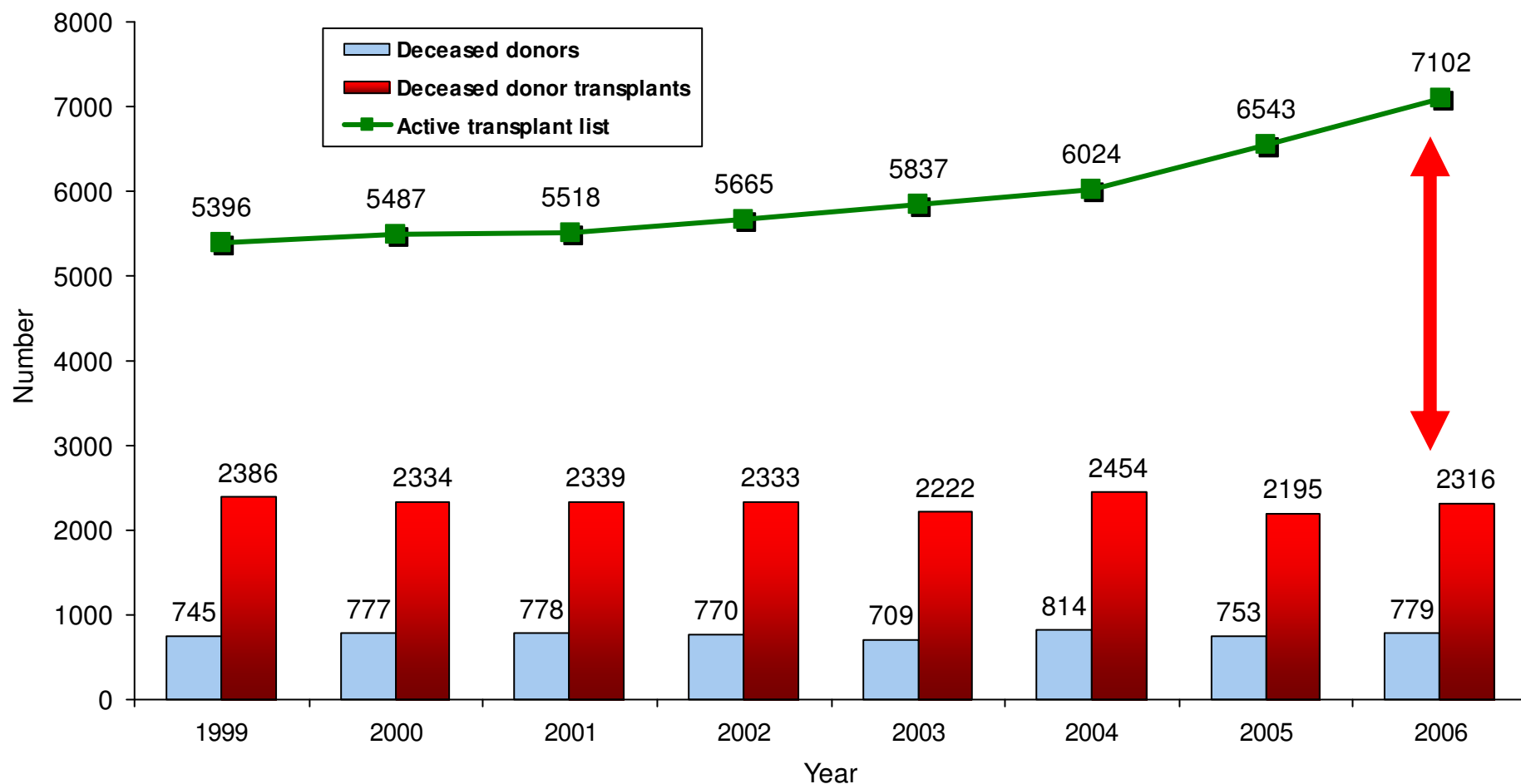
United Kingdom

Outline

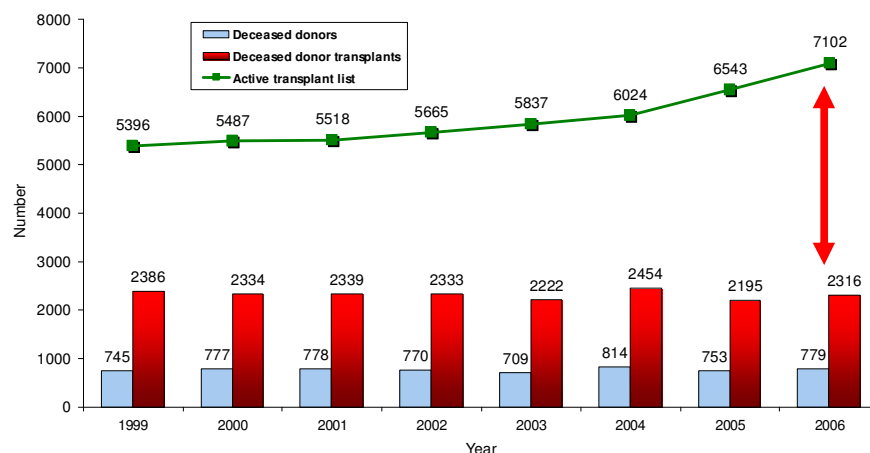
- Organ donation in the UK, 2006
- Organ Donation Taskforce Report, 2008
 - Clinical Leads for Organ Donation
 - Resolution of obstacles
- Current status in UK
- ACCORD project
 - Variations in end of life care in EU



Deceased donors and transplant waiting lists, 2006



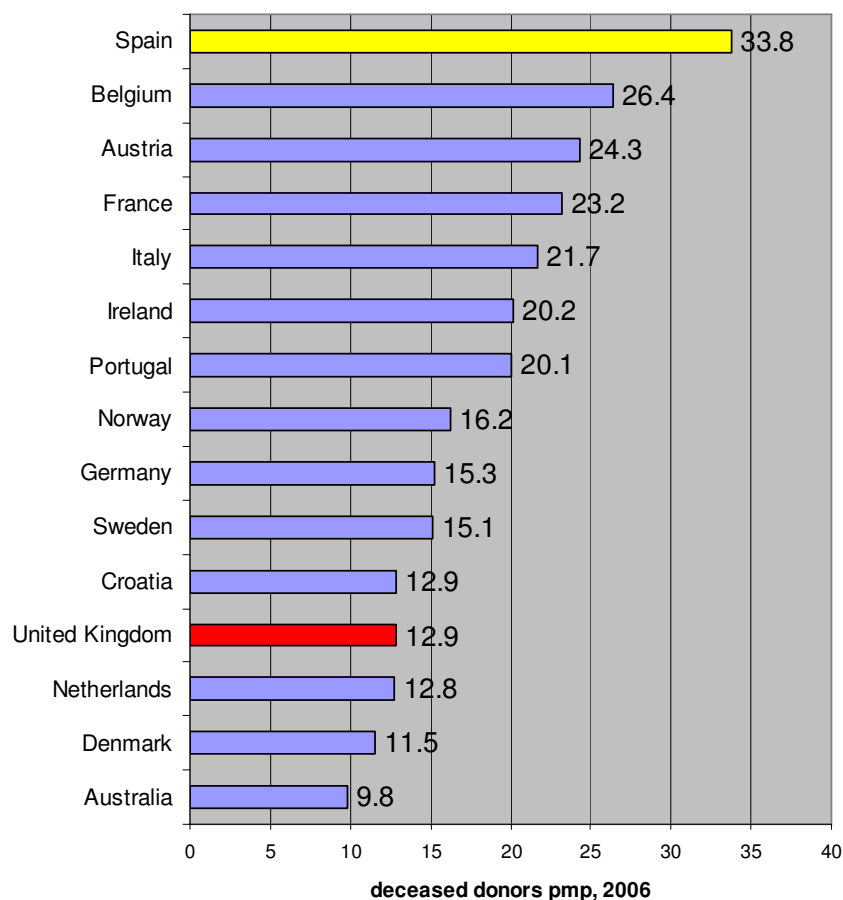
Deceased donation, 2006



A series of ineffective interventions

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

UK Organ Donation Taskforce



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.

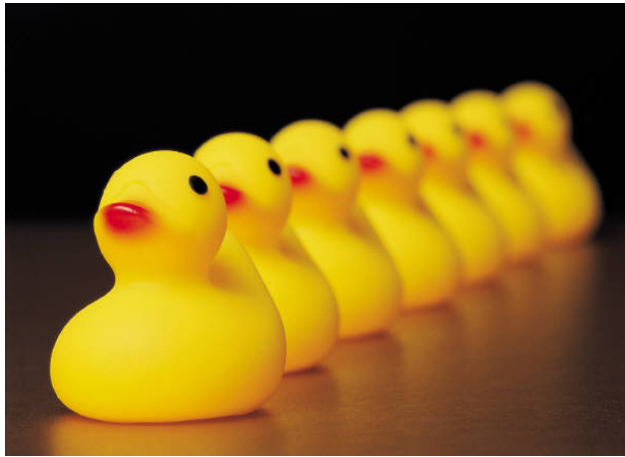
To identify barriers to any part of the transplant process and recommend ways to overcome them to support and improve transplant rates

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

Making a donation happen



Wrong place of death
Wrong kind of death
Unknown wishes

- 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

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

Funding
Resolution of ethical and
legal obstacles
Regulation
Public recognition

Departments of Health

Clinical leads
Embedded coordinators
Donation Committees

Acute hospitals

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



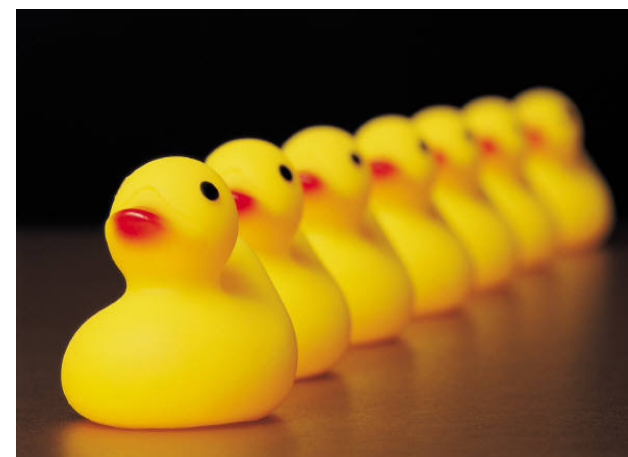
Rafael Matesanz
Director
**National Donation and
Transplant Organisation
Spain**

“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.”

Overcoming the obstacles

Frameworks of Practice

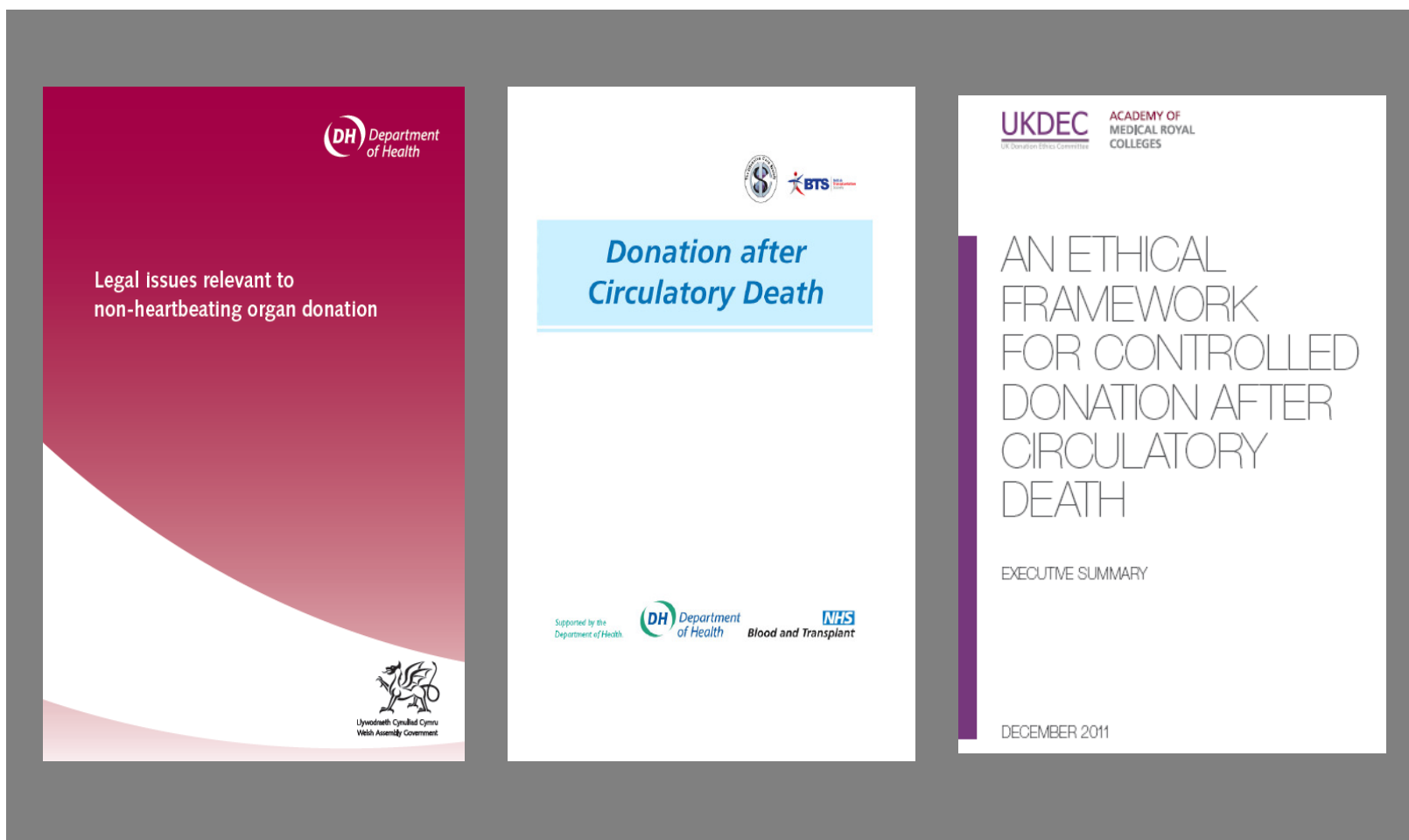
Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established.



Wrong place of death
Wrong kind of death
Unknown wishes

Overcoming the obstacles

Donation after Circulatory Death

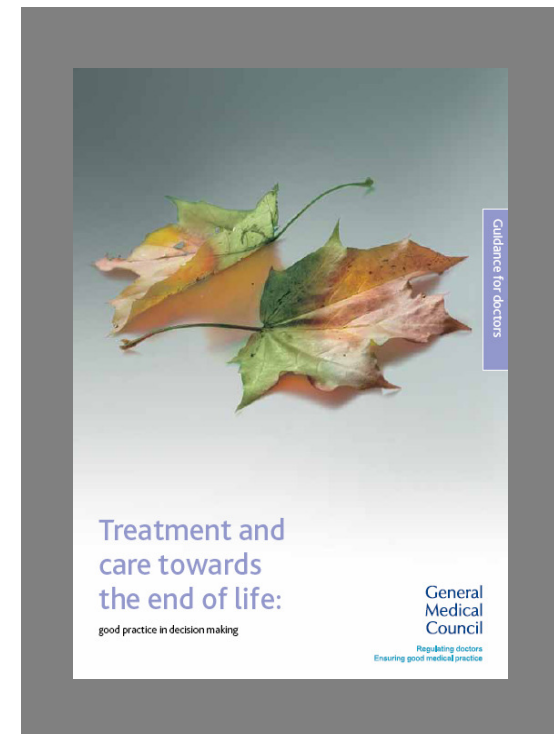


<http://www.odt.nhs.uk/donation/deceased-donation/>

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.

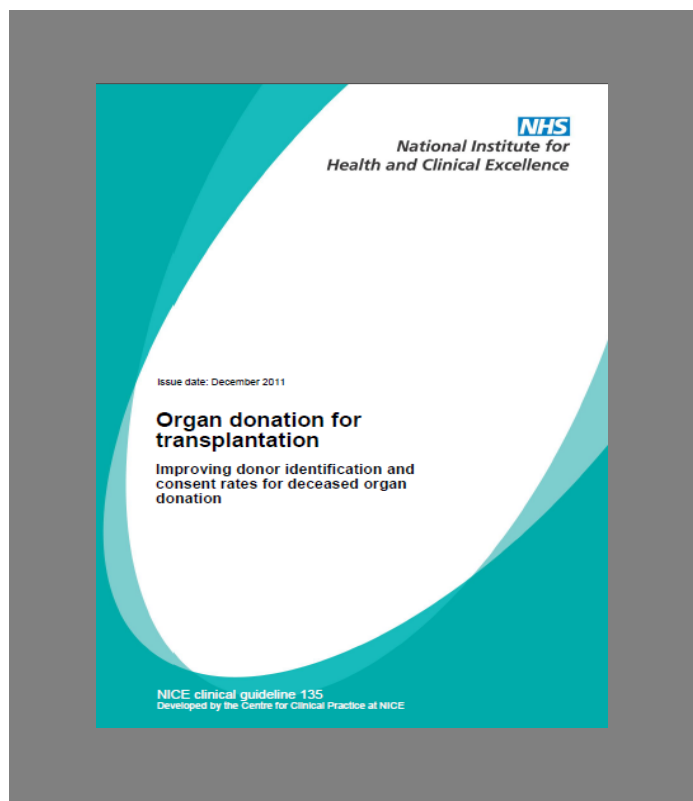
82. You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator.



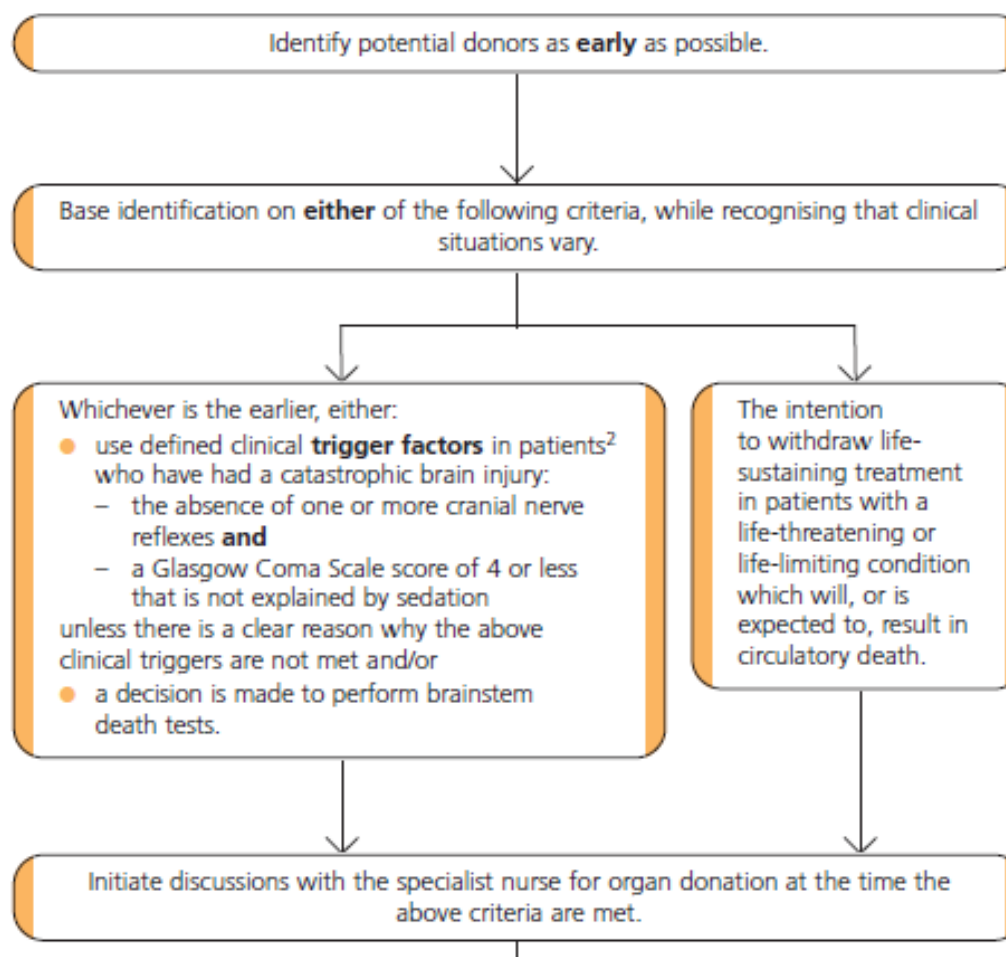
UK GMC guidance on
end of life care , 2010

Overcoming the obstacles

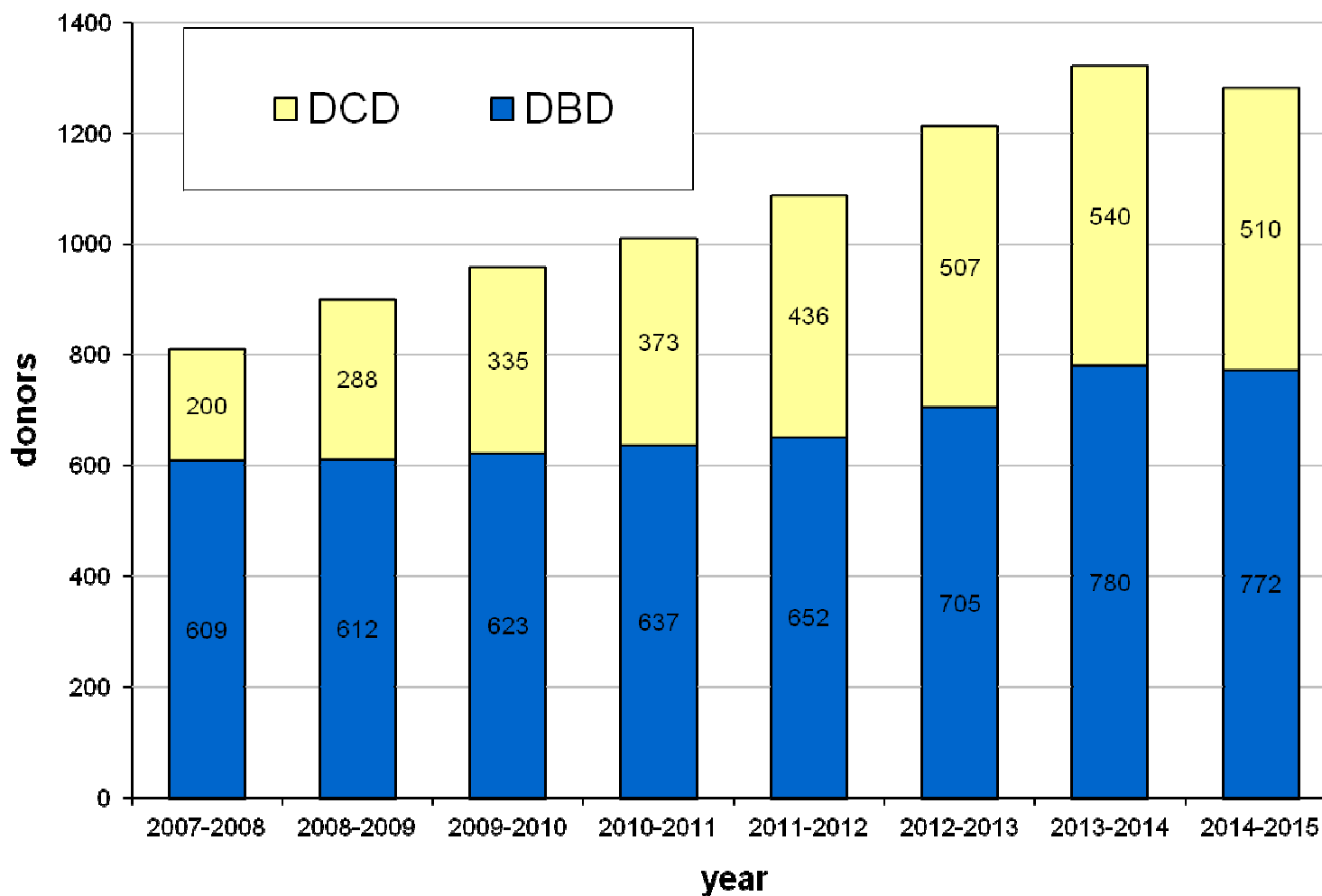
Donor identification



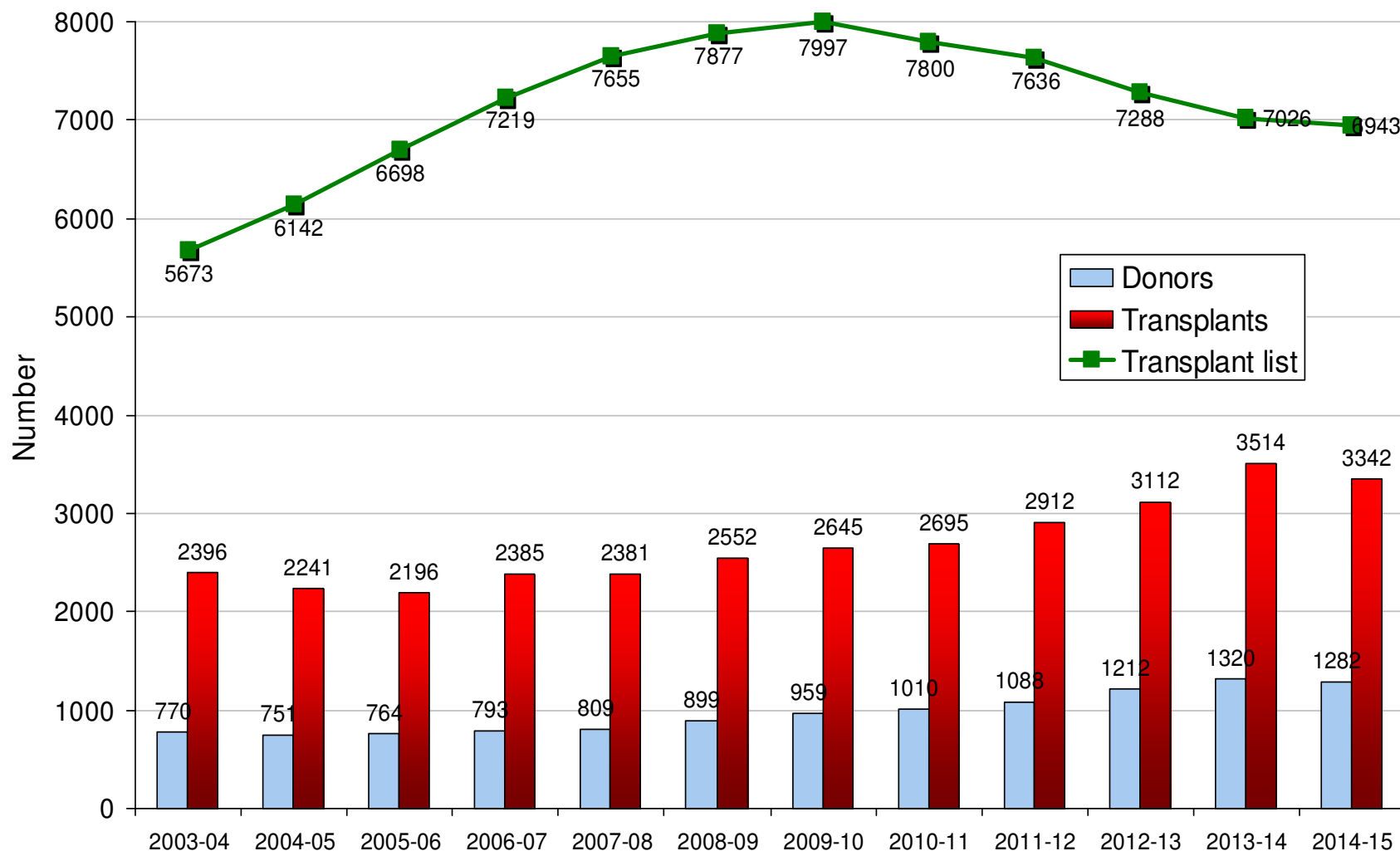
<http://www.odt.nhs.uk/donation/deceased-donation/>



Deceased organ donors in the UK 2007-15

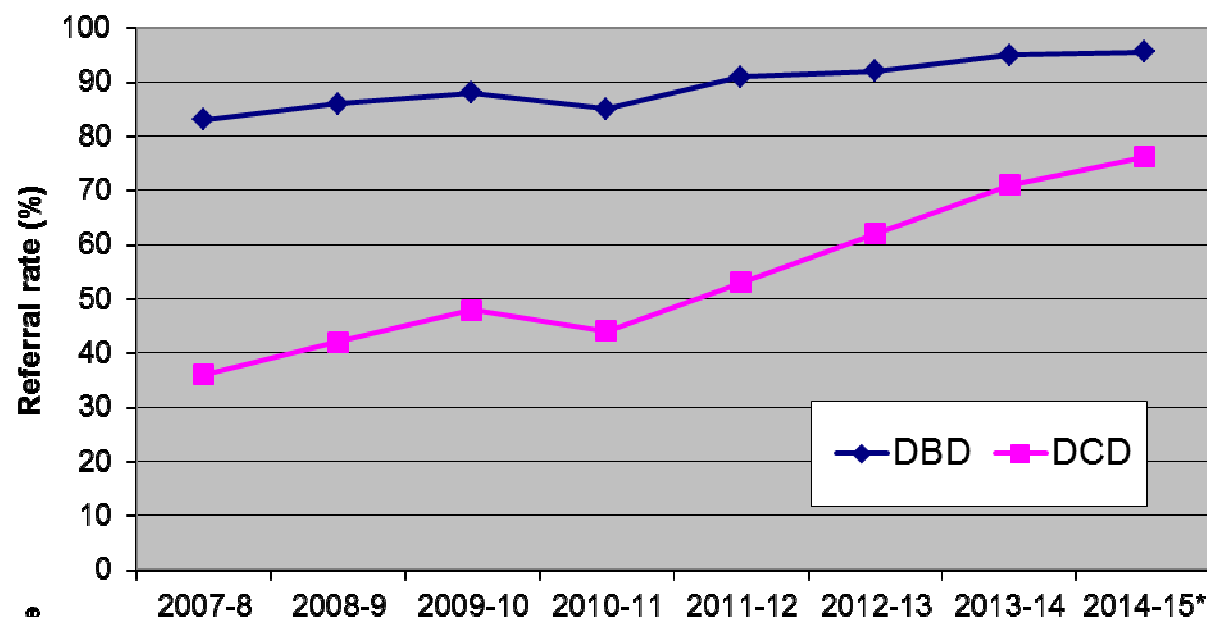


Deceased donors, transplants and the transplant waiting list 2003-2015

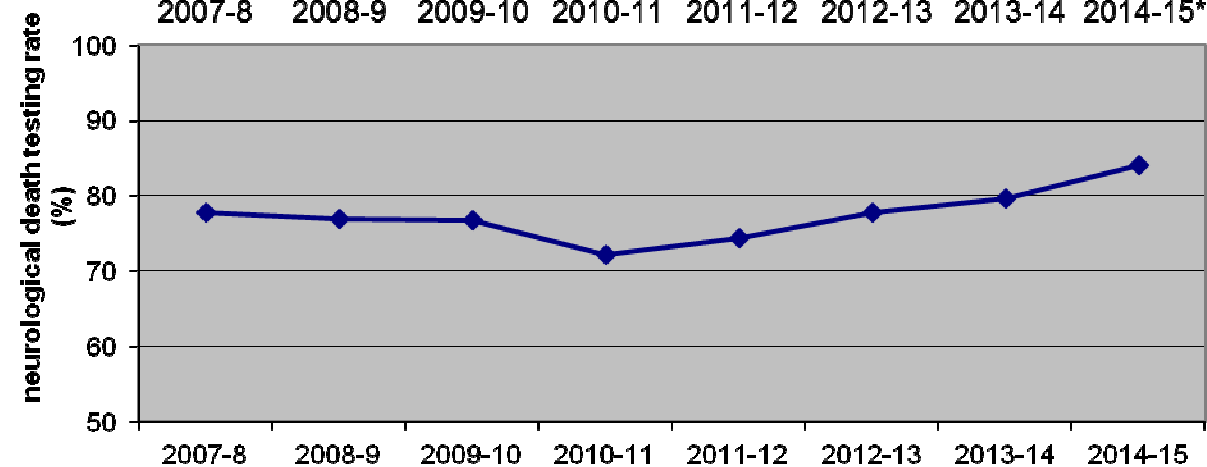


Donor referral and brain death testing

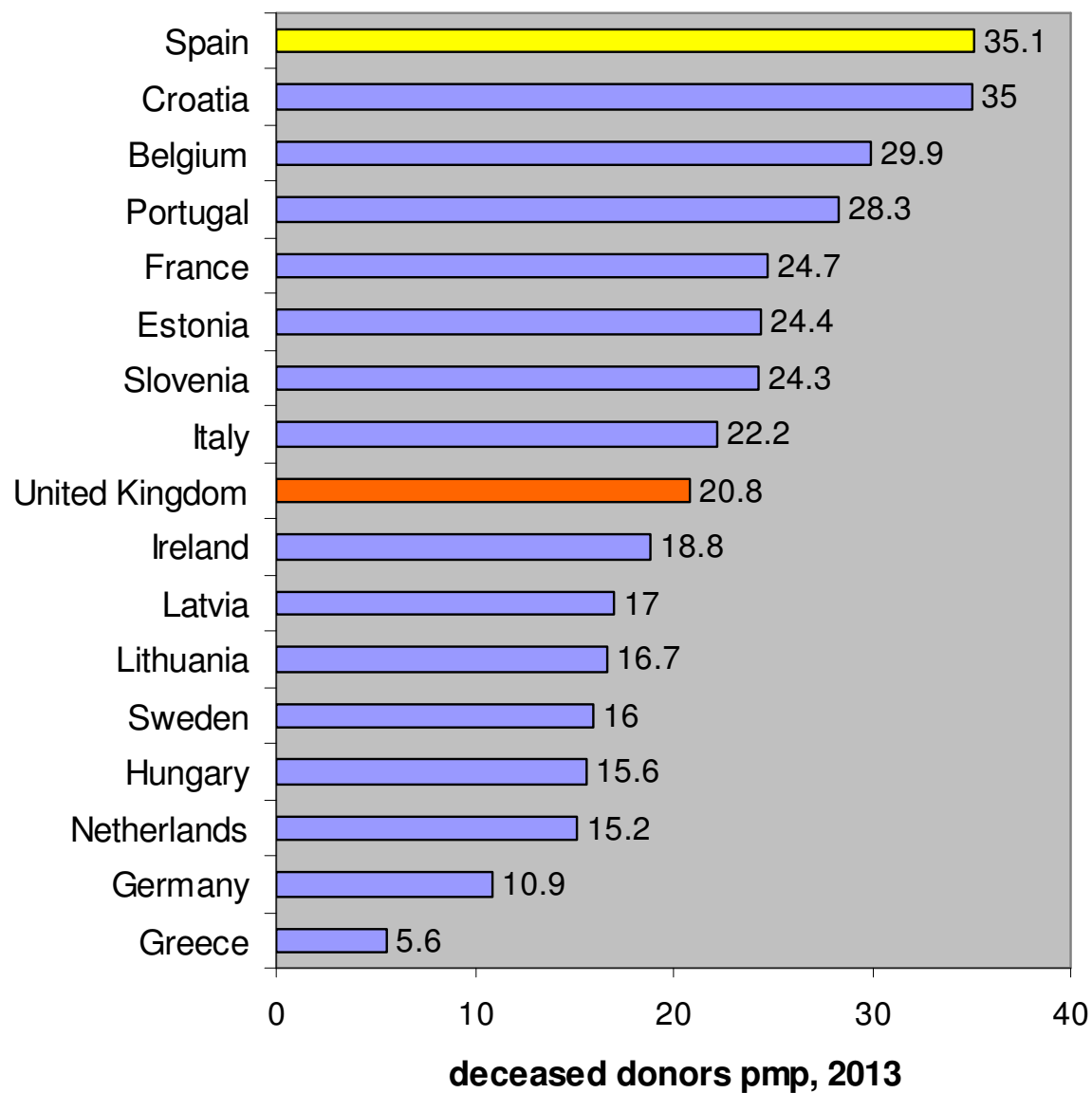
Referral



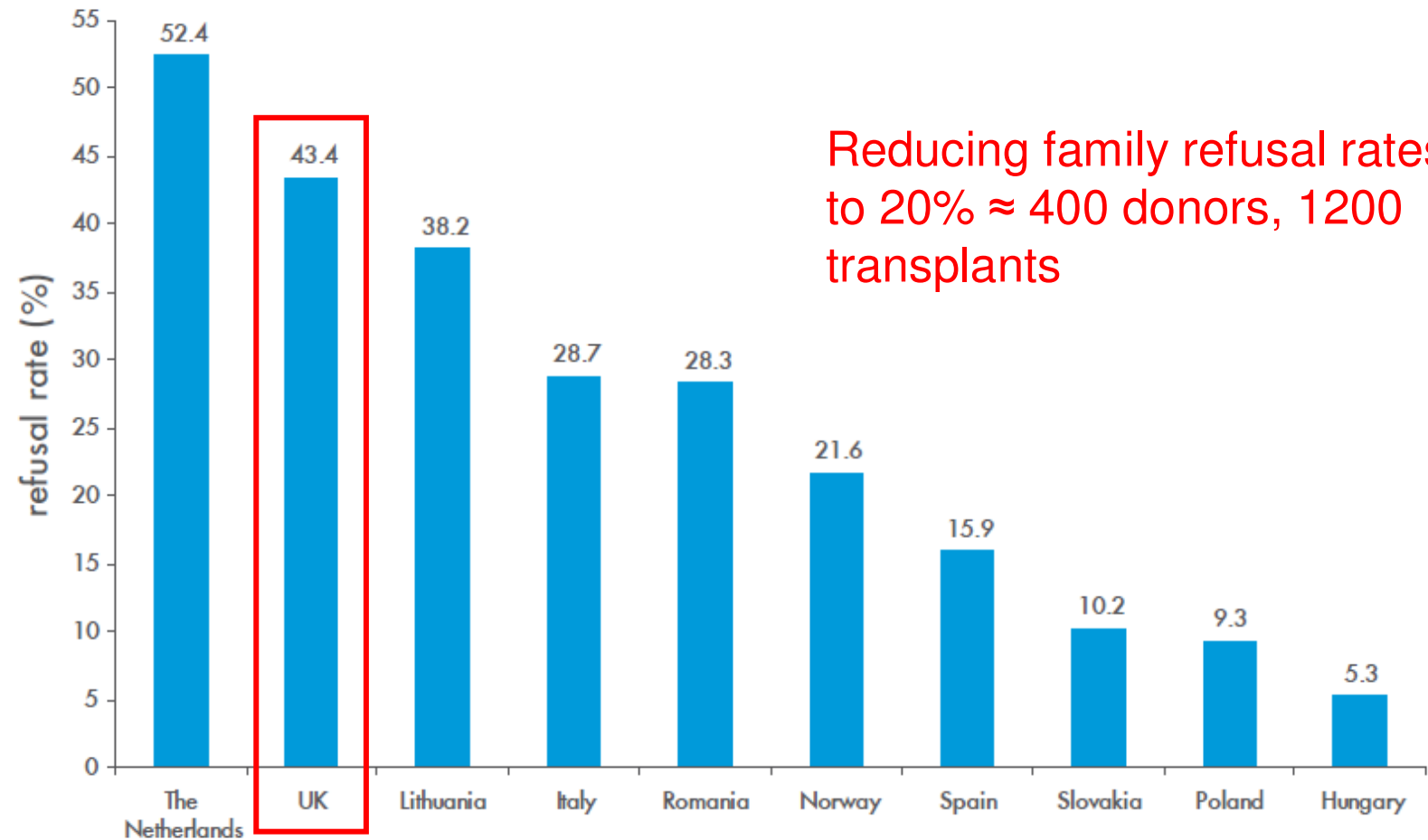
Brain death testing



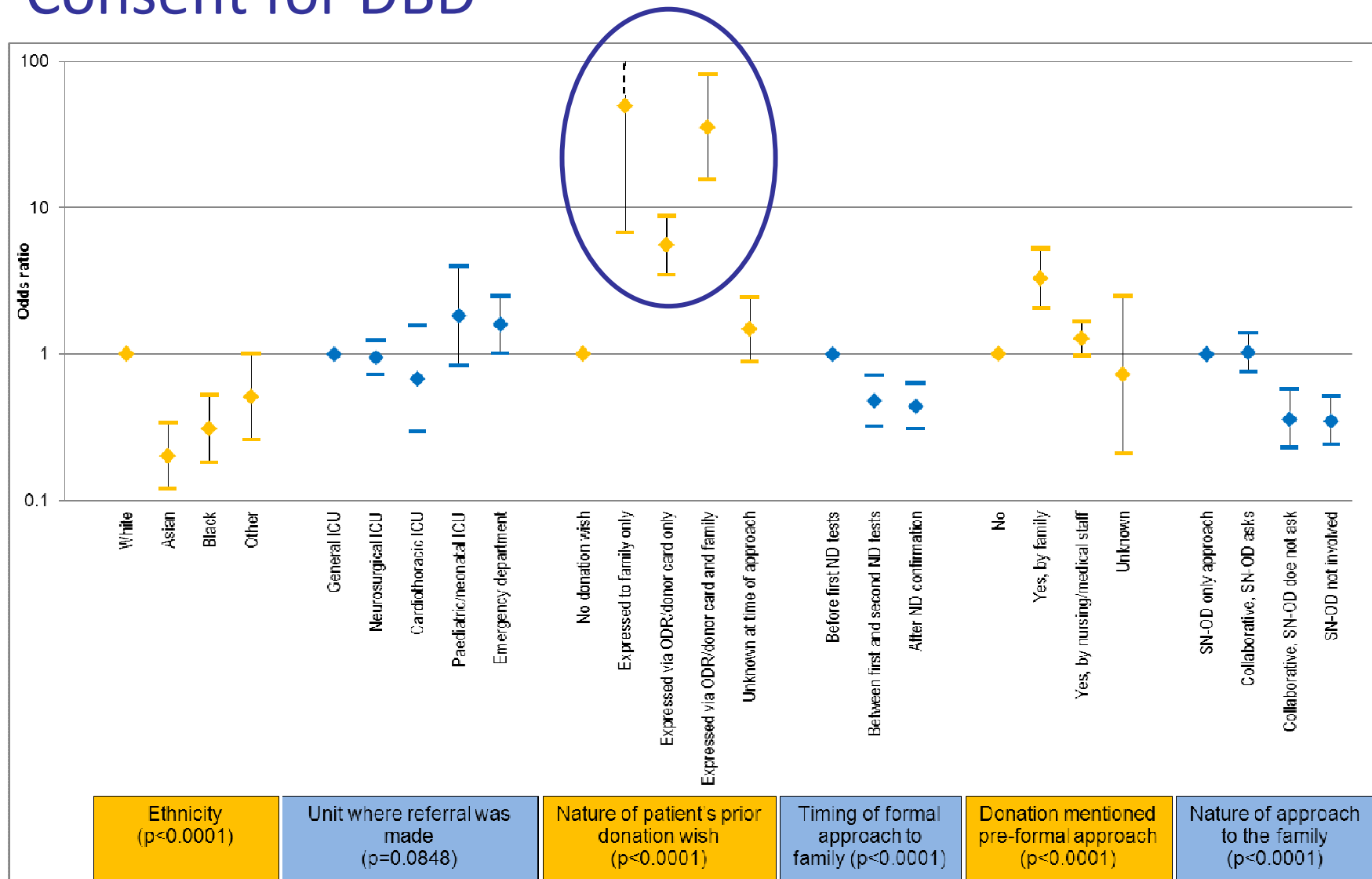
European deceased donation rates, 2013



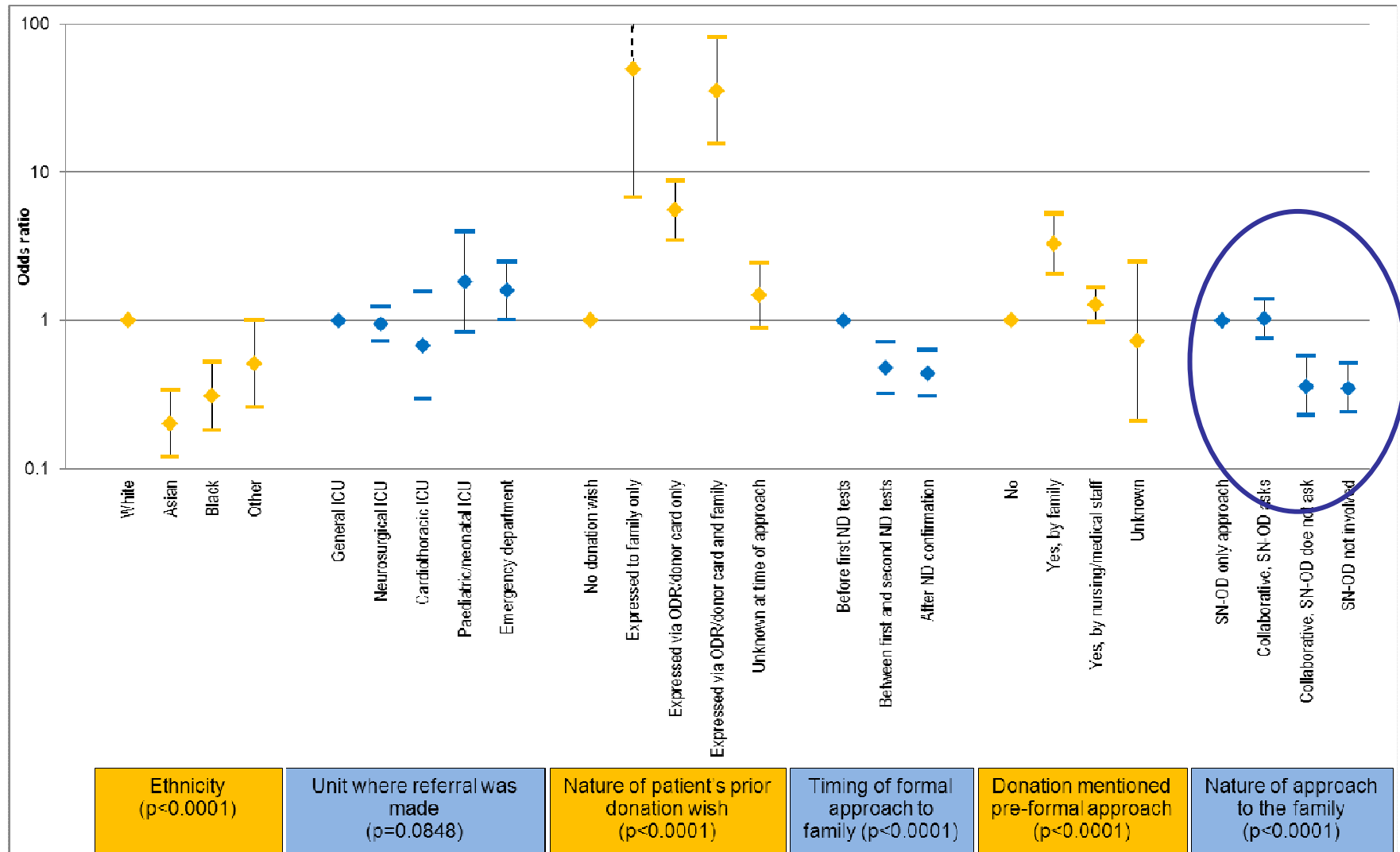
International consent rates



Consent for DBD



Consent for DBD

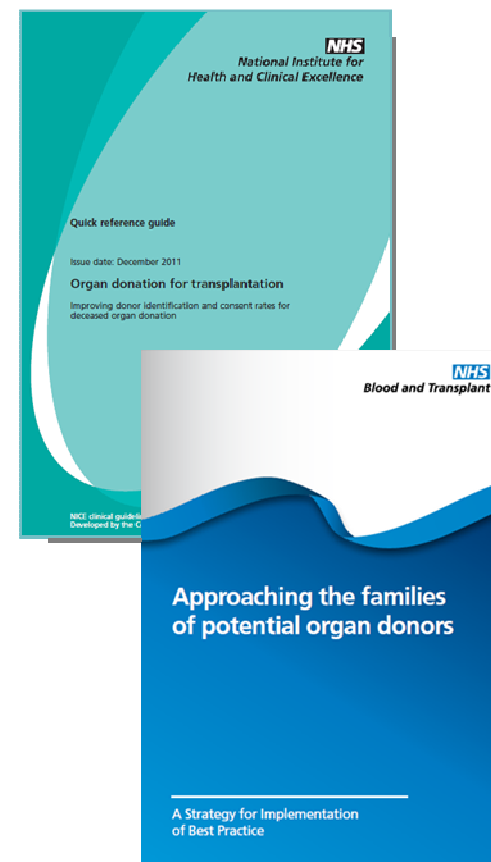


National Guidance on Family Approach

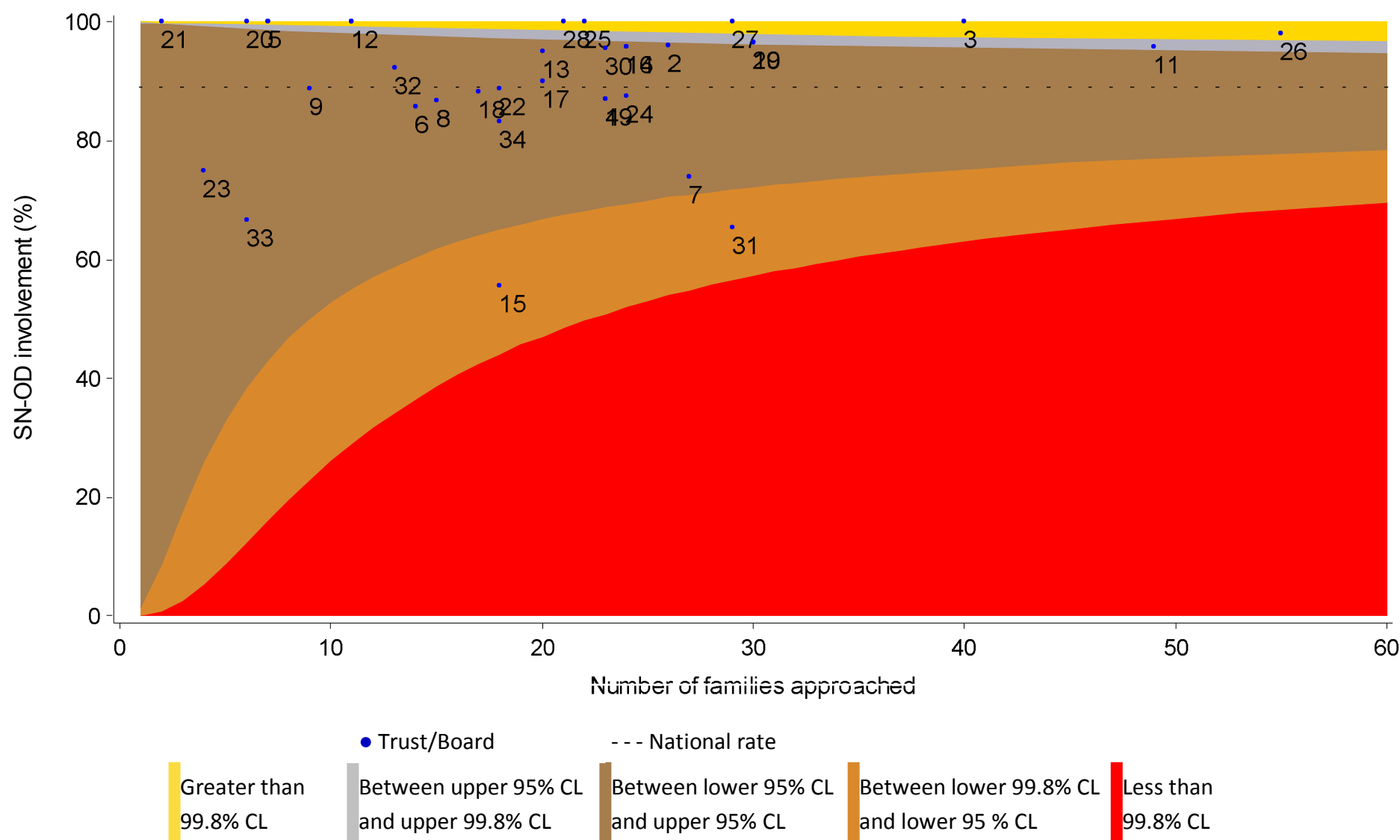
1.1.11 A multidisciplinary team (MDT) should be responsible for planning the approach and discussing organ donation with those close to the patient.

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.

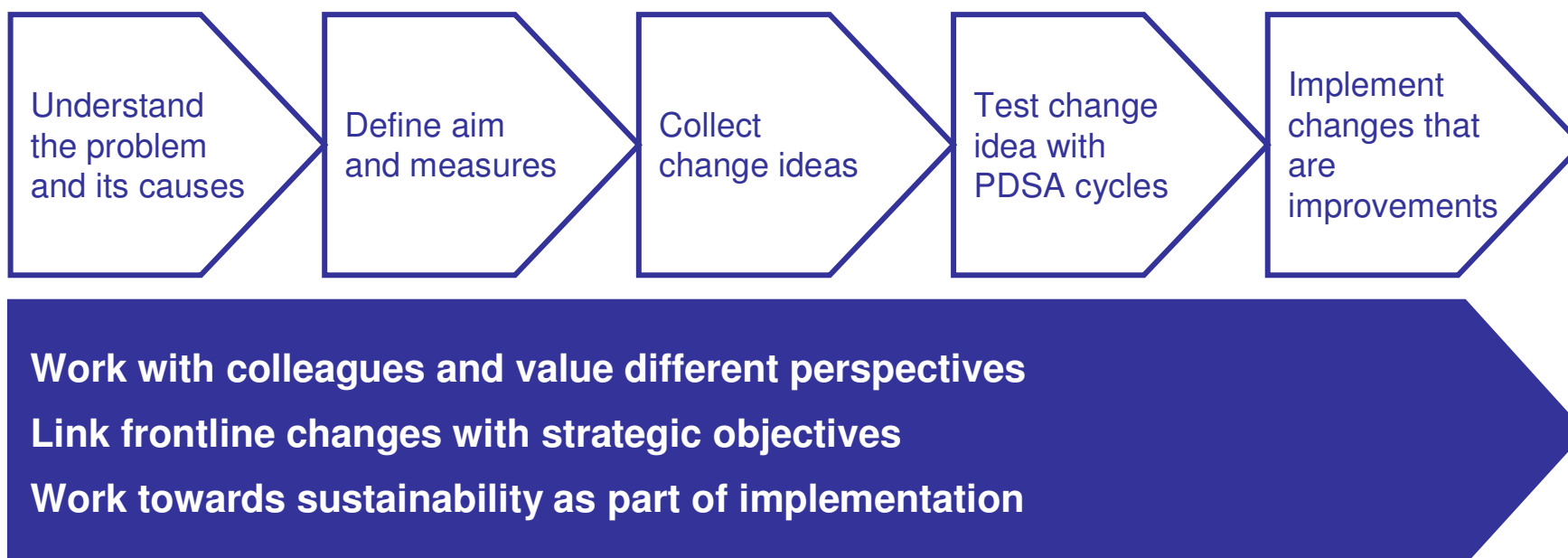


Collaborative requesting in major UK hospitals



Service improvement methodologies

Overview



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.”*

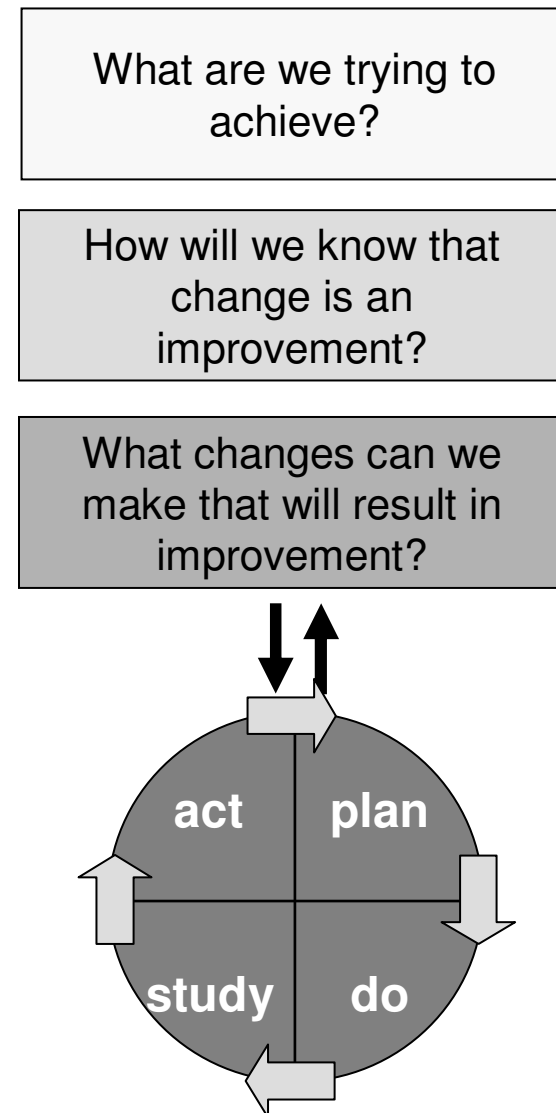
Albert Einstein

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

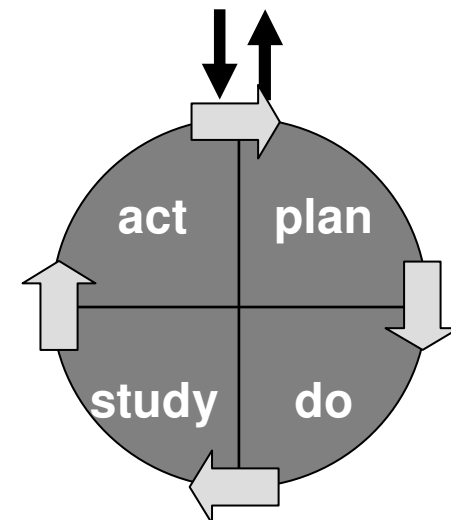
Study: our data from the pilot compare with baseline data in this way. We also had the following problems

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?



Timeliness of referral

- **Problem:** late referral, resulting in delayed arrival of SN-OD
- **Intervention:** inclusion of referral into ICU daily safety briefing
- **Measures:**
 - referral

North Bristol NHS Trust		Safety Briefing Safer Patient Initiative		Quality Improvement & Audit																																																																																																																																																																									
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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

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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

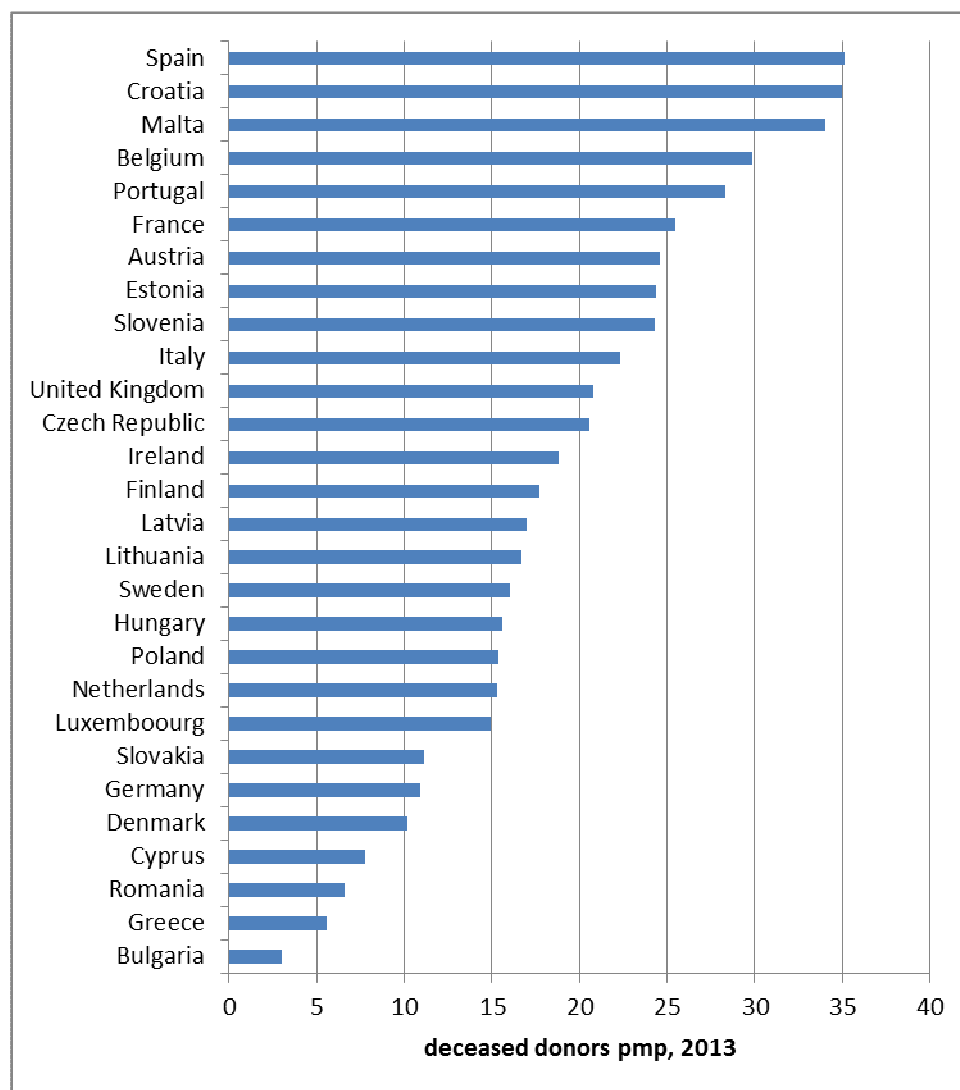
Measures		Before	After
Collaborative requests (%)	DBD	73	87
	DCD	36	69
Consent rate (%)	DBD	64	80
	DCD	68	56

Family refusal

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

Measures	Before	After
Families approached	28	29
Collaborative requests	18 (64%)	25 (86%)
Consents	15 (54%)	22 (86%)

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 Categories (% patients)				
	Unsuccessful CPR	Brain death	Treatment limitation	Treatment withdrawal	Active shortening of dying process
Northern Denmark, Finland, Ireland, Netherlands, Sweden, UK	10.2	3.2	38.2	47.4	0.9
Central Austria, Belgium, Czechia, Germany, Switzerland	17.9	7.6	34.1	33.8	6.5
Southern Greece, Israel, Italy, Portugal, Spain, Turkey	30.1	12.4	39.6	17.9	0.1
Range between countries	5 - 48	0 - 15	16 - 70	5 - 69	0 - 19

End-of-Life Practices in European Intensive Care Units
Sprung et al, 2003. JAMA 290: 790-797.

Ethicus study

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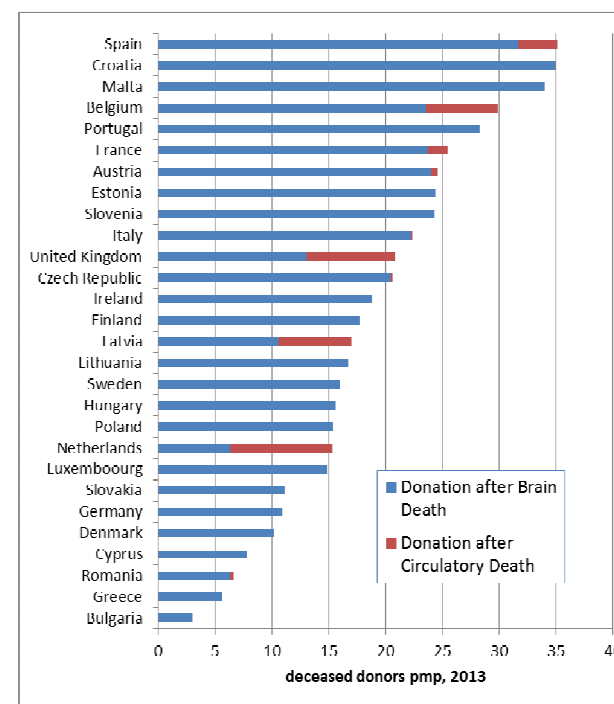
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End of life care and organ donation

- 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?



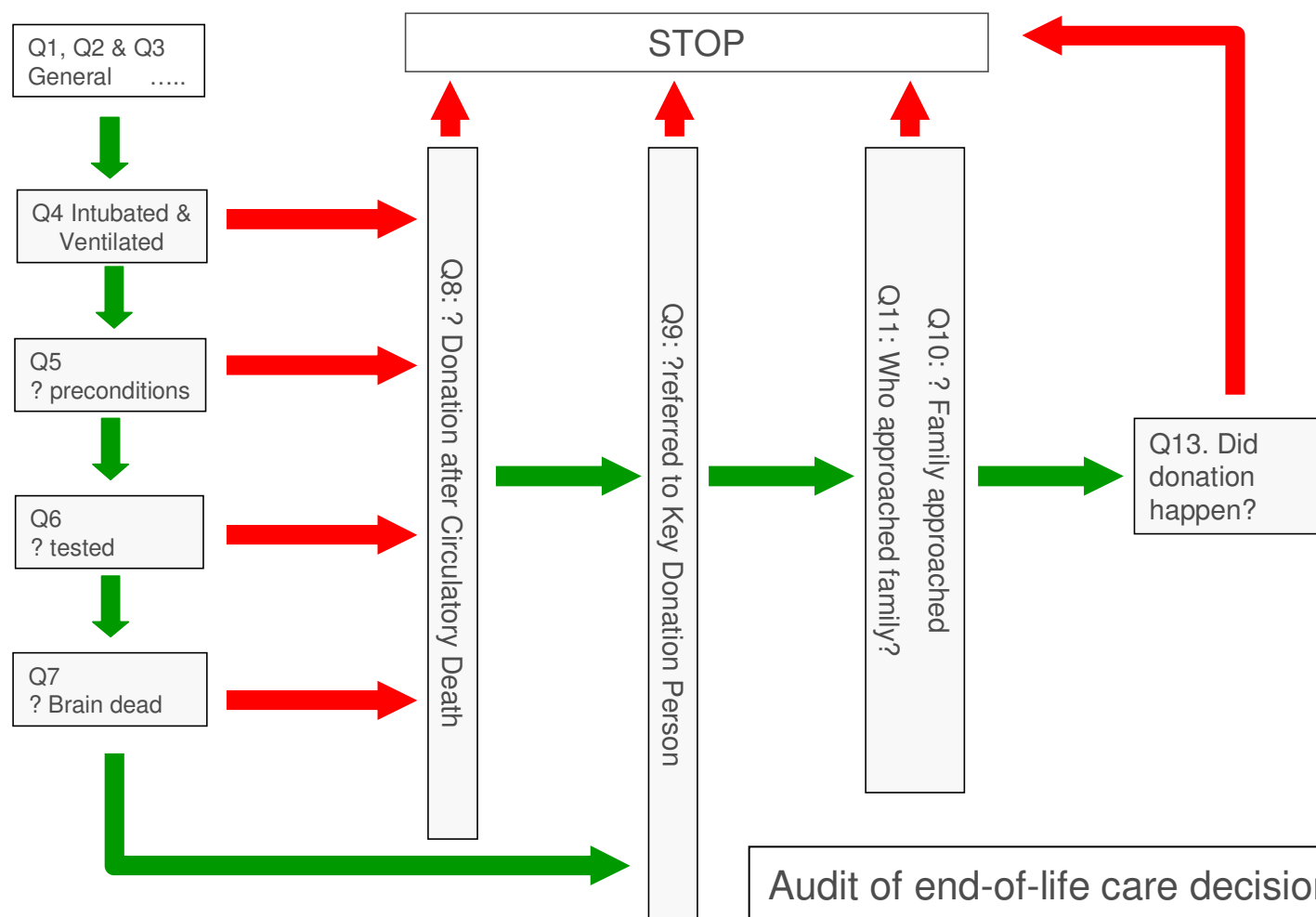
ACCORD: Achieving Comprehensive Coordination in ORgan Donation

- 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

Patient questionnaire



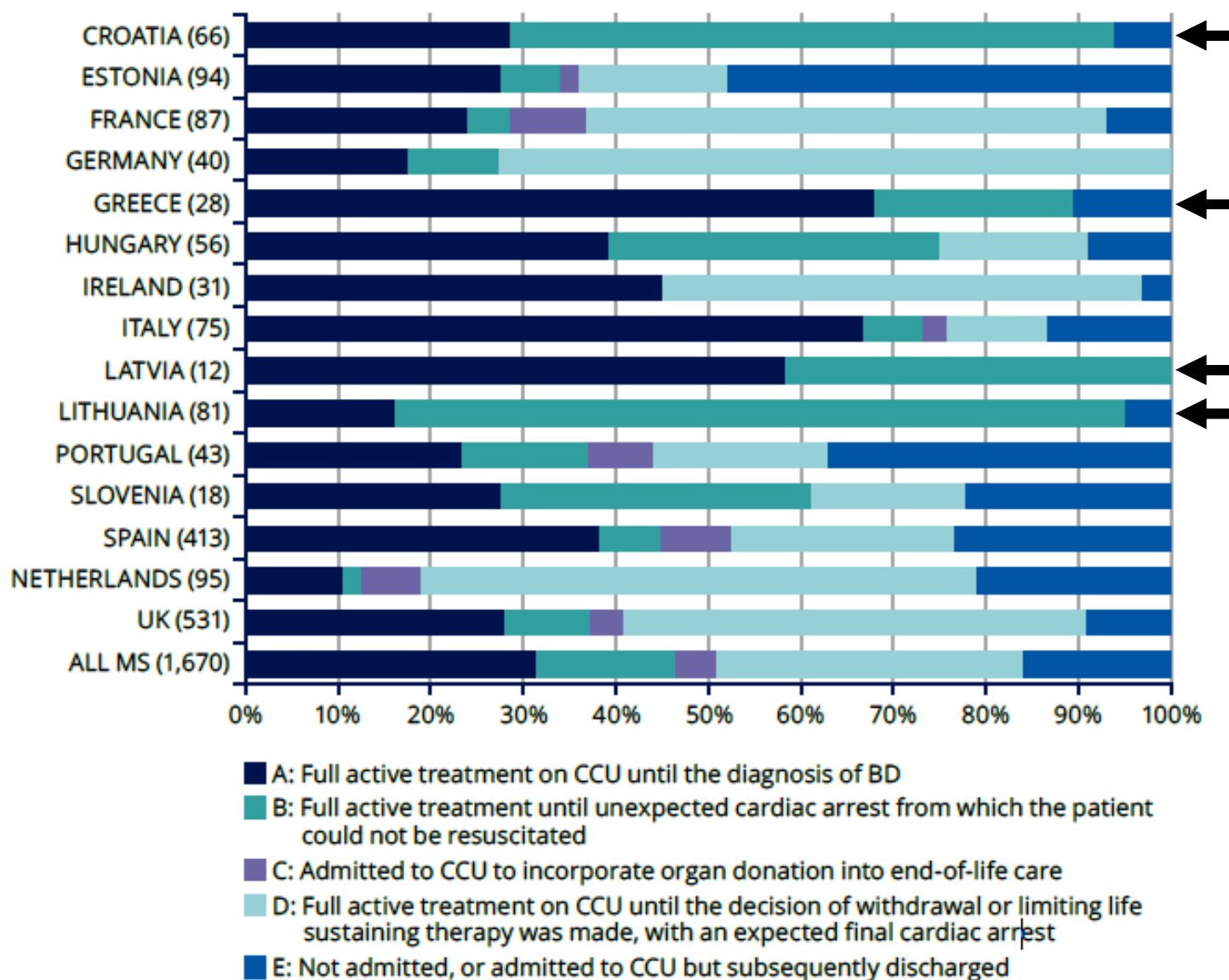
Audit of end-of-life care decision making in consecutive patients (2 months to 80 years) dying of neurological conditions known to be a cause of brain death

Patterns of care

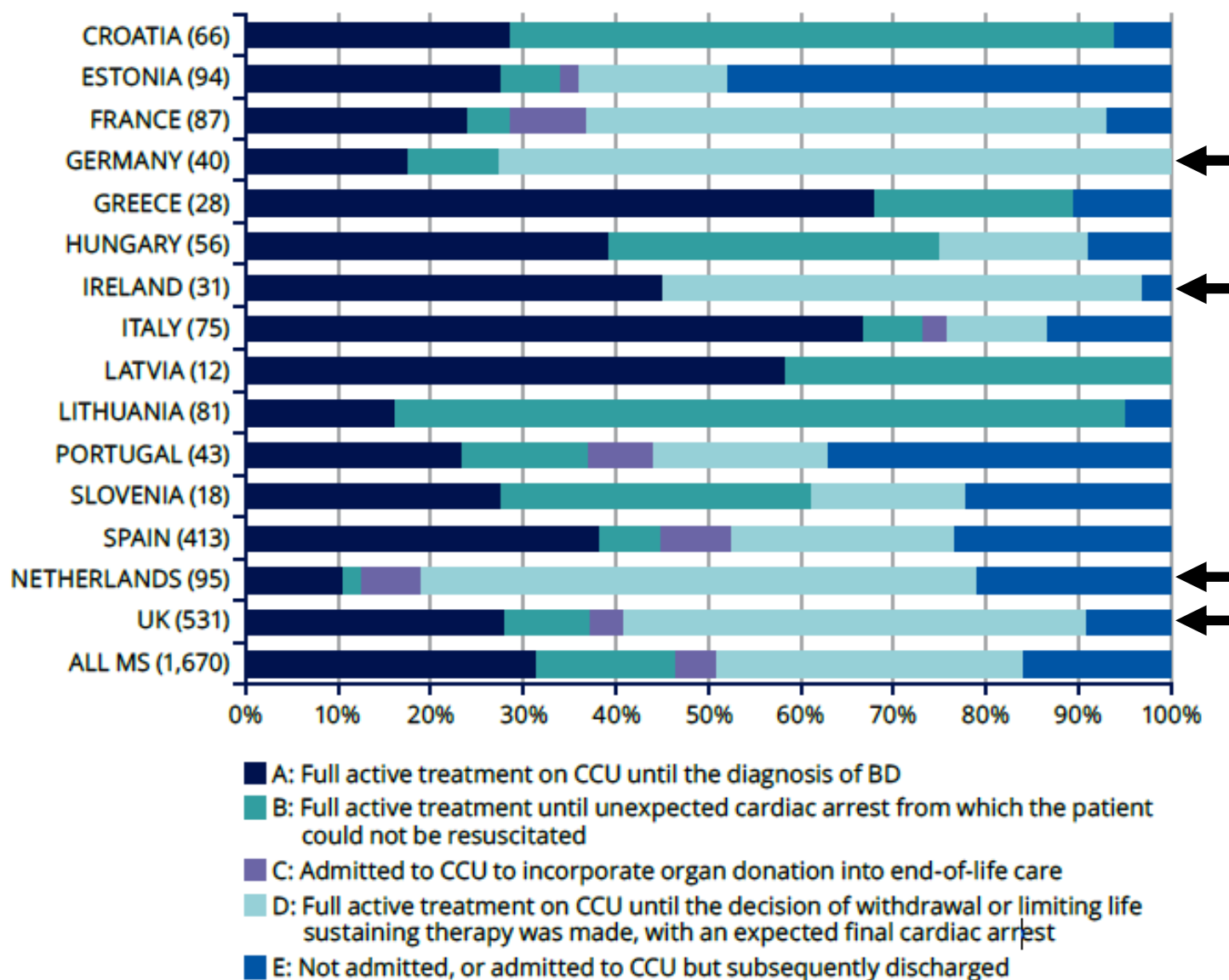
Q1. Which statement best describes the care of the patient during his/her final illness?
Please tick one box only:

- ☐ 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

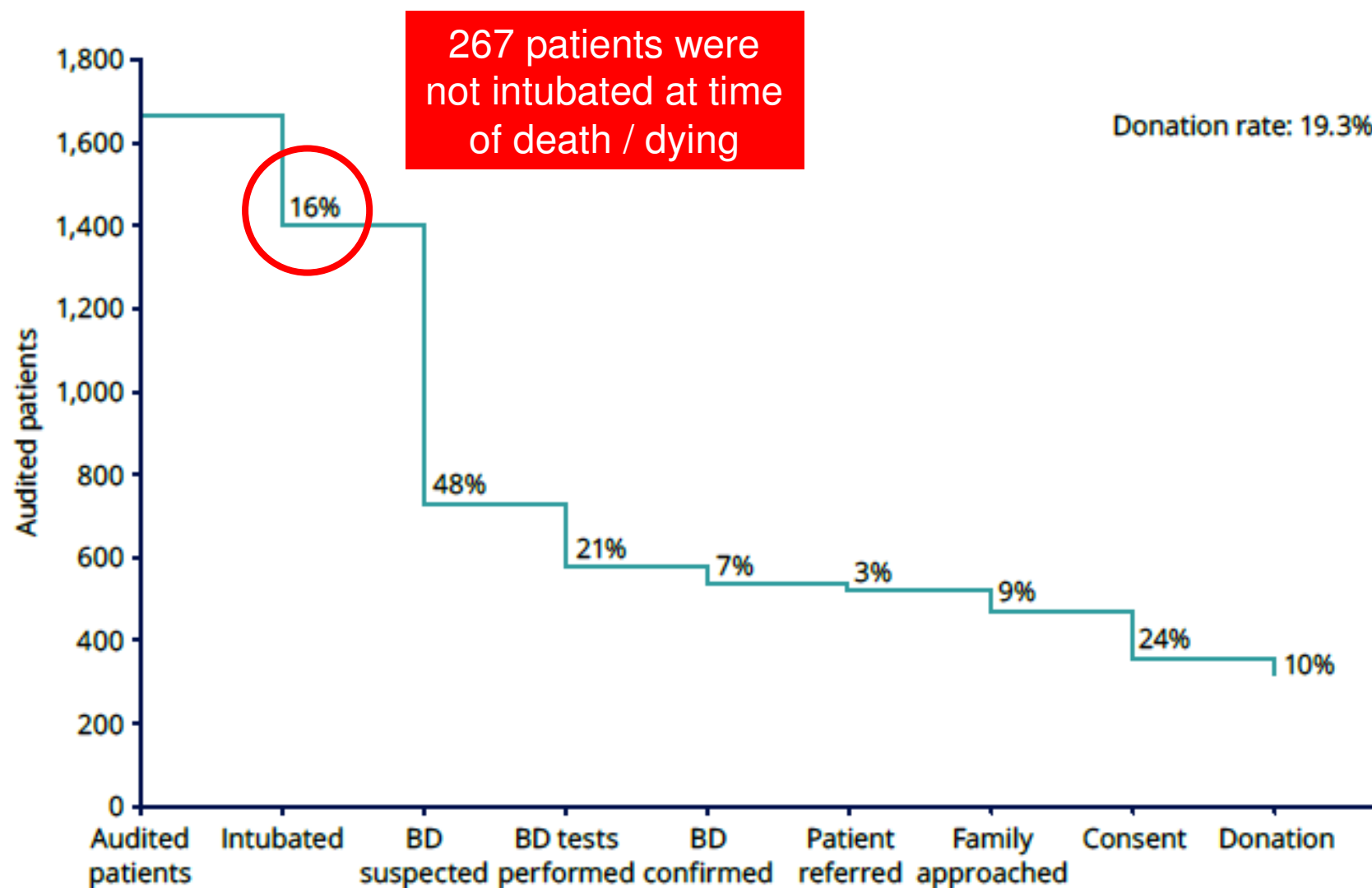


Patterns of care



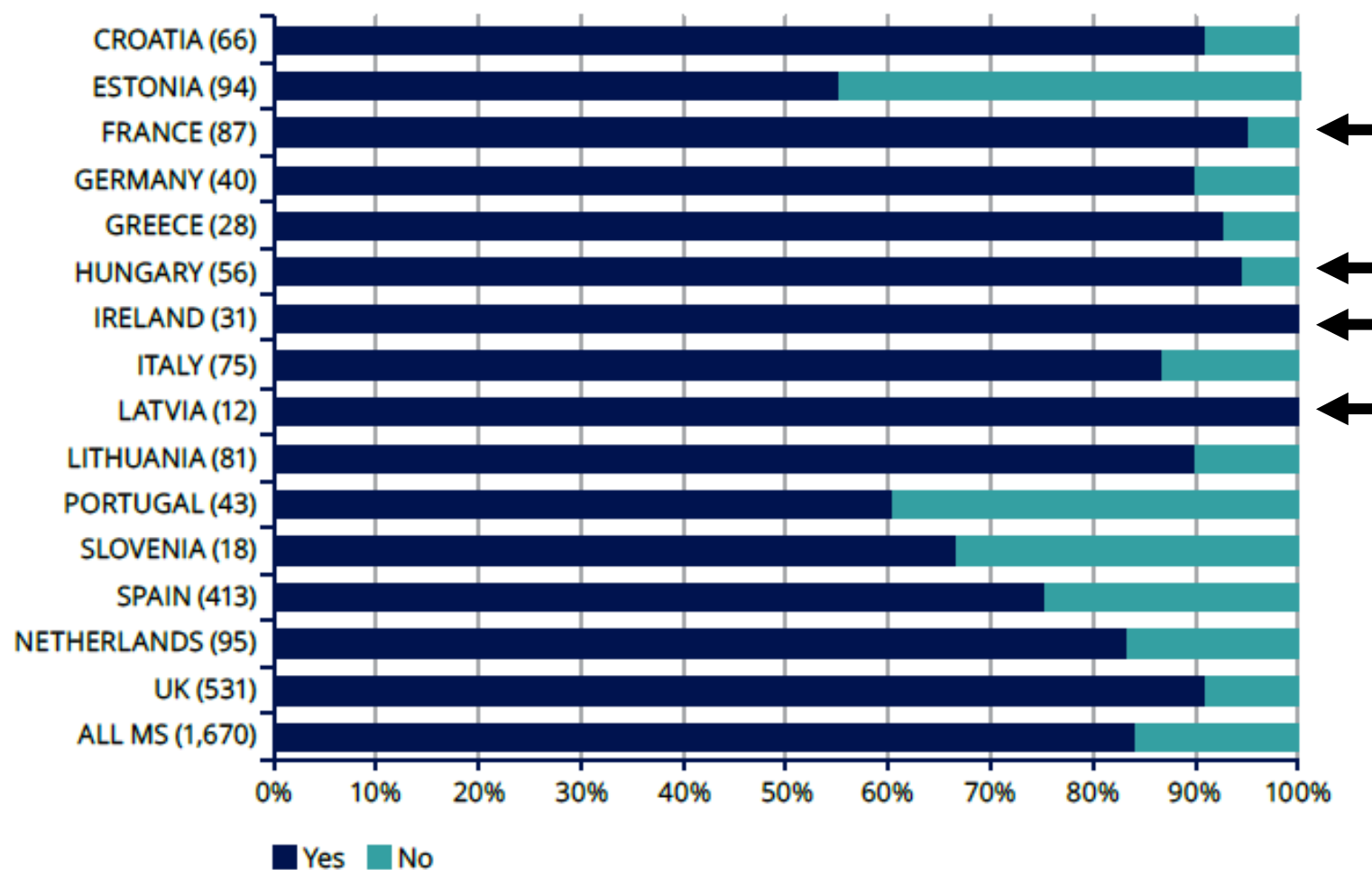
DBD pathway

? intubated



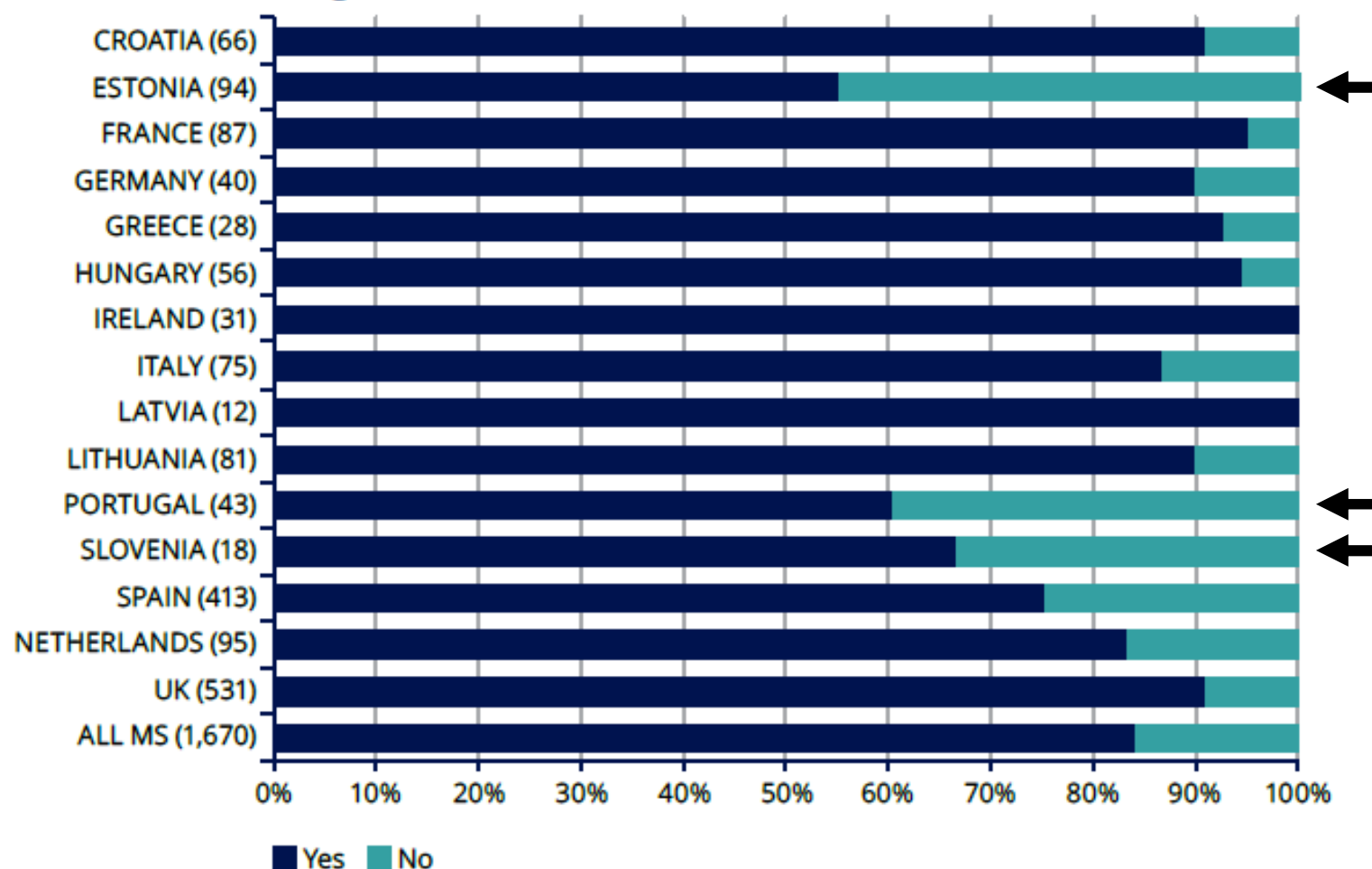
Intubation and ventilation

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?



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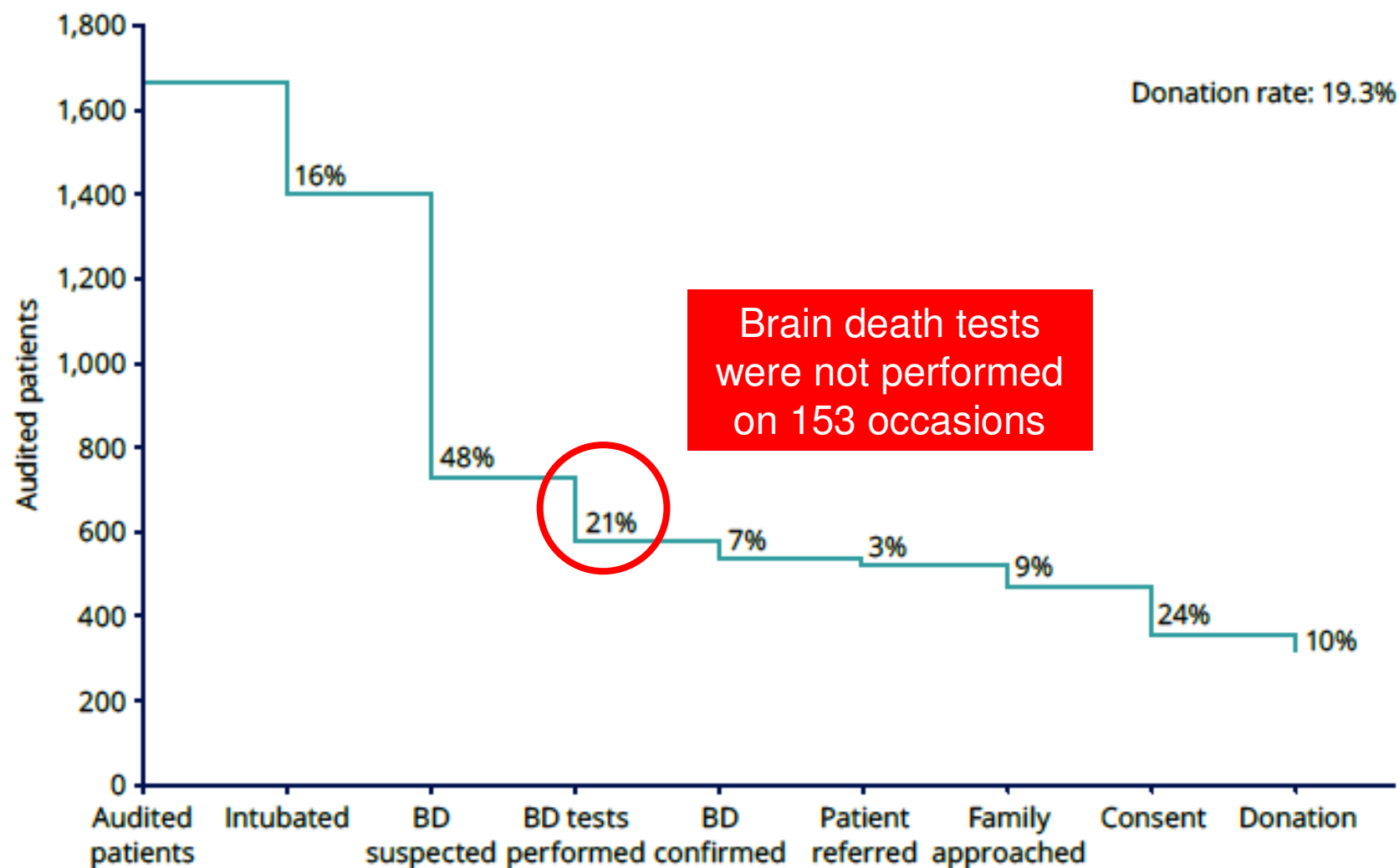


Intubation and ventilation

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

	N	%
Not appropriate	53	21.5
Not needed	34	13.8
Not of overall benefit to the patient due to the severity of the acute event	145	58.9
Other	5	2.0
Not reported	9	3.7

DBD pathway ? tested

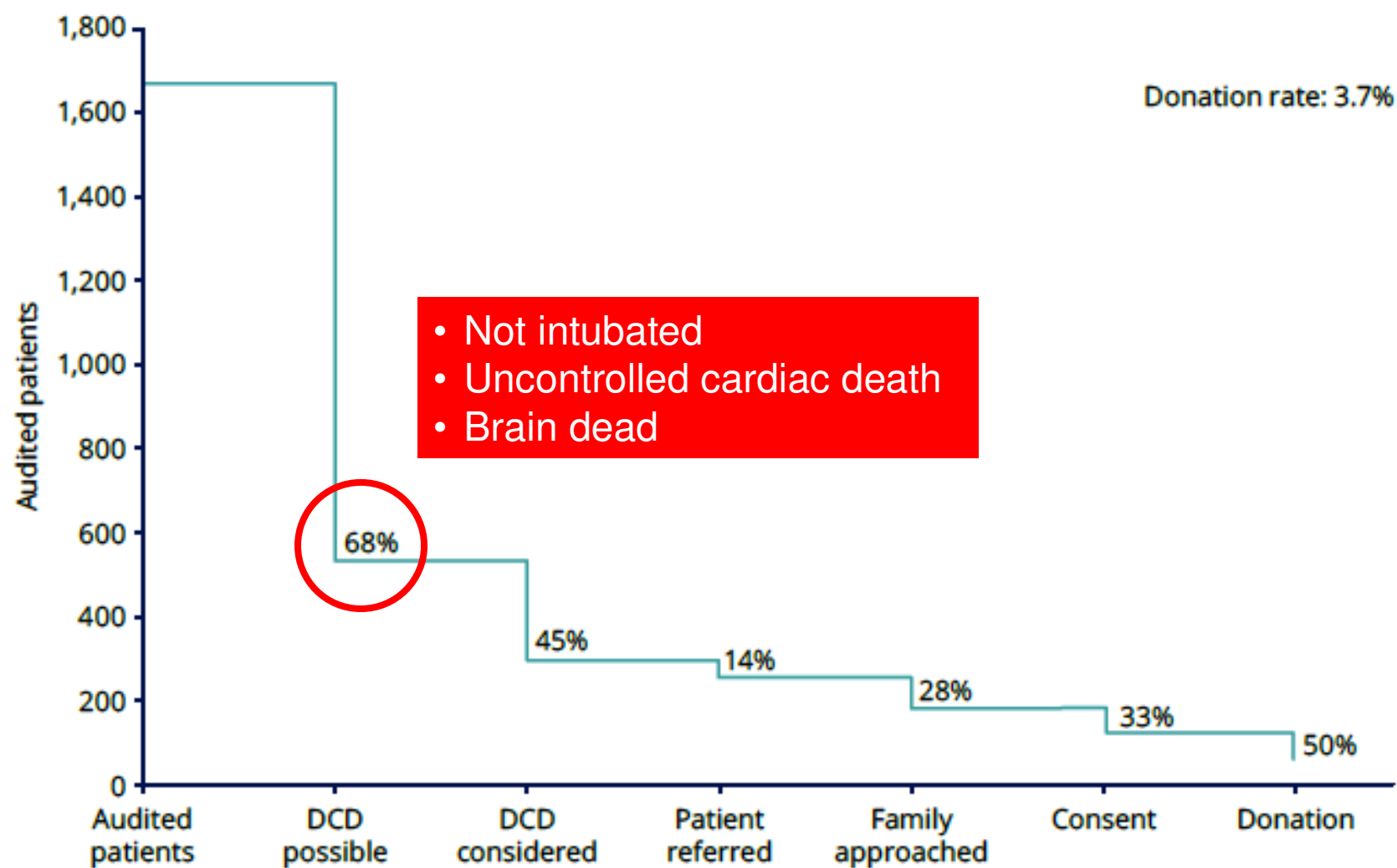


Reasons for not testing

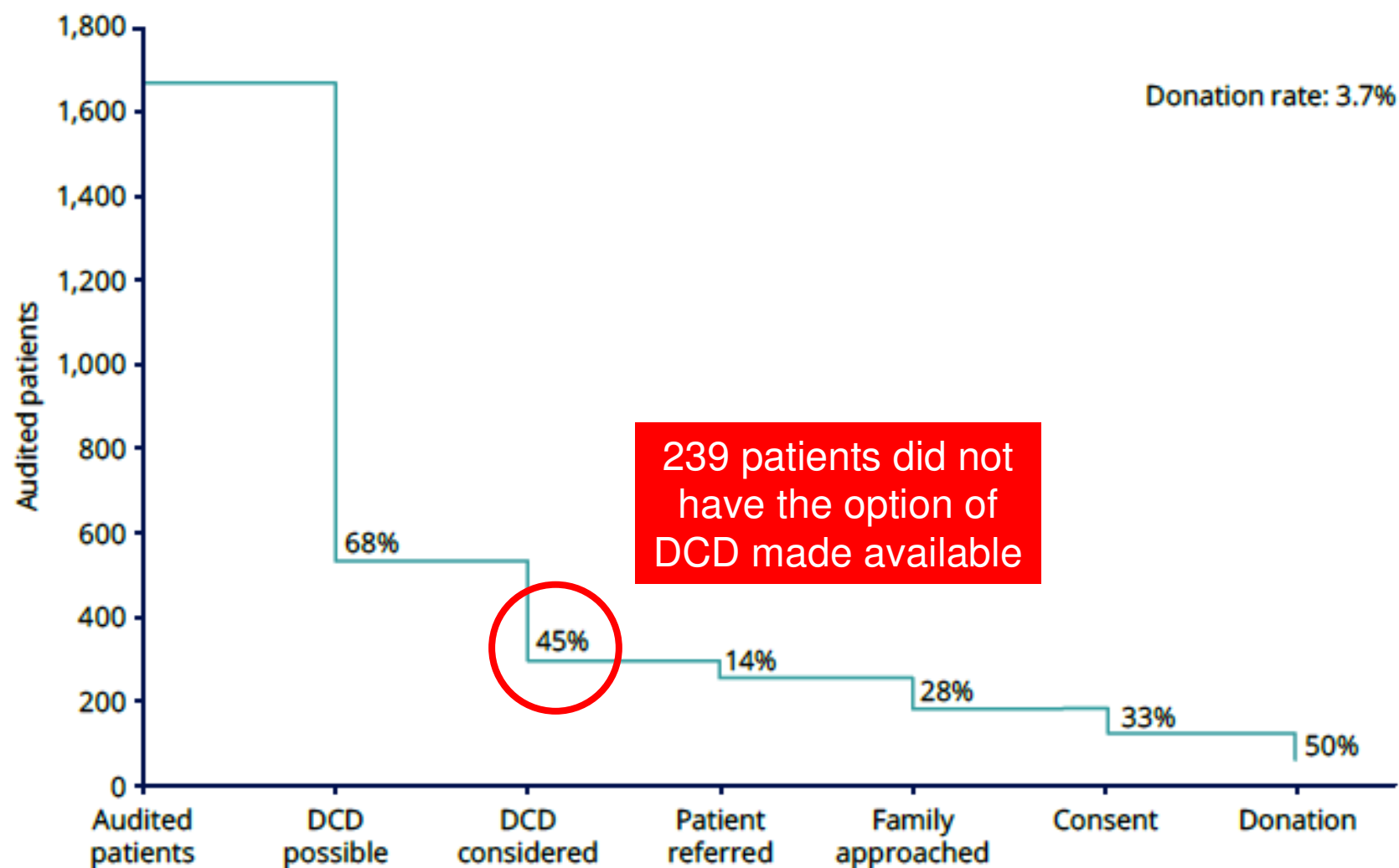
The reasons given for not testing are:

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

DCD pathway

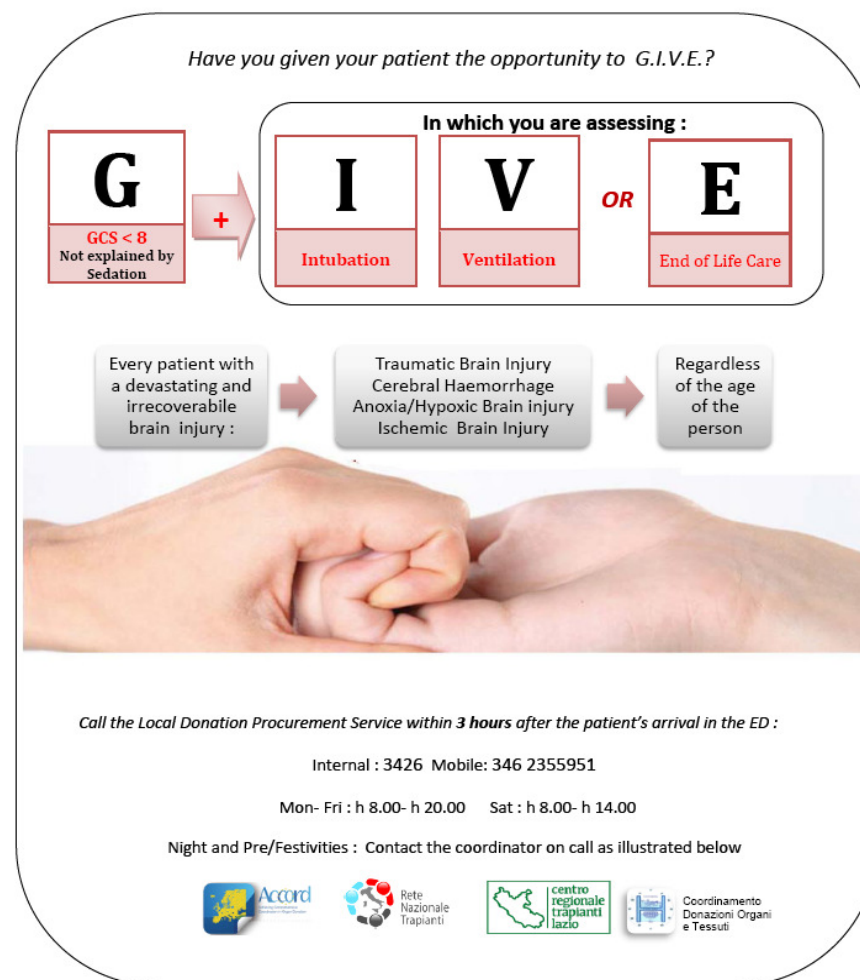


Controlled DCD pathway ? considered



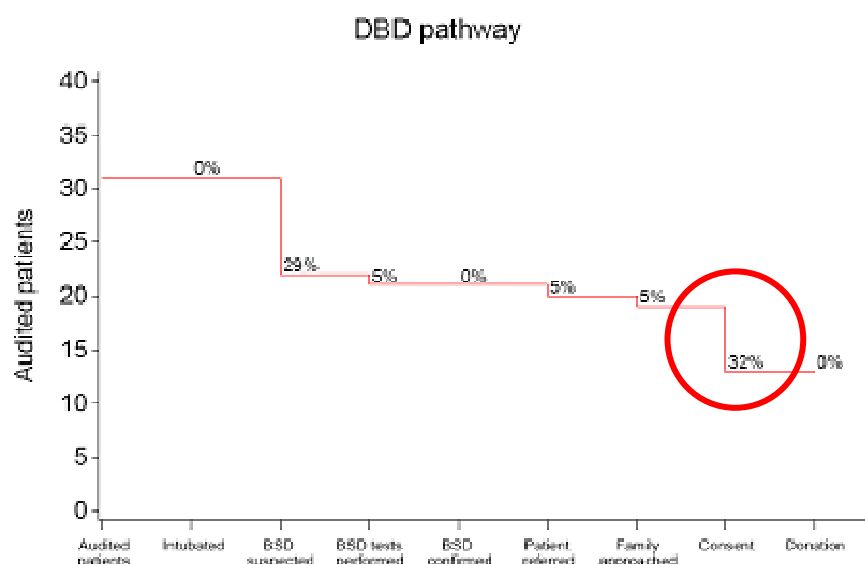
Referral from the Emergency Department

- **Location:** Italian ED
- **Problem:** poor referral rates
- **Interventions:**
 - Staff training
 - Referral poster
- **Measures:**
 - Referral rates
- **Outcomes:**
 - huge improvement in referral
 - Better staff engagement

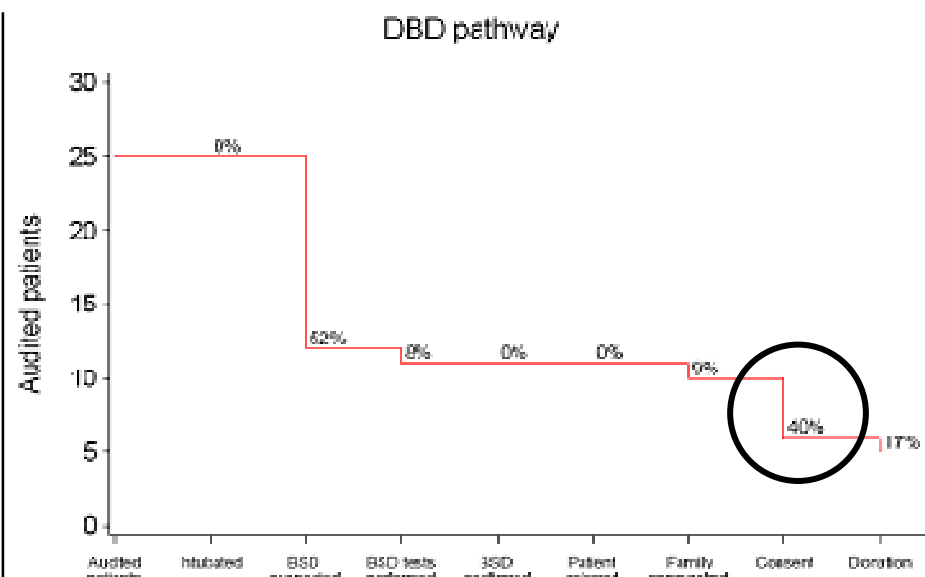


Family refusal

Before



After



Problem: 32% of families refused organ donation.

Intervention: trained clinical psychologist available to support the family.

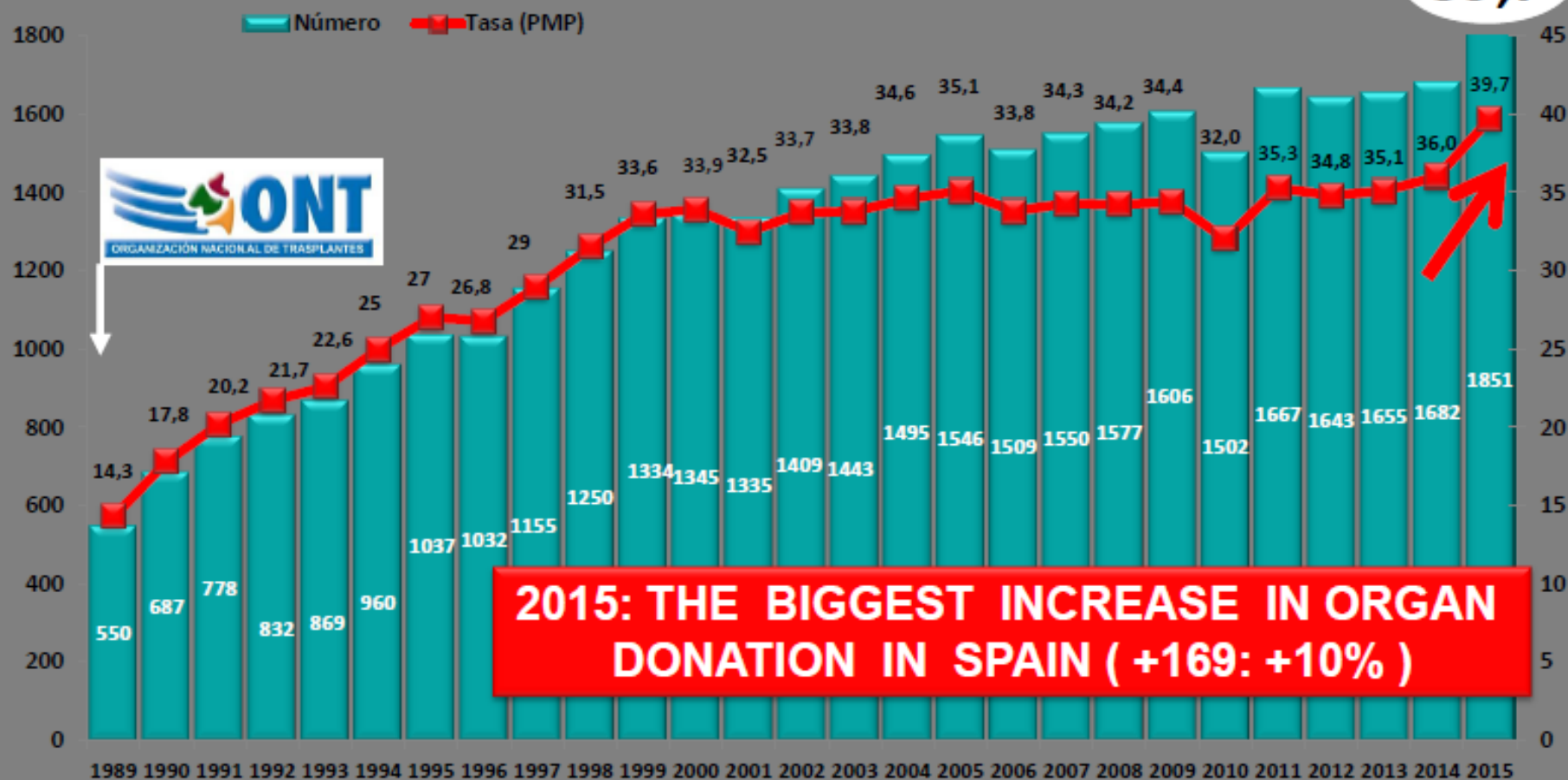
Outcome: Clinical psychologist not well accepted by families who perceived it as an external presence. The family refusal rate increased during the intervention (40%).

550

ORGAN DONORS IN SPAIN SINCE THE START OF O.N.T.

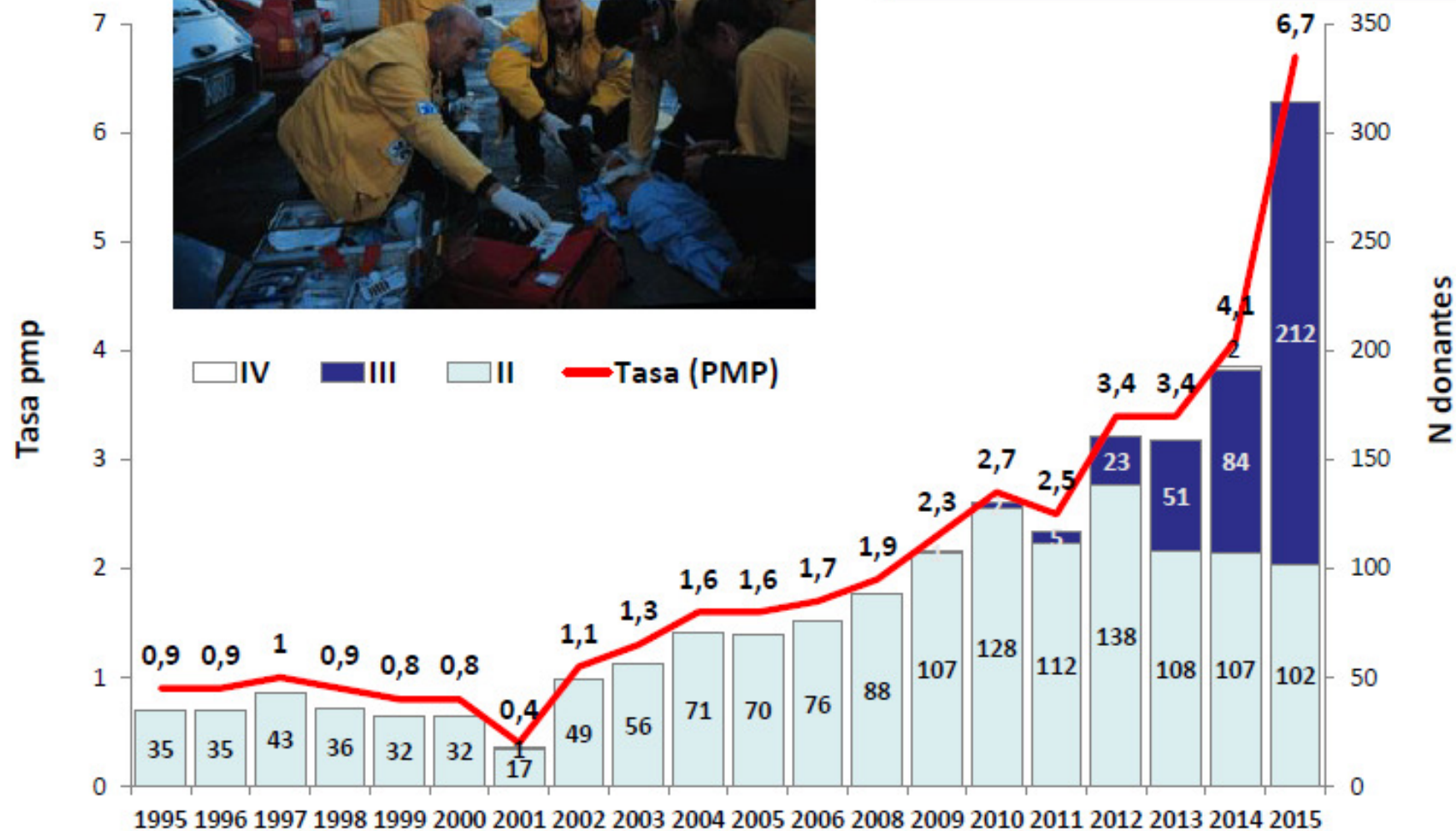
1851

39,7



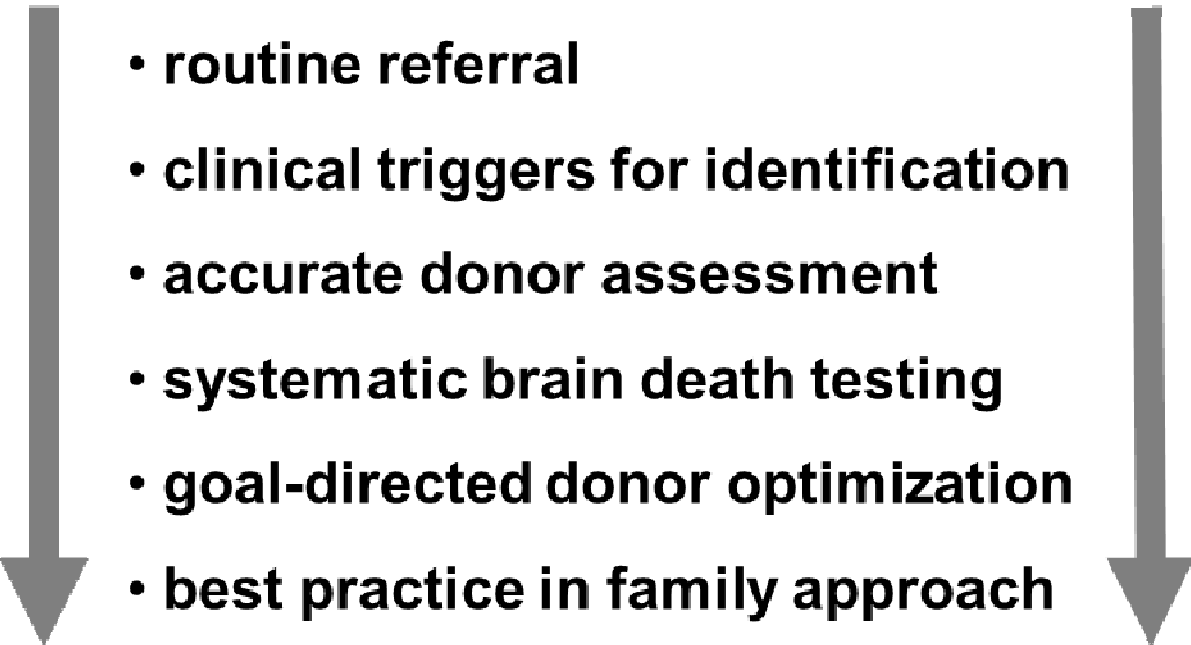
DCD DONORS IN SPAIN -2015

17 % OF TOTAL DONORS



Best practice in organ donation

Possible organ donor

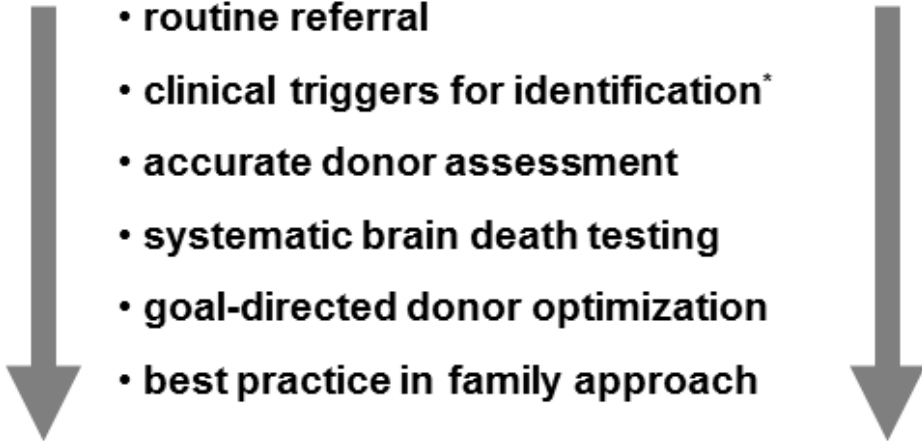
- 
- routine referral
 - clinical triggers for identification
 - accurate donor assessment
 - systematic brain death testing
 - goal-directed donor optimization
 - best practice in family approach

Actual organ donor

Best practice in organ donation

- Education and training
- Audit and performance management

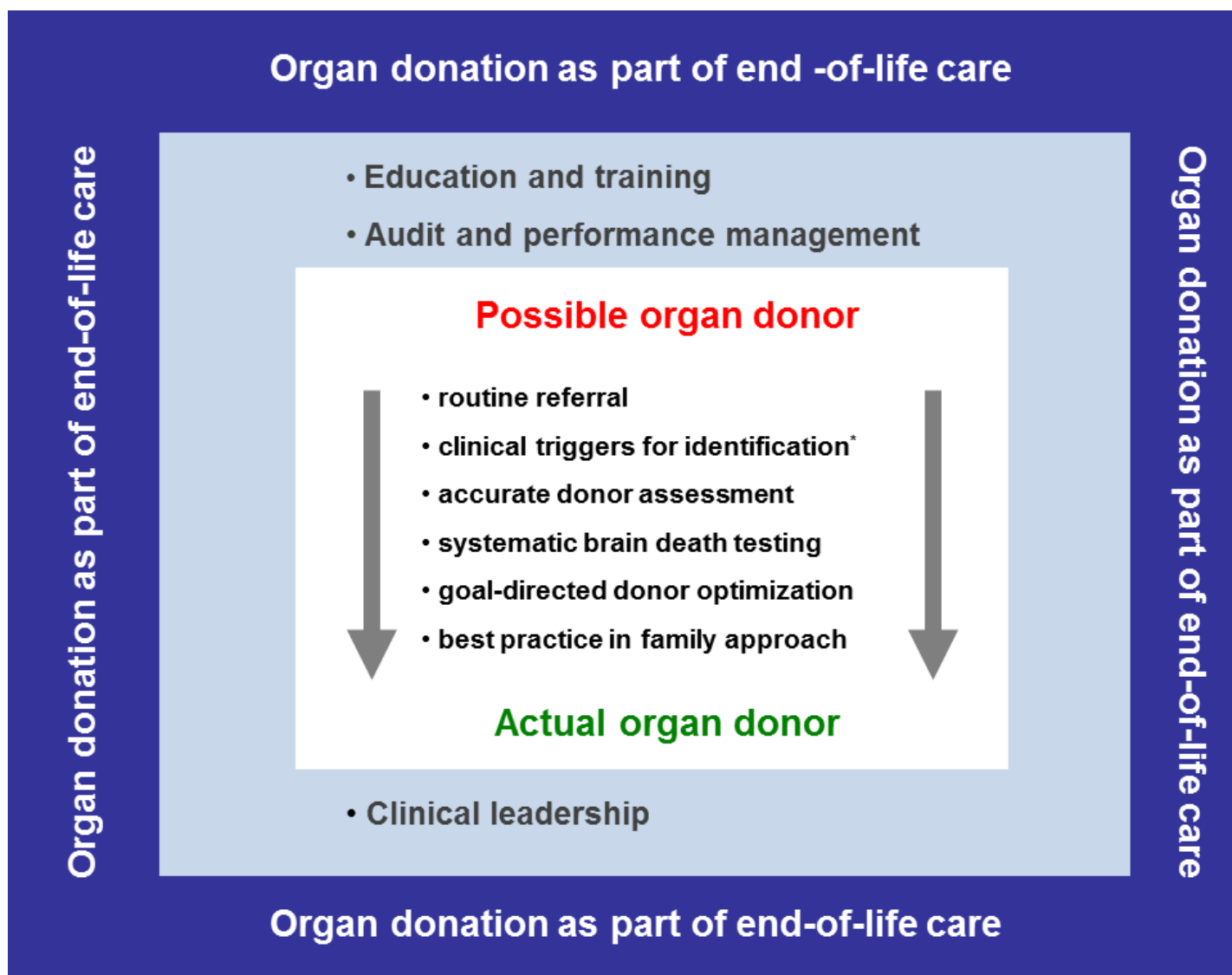
Possible organ donor

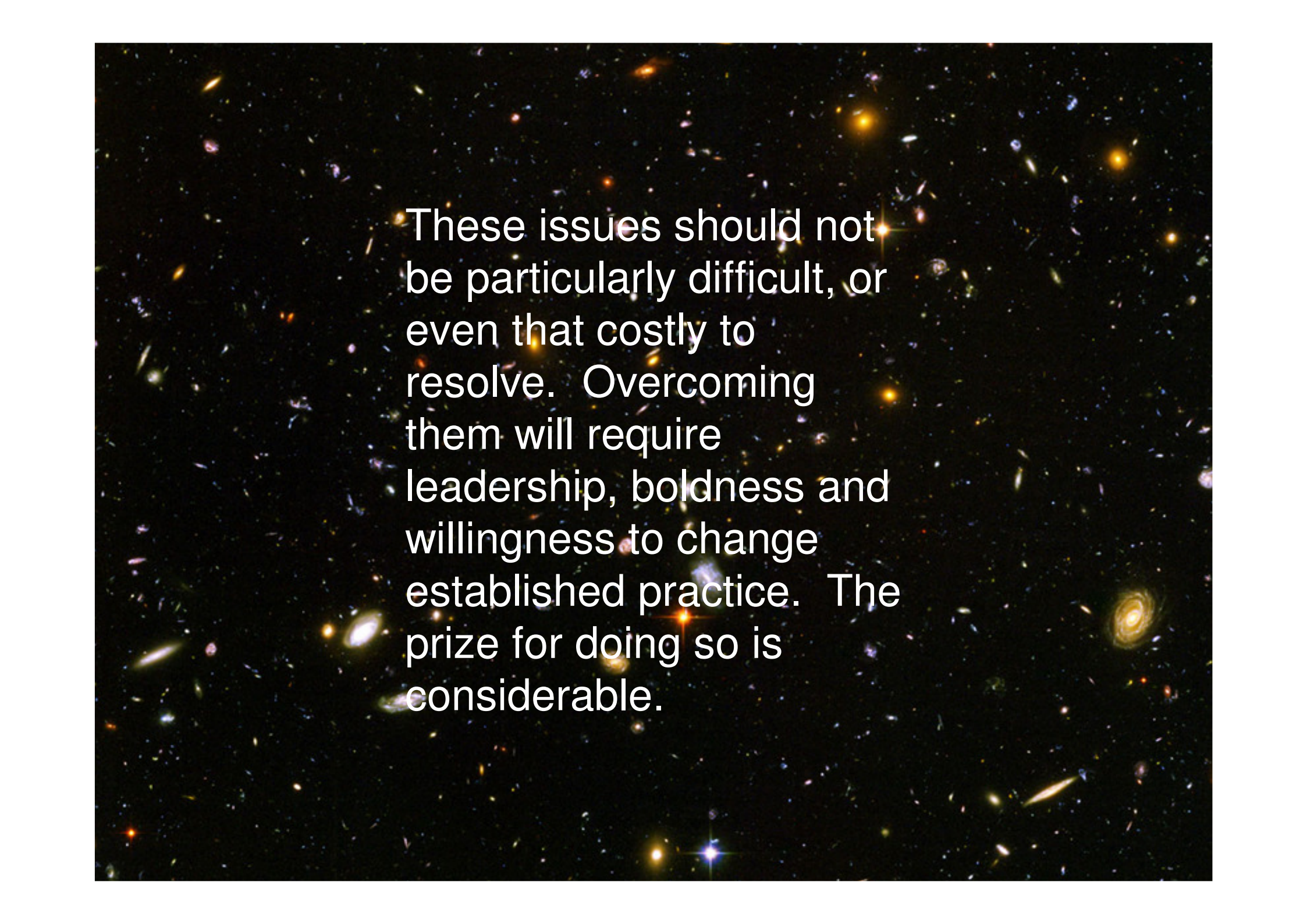
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- routine referral
 - clinical triggers for identification*
 - accurate donor assessment
 - systematic brain death testing
 - goal-directed donor optimization
 - best practice in family approach

Actual organ donor

- Clinical leadership

Best practice in organ donation



The background of the slide is a high-resolution astronomical image, likely from the Hubble Space Telescope, showing a dense field of galaxies. The galaxies are of various shapes and sizes, including spiral, elliptical, and irregular forms. They are scattered across the frame, with some appearing as bright, distinct objects and others as faint, distant points of light. The colors range from deep blues and purples to bright yellows and oranges, representing different wavelengths of light captured in the image. The overall effect is a sense of vastness and the complexity of the universe.

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.



Dad



Who else is brave enough to read me?

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 other 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.