

Towards a framework for organ donation in the UK

P. G. Murphy^{1,2*} and M. Smith³

¹ Directorate of Organ Donation and Transplantation, NHS Blood and Transplant, Bridle Path, Leeds LS15 7TW, UK

² Department of Anaesthesia, The General Infirmary at Leeds, Great George Street, Leeds LS1 3EX, UK

³ Department of Neurocritical Care, The National Hospital for Neurology and Neurosurgery, University College London Hospitals, Queen Square, London WC1N 3BG, UK

* Corresponding author. E-mail: paul.murphy@nhsbt.nhs.uk

Editor's key points

- The gap between numbers of organs needed and those transplanted in the UK is increasing.
- A complete overhaul of organ donation in the UK was required to address this.
- The UK Organ Donation Taskforce was created to tackle the issues and improve transplantation rates.
- This article provides a comprehensive overview of the Taskforce's initiatives to date.

Summary. Implementation of the recommendations from the Organ Donation Taskforce has introduced for the first time into the UK a nationwide framework for deceased donation. This framework is based, in principle, upon a conviction that donation should be viewed as part of end-of-life care and that the actions often necessary to facilitate it become justified when donation is recognized to be consistent with the wishes and interests of a dying patient. The implementation of the Taskforce recommendations across the complex landscape of acute hospital care in the UK represents a challenging programme of change management that has three more or less distinct phases. This programme has involved first creating and communicating the Taskforce's vision for donation in the UK, secondly introducing the structural elements of this new framework into hospital practice, and finally creating the environment in which these new elements can deliver the overall programme goals. Implementation has focused heavily upon areas of practice where significant opportunities to increase donor numbers exist. It is recognized that the greatest challenge is to overcome the societal and clinical behaviours and beliefs that currently create barriers to donation. Although national audit data may point to some of these areas of practice, international comparisons suggest that differences in approach to the care of patients with catastrophic brain injury may have a profound influence on the size of the potential donor pool.

Keywords: attitudes to death; end-of-life care; ethics; National Health Service; organ donation; organ transplantation; tissue and organ procurement

The principal factor restricting access to organ transplantation in the UK is the availability of suitable donor organs. A place on a transplantation waiting list is therefore a reason for hope rather than a guarantee of treatment. While future solutions for end-stage organ failure may reside in stem cell technology, genetic engineering and xenotransplantation, and also in preventive programmes that reduce the incidence of end-stage organ failure, current solutions rely on the use of human allografts donated in life or after death.

The demand for donor organs in the UK has increased inexorably over the last decade. This is a consequence of an increasing incidence of end-stage organ failure (which in turn is related to a more elderly population with a higher incidence of co-morbidities such as diabetes mellitus and hypertension) and also a reflection of advances in retrieval, transplantation, and immunotherapy techniques that deliver improved post-transplantation outcomes. However, as demand has increased, the number of deceased donors in the UK, and the number of transplants that result, has remained more or less static. As a result, the gap between those needing a life-saving or life-transforming transplant and the number of individuals whose desire to donate is recognized and fulfilled is now wider in the UK than ever before (Fig. 1).¹

Rates of deceased organ donation in the UK fall well short of those reported from many parts of mainland Europe and North America (Fig. 2).² Although in the UK, this has in part been compensated for by a substantial increase in living donation,¹ such programmes are inherently limited in their potential. They are also associated with morbidity and mortality for healthy donors that can be considered an indictment of UK deceased donation programmes. Patients in the UK with end-stage organ failure face an unacceptable incidence of mortality while on the transplant waiting list. Furthermore, there are artificial limitations in access to transplantation that are driven by organ availability rather than anticipated benefit of transplantation to the recipient. Such problems are particularly extreme in minority ethnic groups which face the unenviable combination of a higher incidence of end-stage renal and liver failure and lower availability of suitable donor organs. Reduced availability is related to lower donation rates from these groups and a higher incidence of blood group B than that of the general population.

The benefits of transplantation are indisputable, and for kidney transplantation include longer life expectancy, improved quality of life, and very significant cost savings compared with long-term dialysis. Few individuals would decline

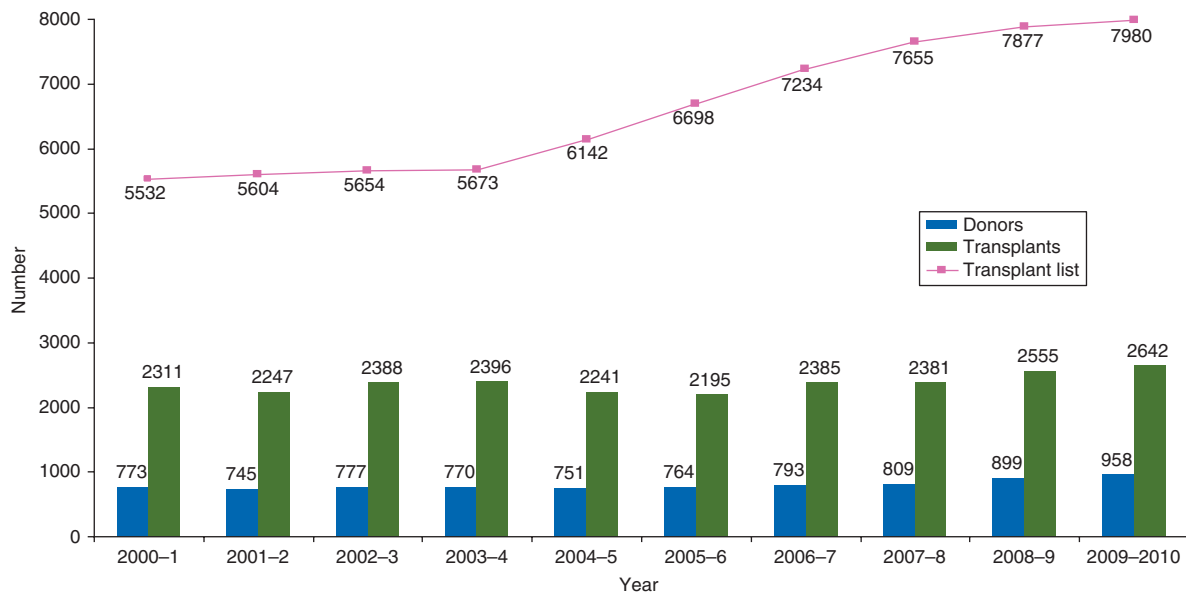


Fig 1 The number of deceased organ donors in the UK from 2000 to 2010, together with the number of subsequent organ transplants that result and the number of patients on the active transplant waiting list on March 31, each year. Data courtesy of NHS Blood and Transplant.¹

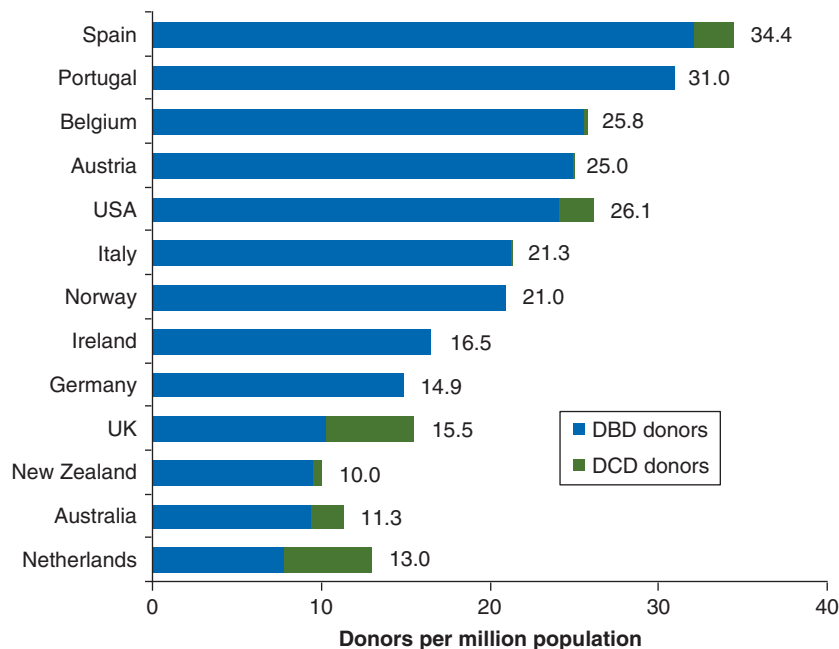
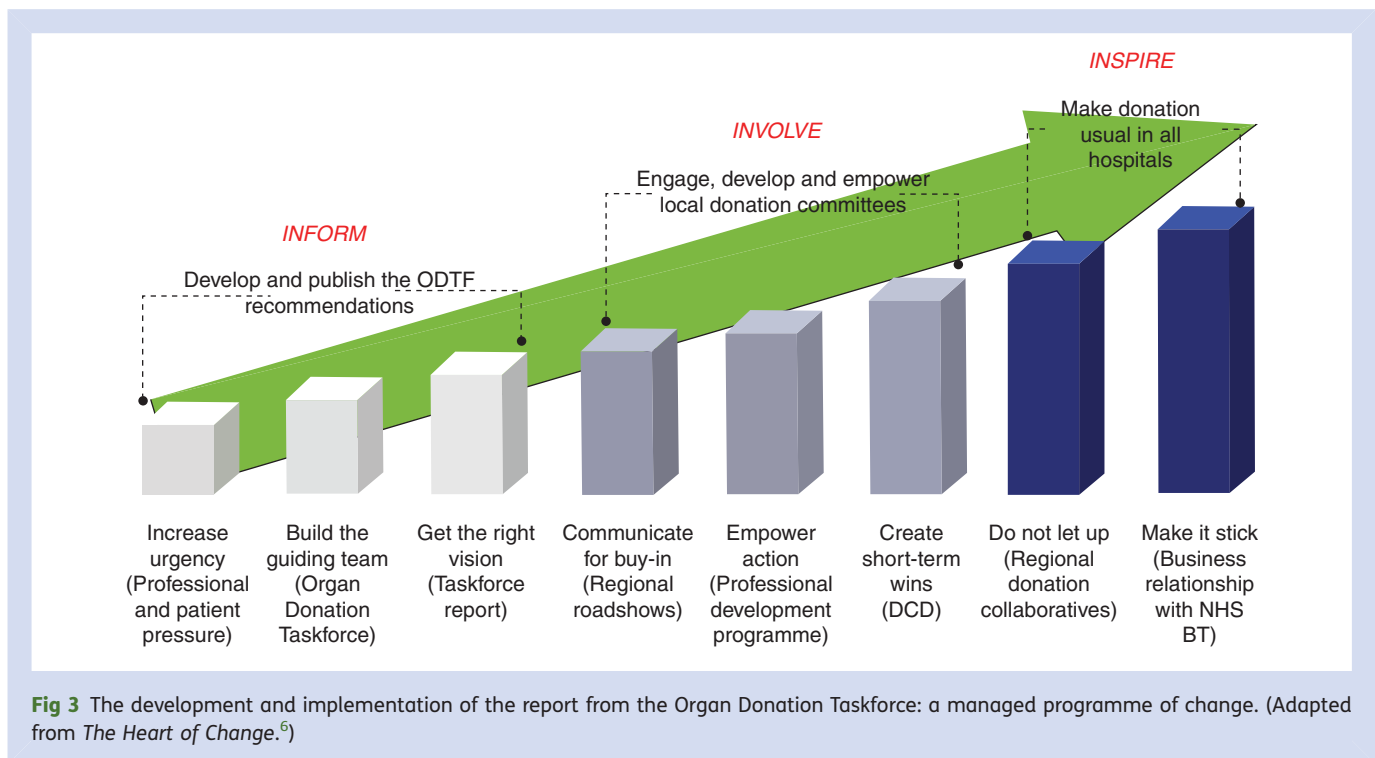


Fig 2 International rates of DBD and DCD, 2009, ranked by DBD and expressed as donors per million of population. Numeric indicates total number of deceased donors. DBD: donation after brain-stem death; DCD: donation after circulatory death. Data courtesy of Transplant Procurement Management.²

the opportunity of a life-saving transplant and opinion polls suggest that few would also decline the opportunity to donate their own organs at the time of their death.^{3 4} However, this expressed willingness to donate contrasts with the relatively low rates of deceased organ donation in

the UK, and it is not immediately obvious how this dichotomy can be overcome. In 2006, the four Health Departments of the UK established a governmental taskforce to examine this issue and recommend solutions to the barriers to donation that were identified. The recommendations of the Organ



Donation Taskforce require a complete overhaul of organ donation in the UK,⁵ and their implementation has necessitated a comprehensive and lengthy programme of managed change. This can be divided into three distinct phases based upon a well-known and well-validated model of change management (Fig. 3):⁶

- Phase I: Inform: create a vision for organ donation in the UK through the publication and development of the report and recommendations of the Organ Donation Taskforce.
- Phase II: Involve: establish and empower local clinicians and donation committees, through implementation of the 14 recommendations of the Taskforce, to create a new structural framework for organ donation in the UK.
- Phase III: Inspire: make donation usual by incorporating it into the core business of NHS organizations, using the new framework to deliver the overarching objectives of the Organ Donation Taskforce.

Phase I: Inform: developing and promoting the Organ Donation Taskforce recommendations

The Organ Donation Taskforce began its work in December 2006. Its terms of reference were:

- (i) to identify barriers to donation and transplantation and recommend solutions within existing operational and legal frameworks in England;

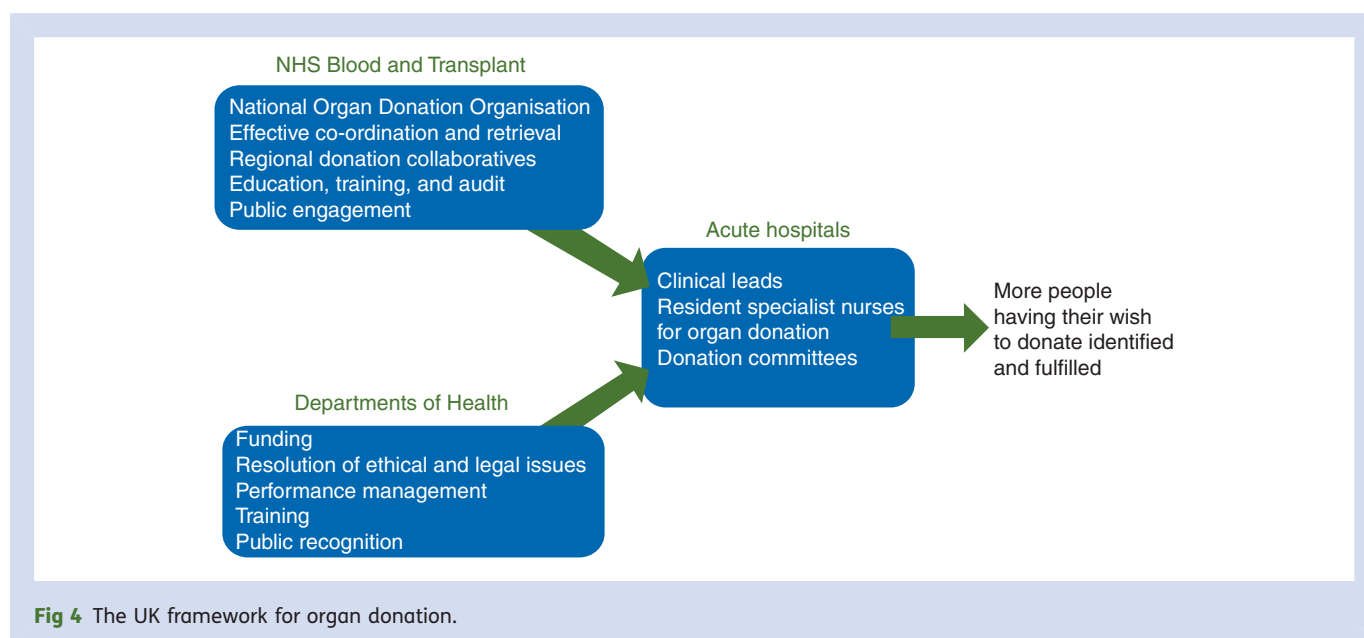
- (ii) to identify barriers to any part of the transplant process and recommend ways to overcome them to support and improve transplant rates.

Members of the Taskforce included clinicians working in critical care, donor transplant coordination and transplantation, experts in medical ethics and social engagement, and representatives from various government and health agencies in the UK. The Taskforce report, *Organs for Transplants*, was published in January 2008^{7 8} and accepted in full by all four UK Health Departments.

The Taskforce report highlighted three key elements of the donation pathway where improvements needed to be made: donor identification and referral, donor transplant coordination, and organ retrieval. In particular, the Taskforce recommended:

- more effective organizational support for donation from the wider NHS;
- unification of the hitherto disparate elements of donor transplant coordination and organ retrieval;
- provision of comprehensive and workable professional, ethical and legal frameworks for deceased donation;
- resolution of the discrepancy between the expressed level of public support for organ donation and the actual proportion of families who give permission for donation after the death of a relative.

The Taskforce also recognized that while the majority of critical care staff support donation *in principle*, such support might be conditional in circumstances that are less than ideal and where active steps are needed to facilitate donation. This is at least partly because certain aspects of



donation can be challenging from a professional, ethical, and even legal perspective. Donation is also uncommon for many donor hospitals. Thus it might not occur at all, and when it does, might disrupt other emergency services, particularly out of hours. In many respects, the philosophy of the Taskforce report was to support the more consistent application of existing examples of best practice, particularly in the smaller hospitals with a lower donation potential. Fundamentally, the Taskforce perceived the need to establish donation as a ‘usual not unusual’ component of end-of-life care in appropriate patients and recognized that, for every hospital to make donation ‘core business’, additional clinical and operational support would be required locally and nationally. The Taskforce recommendations are directed towards achieving the goal of establishing donation as ‘core business’. When viewed as a whole, these represent a coherent and comprehensive framework for deceased donation in the UK.⁹ Rather than being aligned against specific elements of the donation pathway, the recommendations create a framework in which the specific obstacles to donation can be systematically identified and overcome (Fig. 4). The Taskforce recognized that while some financial investment might be required to implement its recommendations, the delivery of its objectives would be more dependent on people, and noted that overcoming the obstacles to donation would require ‘leadership, boldness and willingness to change established practice’.⁷

Phase II: Involve: engaging, developing and empowering local donation committees and clinicians

The work of implementation of the 14 Taskforce recommendations began in the autumn of 2008, becoming the joint responsibility of the four UK Health Departments and NHS Blood and Transplant (NHS BT), which was designated as

the UK Organ Donation Organisation. The operational framework and specific responsibilities of the new arrangements are shown in Figure 4.

The UK Organ Donation Organisation—NHS Blood and Transplant

NHS BT incorporated the new Directorate for Organ Donation and Transplantation (ODT) into its existing organization in September 2008. In doing so, it not only assumed the existing responsibilities of NHS BT relating to organ allocation, audit, and maintenance of the UK Organ Donation Register (ODR), but also managed the transition to central employment of all the donor transplant coordinators in the UK who were, until this point, employed by individual transplant centres or NHS Trusts. In April 2010, ODT commissioned a new national organ retrieval service to work to common standards of quality and efficiency, thereby addressing previous concerns about variable, and sometimes unreliable, organ retrieval support. Finally, and perhaps most importantly, NHS BT was charged with supporting every acute hospital and Health Board in the UK to:

- (i) appoint a clinician to ‘champion’ the cause of organ donation within their organization,
- (ii) allocate a specific donor transplant coordinator (now known as specialist nurses for organ donation) to work with clinicians locally,
- (iii) establish a local donation committee to oversee and support organ donation in the organization.

This work began in September 2008 and was essentially completed by February 2010 in preparation for the delivery of a year-long programme of professional development for UK donation leads (see below).

Enabling work from the health departments

Although the funding to establish the new arrangements was identified early by the four health departments, a more important role for them was to provide resolution to the outstanding professional, legal, and ethical obstacles to donation. As a result, legal guidance concerning the vexed issue of non-heartbeating organ donation [now referred to as donation after circulatory death (DCD)] was provided, with jurisdiction-specific guidance for clinicians working in England and Wales published in 2009,¹⁰ for Scotland in 2010,¹¹ and for Northern Ireland in 2011.¹² After this, an independent UK-wide Donation Ethics Committee, hosted by the Academy of the Medical Royal Colleges and chaired by Sir Peter Simpson, was established in 2010 and has recently invited consultation on draft guidance on DCD. Finally, suitable key performance metrics to assist hospitals to track their own progress against the overall objectives of the programme, and benchmark their practice against similar organizations, were produced.

Communicating the vision and engaging the NHS

The Taskforce report created an undeniable case for change and presented a clear vision for how this might be achieved. An early imperative for implementation was to share this vision with the wider NHS and thereby attract commitment from those able to influence practice and behaviour in acute hospitals. While preliminary publications in professional journals set the scene,^{5 8 9} an early objective was to share the vision of the Taskforce with all stakeholders. A series of road shows was used to portray (sometimes in emotional terms) the truth about donation and transplantation in the UK. This proved a powerful means of attracting 'buy-in' and visible public commitment from clinicians and hospital executives for the initiatives that were to follow.

Donation as part of end-of-life care

The most important theme of the road shows was that donation should be viewed as a usual, not unusual component of end-of-life care when appropriate. Indeed, it can be argued that all of the Taskforce recommendations are, directly or indirectly, designed to facilitate this important change of emphasis. The Taskforce believed that this change would only occur through changes in practice to ensure that

- all possible donors are identified and referred in a timely fashion,
- hospital executives provide the necessary operational and strategic support for donation,
- families of potential donors receive the best possible support, particularly with regard to the consent process,
- coordination and retrieval services are available in a more timely and effective fashion, and
- societal attitudes to donation are more accurately reflected in the outcome of a family approach.

A vital and continuous theme of the Taskforce report is that donation should be viewed as something that should be

expected by patients and families rather than something that is 'inflicted' upon them. Recent guidance on end-of-life care from the General Medical Council endorses this view.¹³

Elaborating the vision

The Taskforce was driven by the observation that deceased donor rates are so much higher elsewhere in the world. While this might justify an expectation for change and help quantify the overall objective, that is, an increase in donation rates, it does not describe how such increases might be achieved. It was therefore imperative to define clearly where specific opportunities to increase deceased donation occur and how they might be realized.

The Potential Donor Audit and the six big wins

Since April 2003, NHS BT has conducted an on-going audit of the potential for deceased organ donation in the UK.¹⁴ The audit assesses the potential for donation after brain-stem death (DBD) and controlled DCD in intensive care units (ICUs) and Departments of Emergency Medicine across the UK. Summary Potential Donor Audit (PDA) data are published annually¹ and consistently demonstrate specific elements of the donation pathway where significant opportunity to increase donor numbers exist (Table 1).¹⁵ Collectively, these opportunities have become referred to as 'the six big wins'.

Family consent/authorization

While around 90% of the UK population declare support for both donation and transplantation, only 30% have confirmed this support by registering with the UK ODR, and actual family consent/authorization rates hover around 60%. An increase in consent/authorization rates to 85% would all but deliver the overall Taskforce objective by increasing the annual number of deceased donors by a total of 6 per million population (pmp) per year. Improvement of the consent rate is rightly seen as a key priority in efforts to increase donor numbers, with possible interventions being broadly directed towards promoting greater engagement with the general public,¹⁶ consideration of changing the legislative framework for donation,^{17 18} or through modification of the outcome of the family approach.^{19–21}

The initial terms of reference for the Taskforce precluded changing the existing legislative framework for deceased donation, although it was subsequently asked to consider the potential impact of introducing an opt-out system for organ donation into the UK. Although aware that such systems were in operation in a number of European countries, including Belgium, Norway, Portugal, and Spain, it concluded that there was 'no convincing evidence that [an opt-out system] would deliver significant increases in the number of donated organs', and that it would 'distract attention away from essential improvements to systems and infrastructure and from the urgent need to improve public awareness and understanding of organ donation'.²² However, the Taskforce did not rule out a review of this decision were donation rates resistant to the interventions

Table 1 The potential opportunities to increase deceased organ donation in the UK as indicated by the national PDA (expressed as additional annual donors pmp), together with some of the specific interventions that may help deliver such improvements. DBD, donation after brain-stem death; DCD, donation after circulatory death; ED, Emergency Department

Element of donation pathway	Possible interventions	Potential benefit (donors pmp)
Increasing family consent/ authorization ratios to 85%	<ul style="list-style-type: none"> Improving outcome of family approach <ul style="list-style-type: none"> Training for the family approach Planning for the approach Increased involvement of specialist nurses for organ donation Increasing public engagement <ul style="list-style-type: none"> Media campaigns, including use of social networking Prompted choice Honouring the gift of donation Altered legislative framework <ul style="list-style-type: none"> Opt-out Mandated choice Ethical, professional, and societal debate regarding incentives for donation 	3.6 DBD donors; 2.5 DCD donors
Confirmation of brain-stem death in all possible cases	<ul style="list-style-type: none"> Enhanced training programmes for clinicians involved in care of patients who meet the preconditions for confirmation of death by neurological criteria, particularly advanced trainees in intensive care medicine Additional analysis and audit of the group of patients who are not tested despite meeting the preconditions for the diagnosis of death by neurological criteria Additional guidance for testing in difficult cases, including the use of confirmatory tests such as computerized tomography (CT) angiography Provision of expert guidance from, e.g. regional neurosurgical centres Clarification on professional, ethical, and legal aspects of interventions and treatments that might be necessary to allow confirmation of death by neurological criteria 	Up to 2.7 DBD donors pmp
Support DCD in all possible circumstances	<ul style="list-style-type: none"> Operational implementation of key recommendations contained in the recent Consensus Statement from Intensive Care Society and British Transplantation Society²⁷ <ul style="list-style-type: none"> Diagnosis of death Simultaneous offering of potential DCD donors to all recipient centres Consistent application of minimum acceptance and retrieval criteria Continued development of post-mortem organ reperfusion technologies Dissemination and implementation of guidance from UK Donation Ethics Committee 	3.5 donors pmp
Donation from Emergency Departments	<ul style="list-style-type: none"> Disseminate PDA data regarding potential for organ donation from Emergency Departments (EDs) Establish organ donation into end-of-life care policies in all EDs Develop collaborative links between EDs and critical care teams to provide support for potential donors identified in the ED Describe an acceptable professional, ethical, and legal framework for identification of donors from ED 	As yet poorly quantified, although there were 73 deceased donors identified and referred from EDs in 2010–11
Increased and more timely referral	<ul style="list-style-type: none"> Define and promote the benefits of early referral Incorporate donor identification and referral into hospital performance improvement framework Establish professional framework to support timely referral Describe the donation potential of general ICU patients dying after withdrawal of life-sustaining treatments Support and evaluate pilots of clinical triggers for referral 	Largely indirect; early and therefore extended involvement with Specialist Nurses should promote other elements of the donation pathway, particularly consent/authorization ratios
Improved donor management	<ul style="list-style-type: none"> Consensus agreement on donor management protocols and minimum acceptance criteria Organ-specific strategies for heart and lung grafts, including review of acceptance criteria Donor management and organ utilization metrics to be incorporated into annual summary statistics Donor management training for intensive care medicine trainees 	Increased number of transplants per donor; increased number of heart and lung transplants

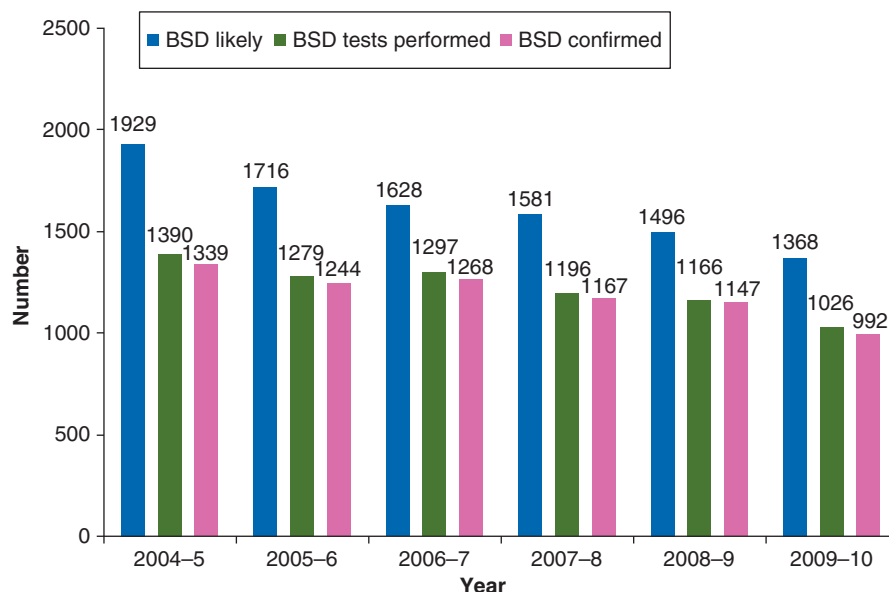


Fig 5 Incidence of brain-stem death (BSD) as demonstrated by the UK PDA, 2004–2010. Data courtesy of NHS Blood and Transplant.

laid out in its original report, and indeed the Welsh Assembly is currently seeking to introduce an Organ Donation Bill to create an opt-out system for organ donation in Wales.²³ Whether such legislative change alone will result in any increase in donor numbers will be monitored with intense interest by the rest of the UK.

Regardless of the direct impact of an opt-out system on donor numbers, it serves to embed donation into the culture of society as being something that individuals can be assumed to support. Other recent interventions in the UK, while less drastic, similarly seek to establish donation as the normal (if still special) thing for society (and therefore its members) to do. For instance, the online application process for a driving licence in the UK now requires individuals to answer questions about organ donation before their application can be completed.²⁴ Recently, an independent UK bioethics group has suggested that the UK Health Service should test the idea of paying for the funerals of organ donors to help tackle the current shortage of organs.²⁵

Failure to confirm death by neurological criteria

The PDA demonstrates that the incidence of brain-stem death has decreased steadily over the last 6 yr and that there is a consistent and significant gap between the number of patients who appear to fulfil the preconditions for neurological determination of death and those who are subsequently tested—currently around 350 patients annually (Fig. 5). The PDA reveals a variety of possible explanations for not testing, not all of which represent accepted contraindications to either testing or donation. While this is a heterogeneous group with an uncertain donation potential, it

nevertheless demands further detailed analysis. Since the PDA is completed in retrospect and not necessarily by those involved in the care of the patient, the accuracy of the data must also be confirmed by prospective audit.

Donation after circulatory death

Although the number of controlled DCD donors in the UK has increased almost 10-fold over the last decade,²⁶ there is the potential for an additional 200 DCD donors per annum if every patient were given the option of donation as a component of their end-of-life care after withdrawal of life-sustaining treatment. While publication of national professional and legal guidance has served to establish DCD in many hospitals, there remains considerable uncertainty over the donation potential of patients in general ICUs whose death follows systemic organ failure rather than an isolated intracranial catastrophe. In such circumstances, doubts over graft viability lead to intolerable delays in decision-making by recipient centres. These are compounded (for referring hospitals and families at the bedside) by the current adherence to sequential offering protocols that refer potential donors to transplantation centres in turn rather than simultaneously. Somewhat paradoxically, closer adherence to recent recommendations concerning the confirmation of death using cardiorespiratory criteria would be likely to increase the willingness of centres to accept organs in such circumstances. Bringing donation and retrieval services into greater synchrony is one of the major future imperatives for DCD in the UK.²⁷ This will partly depend on greater clarity and acceptability of the criteria for the confirmation of death and subsequent organ retrieval interventions after withdrawal of life support.

Donation from emergency medicine departments

As previously discussed, the UK has a relatively low incidence of diagnosed brain-stem death and it is likely that this is, at least in part, a result of decisions to withdraw or limit the treatment of patients with catastrophic brain injury before the condition has evolved to its inevitable conclusion, or before the diagnosis of brain-stem death can be made. On many occasions, the futility of continued treatment precludes admission to an ICU and, in such circumstances, death occurs within the Emergency Department (ED), or elsewhere in a hospital.

The PDA reveals an important and largely unrealized potential for both DBD and DCD in EDs. Obstacles to conversion of these potential donors to actual donors include the unfamiliarity of ED staff with donor identification, referral, and management. There is also a lack of appropriate facilities for caring for the potential donor and their family in the ED. Although it may be possible to manage a donation to completion in the ED, such a process most commonly requires involvement and support from intensive care. Consequently, all acute hospitals should develop multi-disciplinary protocols that describe how emergency medicine, intensive care, and operating theatre services will collaborate to support donation. Importantly, these should detail where the key elements of care will be delivered, and by whom. Although some clinicians may be uneasy about the overt use of intensive care facilities to allow donation to proceed, and capacity issues often preclude it, the recent statement from the Intensive Care Society supporting such practice is of considerable importance in this regard.²⁷

Timely referral of all potential donors

The Taskforce defined clear minimum criteria for the referral of potential DBD and DCD donors (Table 2),⁷ based upon the following principles:

- Everyone should be given the option of donation as part of end-of-life care where appropriate, regardless of the criteria used to diagnose death.
- The assessment of an individual's potential for donation is best made in consultation with donor coordination and retrieval services rather than by unit clinicians (in isolation) who might be unfamiliar with modern aspects of retrieval and transplantation, and the needs of specific recipients. This is particularly the case for patients on the national super-urgent waiting list, for example, those with fulminant hepatic failure, whose imminent death may override a relative contra-indication to donation.
- Timely referral streamlines subsequent care because it allows earlier involvement of specialist nurses with expertise in donor assessment and optimization, the family approach, liaison with third parties (e.g. the Coroner), and co-ordination of the retrieval itself.

The Taskforce therefore recommended that as a minimum, referral should occur as soon as a clinical decision

Table 2 Minimum notification criteria for potential deceased donors as published by the Organ Donation Taskforce.⁷ DTC, donor transplant coordinator

Potential DBD donors	When no further treatment options are available or appropriate, and there is a plan to confirm death by neurological criteria, the DTC should be notified as soon as sedation/analgesia is discontinued, or immediately if the patient has never received sedation/analgesia. This notification should take place even if the attending clinical staff believe that donation (after death has been confirmed by neurological criteria) might be contra-indicated or inappropriate
Potential DCD donors	In the context of a catastrophic neurological injury, when no further treatment options are available or appropriate and there is no intention to confirm death by neurological criteria, the DTC should be notified when a decision has been made by a consultant to withdraw active treatment and this has been recorded in a dated, timed, and signed entry in the case notes. This notification should take place even if the attending clinical staff believe that death cannot be diagnosed by neurological criteria, or that donation after [circulatory] death might be contra-indicated or inappropriate

has been made to confirm death using neurological criteria, or to withdraw treatment (in patients with catastrophic brain injury) on the grounds of futility. However, the Taskforce was also aware of the use in the USA of clinical criteria for referral based on the severity of neurological injury rather than an expectation of imminent death.²⁸ Potential benefits of such systems, which require the notification to an organ procurement agency of patients who might still be receiving active treatment, include some assurance that all potential donors will be referred and that advice and support for clinicians less familiar with the neurological determination of death will be more readily available. They also allow donor coordinator and retrieval teams to plan their workload more efficiently and reduce delays in arrival on a unit should donation proceed. While the Taskforce judged in 2008 that it would be counter-productive to introduce such a system in the UK, it did encourage individual centres to pilot the use of clinical triggered referral in order to assess its acceptability and effectiveness (if any) in improving donor numbers. The protocol for clinically triggered referral currently used in Birmingham, UK, is shown in Figure 6.

Donor optimization

Although the primary objective of the Taskforce refers to donation rates, the true objective is of course to increase transplantation rates. It follows that strategic efforts to increase organ transplants should not only include efforts to increase the number of organ donors, but also corresponding initiatives to increase both the number and physiological

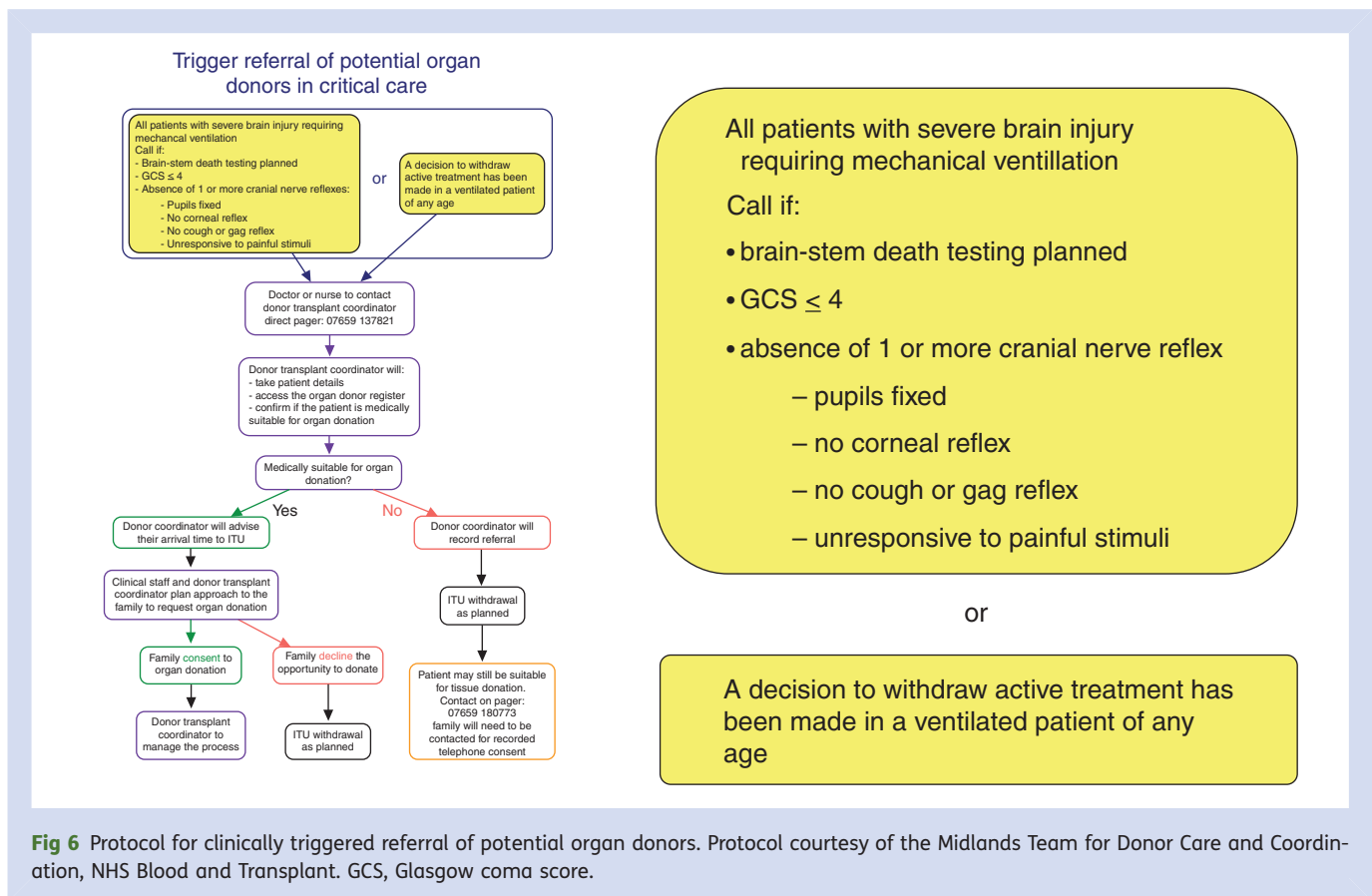


Fig 6 Protocol for clinically triggered referral of potential organ donors. Protocol courtesy of the Midlands Team for Donor Care and Coordination, NHS Blood and Transplant. GCS, Glasgow coma score.

quality of organs retrieved from each donor. This is particularly relevant to thoracic organs.²⁹ While several excellent protocols for donor management and optimization have been developed,^{30–31} their consistent and timely application remains problematic, and represents a specific strategic objective for future work.

Empowerment of clinicians and donation committees

The overall objective of the Taskforce, to increase donor numbers by 50%, would be delivered with just two additional donors per year per acute hospital Trust or Health Board in the UK. The Taskforce was mindful, however, that donation is, and will always be, a relatively infrequent event for some hospitals and that infrequent and challenging occurrences are easily overlooked. The end-of-life care of potential donors is largely the responsibility of staff working in critical care areas and, to a lesser extent, in emergency medicine. During its work, the Taskforce received evidence from international donation leaders, notably Rafael Matesanz (Director of the National Transplant Organization in Spain), Frank Delmonico (Professor of Surgery at the Harvard Medical School and Medical Director of the New England Organ Bank), and Jeremy Chapman (Past President of the Transplantation Society of Australia and New Zealand). In different ways, all three experts highlighted the need to support and develop staff working in areas where donation occurs.^{32–34} Rafael Matesanz (widely recognized as the architect of the hugely

successful ‘Spanish model’ of organ donation) perhaps made the point most succinctly when he noted that ‘The burden of responsibility falls on medical professionals, few of whom receive training for this difficult and delicate task. This is, by far, the target group on which the efforts must be concentrated’.

The Taskforce grasped this advice and recommended that ‘all clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation’.⁷ To meet the needs of those most closely involved in donation, and take the recommendation a little further than initially envisaged, the National Clinical Lead for Organ Donation in association with the Directorate of Organ Donation and Transplantation at NHS BT has recently completed the design and delivery of a 1 yr programme of training and development for clinical leads for donation and donation committee chairs.³⁵ A number of principles underpin this Professional Development Programme (PDP):

- the individual components of the programme should together assist in realizing the overall objectives of the Taskforce report,
- the clinical content should focus on the six big wins and be designed by acknowledged experts in the field (in collaboration with ODT) and overseen by relevant professional bodies and societies,
- the clinical content of the programme should be complemented by modules that develop and enhance

Table 3 Roles and responsibilities of the key elements on the UK organ donation framework

	Strategy development
National organ donation organization	<p>Liaison with national/international agencies and professional bodies</p> <p>Sponsorship of national enquiries and initiatives</p> <p>Governance and audit</p> <p>Commissioning of a national organ retrieval service</p> <p>Organ allocation</p> <p>Donor care and coordination</p> <p>National training programmes for donation leads</p> <p>Maintenance of UK organ donor register</p> <p>Public promotion</p>
Regional donation collaboratives	<p>Focus for future training and development programmes</p> <p>Regional data analysis and objective setting</p> <p>Development of regional strategies</p> <p>Liaison with regional donor coordination, retrieval, and transplantation services</p> <p>Public promotion</p>
Local donation committees	<p>Implementation of national/regional strategies through development and implementation of appropriate policies and guidelines</p> <p>Education and training programmes</p> <p>Data collection and analysis</p> <p>Public promotion</p>

the leadership and communication skills of donation leads, giving them the skills necessary to lead changes in practice locally,

- the consistent application of high-quality donor care is best enabled by formulating donation as a routine component of end-of-life care, and that this approach overcomes many of the apparent obstacles to donation that were identified by the Taskforce.

The final objective of the programme was perhaps the most challenging and far reaching. While there was a pressing need to design and deliver a training programme for the newly appointed donation leads, the potential impact of this remains partially unrealized if it fails to also influence the education and training of future generations of clinicians, particularly those working in critical care and emergency medicine. Current and future initiatives seek to fulfil this educational legacy by incorporating the material developed as part of both the Donation road shows and PDP for organ donation into local, regional, and national educational and training programmes for both undergraduate and postgraduate doctors and nurses.

Phase III: Inspire: making donation usual in all hospitals

Organ donation is a national service that is critically dependent on 200 acute hospital Trusts and Health Boards, countless thousands of healthcare professionals (few of whom are employed by, or accountable to, the national organ donation organization) and, at one crucial pinch point, societal engagement. There is therefore no single solution to donation in the UK; rather, there are a series of barriers and obstacles, each of which requires its own solution. Some of these may appear to challenge existing professional, ethical, and legal boundaries of practice, and therefore significantly complicate the process of change. Furthermore, while some of the barriers to change may require national attention, such initiatives (e.g. legal and professional guidance on DCD) count for little if they do not change the practice that is the focus of their attention.

International experience suggests that significant improvements in donation are delivered in modest increments over the course of a programme of change that spans many years.^{33 34} Those seeking to drive these changes forget this crucially important fact at their peril. Underpinning progress is a coordinated programme of change and service improvement that represents a relentless focus on the specific areas of practice where increases in donation can be made, tracked, and guided by appropriate and reliable metrics. The challenge for the UK is considerable, because such change requires coordination of the business of over 200 acute hospitals and their donation committees, and many thousands of clinical colleagues. This must be done in a way that is consistent with the overall strategic direction of the national organ donation organization but crucially, also accounts for the needs of individual patients and families.

Table 1 lists some of the interventions that are required to deliver the six big wins and while some are the responsibility of local teams and can be delivered relatively quickly, others depend on national initiatives that will take longer to deliver and effect change. International experience strongly suggests that such complex programmes of change benefit from regional ownership,^{33 34 36} not least because there is often a requirement for changes in practice and behaviours locally. The PDP for donation leads was therefore designed not only to provide some basic elements in business planning and the leadership of change in healthcare, but also—through the delivery of much of the material in regional master classes—to the development of a UK-wide network of regional donation collaboratives. It is within this landscape of local donation committees, regional collaboratives, and a single UK-wide national organ donation organization (Table 3), that the overall objectives of the Taskforce will be delivered.

Will the six 'big wins' be enough?

There is striking variation in both the absolute and relative numbers of DBD and DCD donors across Europe (Fig. 2). For

example, while Spain consistently reports in excess of 30 DBD donors pmp per year, in the UK, the figure is just 10. Furthermore, the maximum annual potential for DBD in the UK as assessed by the PDA is just 18 donors pmp, while in Spain and other mainland European countries, it may approach 50. In contrast, the UK has a higher number of DCD and living donors than Spain, with DCD donation now representing approximately one-third of all deceased UK donors.²⁶ In addition, although DCD donors in the UK are almost entirely from the controlled category, those in Spain are uncontrolled.^{37 38}

It is possible that the international variations in deceased donation reflect nothing more than an intrinsic variation in the incidence and severity of particular diseases, the effectiveness of their treatment, or both. A more intriguing, and possibly more plausible, explanation is that the potential for DBD and DCD donation reflects the nature and philosophy of the care given to patients with very severe (and almost certainly life-ending) acute intracranial pathologies and that it might be this difference that drives the headline differences between countries. For example, treatment philosophies which as a minimum offer a period of critical care to all patients, regardless of their likelihood of survival, and which avoid decision-making around the likely benefits of continued treatments, might be expected to lead to a higher potential for DBD and a lower potential for controlled DCD. In contrast, approaches that are based upon the limitation or withdrawal of treatments that are no benefit to a dying patient will have a lower potential for DBD because treatments are withheld or withdrawn before brain death has become established or can be diagnosed. While the latter will promote controlled DCD, it is likely to result in fewer DBD donors. Although variations in both the incidence of brain death and decisions to withdraw life-sustaining treatments in ICU have been described,³⁹ their relationship with the size and nature of the potential donor pool remains uncertain. Further investigation of these fascinating issues is required.

Conclusion

Organ retrieval, allocation, and transplantation are necessarily nationwide processes, while donation is the responsibility of individual acute hospitals. The availability of organs for transplantation therefore depends primarily upon effective functioning relationships between disparate groups of healthcare teams, rather than on the levels of public support for donation or the legislative framework for consent. The report from the Organ Donation Taskforce represented the first serious attempt in the UK to introduce a national framework for donation that would provide the structural arrangements for these crucial relationships to develop and flourish.

Media and professional attention inevitably focus on the publication and recommendations of Government reports such *Organs for Transplants*, but it is the subsequent work of implementation that determines whether the changes in

practice envisaged are successfully enacted. The donation pathway is complex, with pinch points usually occurring around professional and individual behaviours rather than financial resource. International experience suggests that a single cycle of change is unlikely to maximize donation opportunities. A sustained programme of change management, based on an appropriate and reliable measures of activity, will be required if higher donation rates in the UK are to be delivered and sustained. Not only will higher donation rates better meet the needs of those with end-stage organ failure, but they will also allow the wishes of those who wish to donate their organs for transplantation after their death to be fulfilled. If the UK framework for donation had its origins in the need to increase the number of organs available for transplants, its justification for doing so lies in better meeting the wishes and beliefs of our dying patients.

Declaration of interests

Both authors were members of the UK Organ Donation Taskforce. P.G.M. is currently a National Clinical Lead for Organ Donation at NHS Blood and Transplant, and M.S. was the chair of the Donation Advisory Group at NHS Blood and Transplant from 2005 to 2011.

References

- 1 NHS Blood and Transplant. Annual summary statistics on donation and transplantation in the UK. Available from www.uktransplant.org.uk/ukt/statistics/latest_statistics/latest_statistics.jsp (accessed 17 October 2011)
- 2 *Transplant Procurement Management*. Available from www.tpm.org (accessed 17 October 2011)
- 3 BBCs DoNation Survey in 2005. Available from www.bbc.co.uk/pressoffice/pressreleases/stories/2005/08_august/21/donation.shtml (accessed 17 October 2011)
- 4 Available from www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_090296.pdf (accessed 17 October 2011)
- 5 Smith M, Murphy PG. A historic opportunity to improve organ donation rates in the United Kingdom. *Br J Anaesth* 2008; **100**: 735–7
- 6 Kotter JP, Cohen DS. *The Heart of Change*. Boston: Harvard Business School Press, 2002
- 7 *Organs for Transplants. A Report from the Organ Donation Taskforce*. London: Department of Health, 2008. Available from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122 (accessed 17 October 2011)
- 8 Smith M, Murphy PG. Organs for Transplants: a report from the Organ Donation Taskforce. *J Intensive Care Soc* 2008; **9**: 72–6
- 9 Murphy P, Bion J. Organ donation update. *Bull Roy Coll Anaesth* 2010; **61**: 6–8
- 10 Legal issues relevant to non-heartbeating organ donation. Available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108825 (accessed 17 October 2011)
- 11 Guidance on legal issues relevant to donation following cardiac death. Available from [www.sehd.scot.nhs.uk/cmo/CMO\(2010\)11.pdf](http://www.sehd.scot.nhs.uk/cmo/CMO(2010)11.pdf) (accessed 17 October 2011)

- 12 Legal issues relevant to donation after circulatory death (non-heart-beating organ donation) in Northern Ireland. Available from www.dhsspsni.gov.uk/donation-after-circulatory-death-legal-guidance-march-2011.pdf (accessed 17 October 2011)
- 13 Treatment and care towards the end of life: good practice in decision making. General Medical Council. Available from www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp (accessed 17 October 2011)
- 14 Barber K, Falvey S, Hamilton C, Collett D, Rudge C. Potential for organ donation in the United Kingdom: audit of intensive care unit records. *Br Med J* 2006; **332**: 1124–7
- 15 Murphy P. Why do patients who are brainstem dead not go on to donate their organs? An analysis of data from the UK Potential Donor Audit. *J Intensive Care Soc* 2008; **9**: 79–80
- 16 Sign up to save a life campaign. The Scottish Government. Available from www.scotland.gov.uk/News/Releases/2010/02/15104917 (accessed 17 October 2011)
- 17 Bird S, Harris J. Time to move to presumed consent for organ donation. *Br Med J* 2010; **340**: c2188
- 18 Harris J. Organ procurement: dead interests, living needs: cadaver organs should be automatically available. *J Med Ethics* 2003; **29**: 130–4
- 19 Simpkin AL, Robertson L, Barber VS, Young JD. Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *Br Med J* 2009; **339**: b991 doi:10.1136/bmj.b991
- 20 Vincent A, Logan L. Consent for organ donation. *Br J Anaesth* 2012; **108** (Suppl. 1): i80–i87
- 21 Farsides B. Respecting wishes and avoiding conflict: understanding the ethical basis for organ donation and retrieval. *Br J Anaesth* 2012; **108** (Suppl. 1): i73–i79
- 22 The potential impact of an opt out system for organ donation in the UK: an independent report from the Organ Donation Taskforce. Available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312 (accessed 17 October 2011)
- 23 Available from <http://wales.gov.uk/newsroom/firstminister/2011/110712legislative/?lang=en> (accessed 17 October 2011)
- 24 Available from http://www.direct.gov.uk/en/N11/Newsroom/DG_198724 (accessed 17 October 2011)
- 25 Human bodies: donation for medicine and research. London: The Nuffield Council on Bioethics. 2011. Available from http://www.nuffieldbioethics.org/sites/default/files/Donation_full_report.pdf (accessed 17 October 2011)
- 26 Manara AR, Murphy PG, O'Callaghan G. Donation after circulatory death. *Br J Anaesth* 2012; **108** (Suppl. 1): i108–i121
- 27 Donation after Circulatory Death: a Consensus Statement from the British Transplantation Society and Intensive Care Society. Available from www.ics.ac.uk/intensive_care_professional/standards_safety_and_quality (accessed 17 October 2011)
- 28 Ehrle R. Timely referral of potential organ donors. *Crit Care Nurse* 2006; **26**: 88–93
- 29 Rosendale JD, Kaufmann HM, McBride MA, et al. Hormonal resuscitation yields more transplanted hearts with improved early function. *Transplantation* 2003; **75**: 1536–41
- 30 Shemie SD, Ross H, Pagliarello J, et al. Organ donor management in Canada: recommendations of the forum on Medical Management to Optimize Donor Organ Potential. *Can Med Assoc J* 2006; **174**: S13–30
- 31 McKeown DW, Bonser RS, Kellum JA. Management of the heartbeating brain-dead organ donor. *Br J Anaesth* 2012; **108** (Suppl. 1): i96–i107
- 32 Shafer TJ, Wagner D, Chessare J, Zampiello FA, McBride V, Perdue J. Organ donation breakthrough collaborative: increasing organ donation through system redesign. *Crit Care Nurse* 2006; **26**: 33–48
- 33 Matesanz R, Miranda B. A decade of continuous improvement in cadaveric organ donation: the Spanish model. *J Nephrol* 2002; **15**: 22–8
- 34 Rodríguez-Arias D, Wright L, Paredes D. Success factors and ethical challenges of the Spanish Model of organ donation. *Lancet* 2010; **376**: 1109–12
- 35 Murphy PG, Logan L, Aldridge D. The professional development programme for clinical leads for organ donation. *Bull Roy Coll Anaesth* 2010; **64**: 23–7
- 36 Rudge C, Matesanz R, Delmonico FL, Chapman J. International practices of organ donation. *Br J Anaesth* 2012; **108** (Suppl. 1): i48–i55
- 37 Fabre J, Murphy P, Matesanz R. Presumed consent: a distraction in the quest for increasing rates of organ donation. *Br Med J* 2010; **341**: c4973
- 38 Domínguez-Gil B, Haase-Kromwijk B, Van Leiden H, et al. Current situation of donation after circulatory death in European countries. *Transplant Int* 2011; **24**: 676–86
- 39 Sprung CL, Cohen SL, Sjøkvist P, et al. End-of-life practices in European intensive care units. The Ethicus Study. *J Am Med Assoc* 2003; **290**: 790–7