Department of Health

Organs for Transplants

A report from the Organ Donation Taskforce




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Policy	Estates
HR/Workforce	Performance
Management	IM&T
Planning	Finance
Clinical	Partnership Working

Document purpose	Policy	
ROCR ref:		**Gateway ref:** 9291
Title	Organs for Transplants: A report from the Organ Donation Taskforce	
Author	Organ Donation Taskforce	
Publication date	January 2008	
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, Communications Leads, Emergency Care Leads	
Circulation list		
Description	A report from the Organ Donation Taskforce, making recommendations on action to take to increase the number of organs available for transplantation.	
Cross ref		
Superseded docs		
Action required	N/A	
Timing	N/A	
Contact details	Mr Neil Moors Transplant Policy Team Room 611, Wellington House 133–155 Waterloo Road London SE1 8UG 020 7972 4323 Neil.Moors@dh.gsi.gov.uk	
For recipient's use		

Organs for Transplants

A report from the Organ Donation Taskforce

Contents

Organ donation occurs at a time of great emotional distress.
The terminology and phraseology in this report are necessarily factual and might appear unsympathetic to those most closely affected by organ donation. This dispassionate reporting of events and outcomes should not be taken as disrespect to deceased donors, their families, and the amazing gift of life that they make.

Chair's introduction

I feel privileged to be the Chair of the Organ Donation Taskforce and to present our report.

Organ transplantation is one of medicine's great success stories, transforming tens of thousands of lives each year. And yet, tragically, hundreds of people die each year in the UK, which was a pioneer of transplantation, because organs are not available.

The Taskforce began work in December 2006 with a brief to identify the obstacles to organ donation and suggest solutions which would deliver the increase in transplants that is so desperately needed.

The UK has one of the worst records for organ donation in western Europe. The Taskforce was, however, greatly encouraged by the evidence it considered from across the world and believes that a 50% increase in organ donation is possible and achievable in the UK within five years. We are convinced that this goal will only be realised if our recommendations are considered and acted on as a whole. Piecemeal solutions have been attempted in the past. They have not worked and now is the time to act in a concerted manner to tackle the UK's donor shortage and to improve the country's poor transplant record.

Throughout our debates over the last ten months Taskforce members have worked with a great sense of purpose and I would like to pay tribute to their knowledge, energy and commitment. They remain so optimistic about the potential for improvement that they have undertaken to meet annually to review progress and consider what else might be done to accelerate it further.

Finally, I would like to express sincere appreciation for the devolved administrations, advisers and professional associations which have supported our approach. We have been assisted by many whose help has made this work both fascinating and rewarding, and the potential for donor families and transplant patients so much greater.

Elisabeth Buggins CBE
Chair, Organ Donation Taskforce

Section 1 provides an overview of the issues discussed by the Taskforce, followed by its recommendations. Further evidence and the rationale that underpins each of the recommendations are presented in Section 4. The Supplement Report containing the detailed analysis is available on the Department of Health website.

1. Summary of the main issues and recommendations

1.1 Following extensive analysis of systems in the UK and in other countries, the Organ Donation Taskforce is convinced that a 50% increase in organ donation after death is possible and achievable in the UK within five years.

1.2 This increase is dependent upon the resolution of three key issues within the NHS which have been highlighted by the Taskforce's systematic review as being barriers to organ donation: donor identification and referral; donor co-ordination; and organ retrieval arrangements.

1.3 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. The Taskforce estimates that a 50% increase in donation would enable an additional 1,200 transplants a year, of which over 700 would be kidney transplants, with very significant cost savings when compared with the costs of dialysis (see Section 1 of the Supplement Report).

1.4 Given the experience of other countries, the Taskforce is confident that if the recommendations of this report are implemented in full, a major difference in terms of transplants enabled and lives saved could be seen in as little as a year. This will only be achieved with the type of clear political leadership and commitment to the realisation of these recommendations that was demonstrated in the USA by Secretary of Health Tommy Thompson.

1.5 Spain has the highest organ donation rate in Europe at 35 donors per million of population (pmp). The UK has one of the lowest rates at just 13 pmp. But fifteen years ago, before the Spanish began systematically to address barriers to organ donation, they had a rate similar to that of the UK today. Recently, lessons from the Spanish model have been implemented in Italy and several South American countries. All experienced an immediate and rapid rise in organ donation. It is entirely possible for the same to happen in the UK.

1.6 Transplants save lives. In 2006/7 over 3,000 patients in the UK received an organ transplant, but another 1,000 died whilst waiting or after being removed from the waiting list because they had become too ill. The current active transplant waiting list stands at 7,235 and is rising by approximately 8% each year. This list does not reflect the true extent of need, as many clinicians are reluctant to list more patients than are realistically likely to receive organs. The true need is, at minimum, 50% more than currently available and is rising rapidly with changing demographics in the UK. Of particular note are an ageing population and an anticipated surge in the incidence of Type 2 diabetes, a condition which can cause kidney failure and lead to the need for a kidney transplant.

1.7 The shortage of deceased donors has resulted in an increased interest in living donation, but it must be noted that living donation of a kidney is associated with a risk of death to the donor of about 1 in 3,000, whilst living liver donation (adult to adult) carries a risk of death to the donor of up to 1 in 100. Nothing demonstrates the critical shortage of deceased donors more clearly than the acceptance – by patients, clinicians and commissioners – of such risks to the life of a fit, healthy person.

1.8 There is also an urgent need to address health inequalities. People of Asian or African-Caribbean descent are three to four times more likely than white people to develop end-stage renal failure and need a kidney transplant. UK Transplant (UKT) data shows that such people make up 23% of the kidney waiting list, whilst representing only 8% of the population. Only 3% of deceased donors are of Asian or African-Caribbean descent.

1.9 Funding provided by NHS Blood and Transplant (NHSBT) has resulted in increases (sometimes very considerable) in certain types of organ donation. For instance, between 2000 and 2006 there was a 93% increase in the annual rate of living donation for kidney transplants, from 348 to 671, and a 284% increase in donation after cardiac death (DCD), from 38 to 146. And thanks to the activity of NHSBT, the number of people registering to be an organ donor on the NHS Organ Donor Register continues to rise and currently stands at nearly 25% of the population.

1.10 But it is donation after brain stem death (DBD) (ie death that is confirmed by neurological criteria) – typically involving those patients who are being cared for in intensive care units (ICUs) following catastrophic brain injury – that provides organs for virtually all heart and lung transplants, the overwhelming majority of liver transplants and many kidney transplants. The annual rate of DBD has fallen by 14% (from 739 to 633) over the same time period.

1.11 The public is very supportive of organ donation in principle, with 90% in favour in a UKT survey carried out in 2003, and nearly 15 million people already on the NHS Organ Donor Register. However, the actual donation rate in the UK remains poor, and in part this is a consequence of the 40% of relatives who refuse to give consent for donation. The professionals working in critical care and the transplant service offer high-quality care, and Taskforce members have been deeply impressed by their dedication and commitment. But it is the system within which both the public and professionals exist that lets everyone down, most of all those needing transplants. Although there have been many reviews of organ donation in the past, all of them have failed to resolve the problems that result from the lack of a structured and systematic approach to organ donation, and to a lesser extent organ transplantation. These fall into three main categories:

1. Donor identification and referral
2. Donor co-ordination
3. Organ retrieval.

1.12 Across these categories there are a number of matters that need attention:

> legal and ethical issues;

> the role of the NHS;

> organisation of co-ordination and retrieval;

> training;

> public recognition and public promotion of donation.

1.13 Bringing all these considerations together there is one overarching requirement, as follows.

Organ donation – a UK-wide service

1.14 Organ donation is a 'local' activity but transplantation can only be undertaken successfully as a UK-wide integrated service. Patients with severe acute liver failure will die within 72 hours without a transplant, patients with acute irreversible heart failure may die within days, and there are hundreds of patients waiting for a well-matched kidney transplant. Only a UK-wide service can identify and allocate suitable organs to meet the needs of these patients. Substantial resources may be expended by one Trust whilst the benefits accrue to another which may be at the other end of the country. Donor transplant co-ordinators (DTCs) are employed locally but must work to a UK-wide perspective. Any interruption to the local service may have no effect on local patients waiting for a transplant but may lead to the death of patients elsewhere in the country.

1.15 During their review the Taskforce, which included from a very early stage representatives of the devolved health administrations, was struck again and again by the overwhelming need for a UK-wide Organ Donation Organisation to co-ordinate, commission and deploy right across the UK. The Taskforce was mindful that this goes against the general policy of moving resources and decision-making closer to the communities that hospitals serve. It also recognises that different structures exist within the different administrations. But in terms of organ donation there is a compelling case for a UK-wide service. The interests of those who need transplants can be best served by a UK-wide Organ Donation Organisation, which also meets the needs of those who wish to donate their organs after death. Experience in recent years in the UK, and evidence internationally, demonstrates that anything less than this will not achieve the required results.

1.16 There is currently a national body within the NHS that is involved in transplantation – NHSBT. However, while NHSBT is involved in a number of aspects of donation and transplantation it is not, in its current form, the UK-wide Organ Donation Organisation envisaged by the Taskforce.

1.17 Within NHSBT, UKT's remit is to manage transplant waiting lists, allocate organs, collect and analyse transplant data for all transplant units in the United Kingdom, and promote organ donation and the NHS Organ Donor Register. NHSBT also has responsibility for the National Blood Service (NBS), which provides blood and blood products, together with some specialised services and some (but not all) tissue donation, banking and supply, to England and North Wales. The NBS also has considerable experience and expertise in publicising the need for blood donors.

1.18 Whilst UKT provides professional leadership to DTCs across the UK, it does not employ or manage them. These functions are undertaken locally, making a national service vulnerable to local pressures and decisions. The Taskforce felt that the most appropriate organisation to be given responsibility for the Organ Donation Organisation would be NHSBT because of the extensive experience of donation and co-ordination that it has built up over recent years. This move would also make it easier to develop a seamless co-ordination service for the families of all donors, whether of organs, tissues or both. Recommendations 9 and 10 give greater detail about the main roles and responsibilities of the proposed Organ Donation Organisation.

Recommendation 1

A UK-wide Organ Donation Organisation should be established.

Recommendation 2

The establishment of the Organ Donation Organisation should be the responsibility of NHSBT.

Legal and ethical issues

1.19 A patient only becomes a potential organ donor when death is confirmed following clearly defined tests of the brain stem, in which case DBD may be possible; or when a decision has been taken – in the best interests of the patient – that further active treatment is no longer appropriate and should

be withdrawn, in which case DCD (non-heartbeating donation) may be possible. This change of emphasis can only occur when critical care staff have complete confidence in the means by which death is certified, when there is a clear framework that ensures that there is – and is seen to be – no conflict of interests, and when steps to facilitate organ donation are clearly lawful. Currently the legal position with regard to non-heartbeating donation is unclear, in part because it differs across the UK. Particular concerns have been expressed, for example, about the extent to which the timing of withdrawal of active treatment may be influenced by delays resulting from the time necessary to complete the retrieval arrangements.

1.20 The Taskforce was reassured that appropriate guidance is available for the diagnosis of death by brain stem tests and agreed that such testing in accordance with the published code of practice should be seen as routine practice in the best interests of all appropriate patients regardless of donation. Discussions with the British Medical Association and the General Medical Council confirmed their views that brain stem testing of all appropriate patients, whether they are potential organ donors or not, should be normal practice as it is in the patient's best interests. Continued treatment of a patient whose brain stem is no longer functioning is not in the patient's best interests.

1.21 The NHS Organ Donor Register is an invaluable record of the wishes of the individual and it should be consulted during this process. It is a powerful and positive influence for families who may themselves be hesitant about organ donation.

1.22 There are concerns, however, about DCD, where a conflict of interest may be felt to arise between the duty of care of the doctor to the dying patient who is a potential donor after death, and the steps needed to facilitate donation. This is an area that raises many legal and ethical issues and a range of differing opinions. It is essential that these concerns are resolved. The legal issues could be addressed through the Mental Capacity Act 2005, the Human Tissue Act 2004, the Human Tissue (Scotland) Act 2006 and their respective Codes of Practice. Organ donation can present many difficult ethical dilemmas but currently there is no single formal body to which clinical staff may turn for advice and resolution.

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.

Making donation usual, not unusual

1.23 For many Trusts, organ donation is an infrequent event, and because of this it could become an afterthought or be seen as an optional extra. Organ donation should become usual rather than unusual and be a normal part of end-of-life care for appropriate patients, with timely consultation of the NHS Organ Donor Register and appropriate involvement of the DTC. Intensive care should not be the only focus for organ donation; all areas where end-of-life care is provided should be included.

1.24 The Spanish model has demonstrated the importance of a clinical champion in each hospital, responsible for ensuring that all opportunities for donation are realised. This person should be partnered by a non-clinical donation champion, perhaps a patient or well-known local figure, chairing a donation committee accountable to the Trust Board.

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.

Monitoring

1.25 In the past, organ donation has normally been measured in terms of the number of actual donors, but an additional and important measure is the conversion rate, ie the proportion of those patients suitable for donation who are identified and whose personal wishes, or those of their family, are both ascertained and fulfilled. Each stage of the process is currently measured through the UKT Potential Donor Audit (PDA). This audit is being enhanced, expanded and converted into one that is web-based with real-time data input. Data collection should be routine and extended to all areas where critical care is provided, including accident and emergency departments (emergency medicine). In these areas data accrual should be based on robust, simple criteria, allowing a realistic assessment of the size of the possible donor pool. The data should be made publicly available and reviewed by the Trust donation committee before reporting to the Trust Board. The Trust's chief executive and medical director should be accountable for their Trust's performance in supporting donation. Donation monitoring information (in line with the protocol recommended in paragraph 1.28) should be incorporated into the data used by healthcare regulators (for example, the Healthcare Commission in England) in their standards and be part of the assessment of all relevant Trusts.

1.26 The Taskforce heard from Frank Delmonico the importance of the trigger point referral system that has been established in the USA and that underpins the success of the American programme. The Taskforce recognised the importance of clinical indicators as a trigger for notification to the DTC and believed that these might, in conjunction with the changes recommended to the structures which support organ donation and the recommendations for monitoring donation activity, increase the number of organ donors after death. It also recognised how such clinical indicators would provide a comprehensive prospective audit of the number of patients in whom brain stem death (BSD) was a likely diagnosis and provide a robust denominator against which to measure performance. However, the Taskforce was sensitive to the concerns of professional colleagues within intensive care medicine that the introduction of clinical triggers at this stage would be counterproductive.

1.27 The identification of potential organ donors and their notification to the Organ Donation Organisation should be in response to defined criteria that identify, at the appropriate stage, all patients whose death is expected. The Taskforce asked the Donation Advisory Group of UKT, in consultation with the Intensive Care Society, to develop a model to ensure comprehensive potential donor identification in UK ICUs. The Royal College of Anaesthetists was aware of these proposals and, although not formally consulted, supported the views of the Intensive Care Society.

1.28 The Taskforce endorsed proposals for a national protocol for the notification of potential organ donors in the following terms:

> 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.

> 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 cardiac death might be contra-indicated or inappropriate.

1.29 These proposals are an acceptable but minimum description of what is necessary. They should be implemented in all acute Trusts.

1.30 Given the emphasis placed upon clinical triggers in other domains, the Taskforce considers that there is an urgent need for a pilot study looking at the impact of introducing clinical indicators as a trigger for notification. Whilst the methodology of such a study was not considered in detail, the Taskforce believes that it should assess not only the role of triggers in

increasing donation, but also the impact upon staff and patients and their families of introducing what the Taskforce accepts is a radical change of practice. The Taskforce believes that having the evidence from such a study would be critical in gaining the necessary support to be able to move the agenda forward on this important issue.

1.31 Where clinicians in individual Trusts can agree more specific and detailed notification criteria, they should be supported to introduce them in a fashion that will allow a subsequent analysis of their effectiveness, feasibility and acceptability in comparison to the minimum referral criteria described in paragraph 1.28. From the evidence gained through such research over the next one to three years, it may be possible to define more detailed notification criteria that could be recommended and adopted on a national basis.

1.32 These clinical notification proposals should be seen not in isolation, but as part of the overall strategy, with a number of components that taken together should ensure that **all** potential organ donors are identified and referred. The PDA is in place at present but is currently being revised to meet the requirements for monitoring the process more fully. However much of the essential data could be provided immediately.

Recommendation 5

Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis. These criteria should be reviewed after 12 months in the light of evidence of their effect, and the comparative impact of more detailed criteria should also be assessed.

Recommendation 6

Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent to donation should be reported. The Trust donation committee should report to the Trust Board through the clinical governance process and the medical director, and the reports should be part of the assessment of Trusts through the relevant healthcare regulator. Benchmark data from other Trusts should be made available for comparison.

Recommendation 7

BSD testing should be carried out in all patients where BSD is a likely diagnosis, even if organ donation is an unlikely outcome.

Costs of donor management

1.33 The significant costs of donor management fall on the donor hospital. These can be considerable and may be incurred even if donation is not eventually possible. The Taskforce felt that financial incentives were not desirable but that the financial disincentives that currently exist should be removed. Measures for realistic reimbursement for the costs of donation should be developed and introduced in the rest of the UK to mirror the current arrangements in Scotland and Northern Ireland.

Recommendation 8

Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.

Donor transplant co-ordinators

1.34 At present there are approximately 100 DTCs in the UK, working in 18 teams with the majority employed within Trusts, typically in a transplant unit. Employment arrangements, grades, governance and line management vary. There are also 12 (with an additional 10 to be established in 2007/8) 'in-house co-ordinators' – fully trained DTCs who are based full-time within a single critical care unit or a single Trust. The early experience with these recent innovations suggests definite benefits, although they are not yet all achieving the 100% identification and referral of potential donors that is needed.

1.35 The UK system is widely recognised as unsatisfactory and contrasts unfavourably with the Spanish model in which systematic co-ordination is core to success. To achieve a robust, sustainable and effective DTC network in the UK will require a significant increase in the number of DTCs and changes to their employment, training and working arrangements.

The Taskforce is very aware of the possible disruption this may cause but nevertheless feels that these changes are essential.

1.36 The Taskforce was concerned to hear that under current arrangements a single DTC attends the donor hospital from the time of initial referral until the last offices have been performed after organ removal. This rarely amounts to less than 12–18 hours and frequently means that the co-ordinator works for 24 hours or more without a break. In order to resolve this, it is envisaged that up to three individuals may attend each organ donor. One may be required for discussions with the organ donor's family, covering the obtaining of agreement to donation and the medical and social history of the donor. A second person would obtain clinical information, register the donor with UKT and make arrangements for the retrieval team. This individual could also, with appropriate training, play an active role in enhanced donor care. A third person would join the retrieval team and would take responsibility for the continuing processes of liaison with UKT, organ allocation and all the associated documentation.

1.37 Each of these individuals would be integrated within a designated critical care group whilst being part of a local co-ordinator team, having a central office from which the team was co-ordinated. The embedded co-ordinators would work closely and collaboratively with Trust donation champions to ensure that appropriate policies were in place, that any local obstacles were identified and resolved and that all necessary steps were in place to realise every opportunity for donation. This proposal is a critical part of the revised co-ordinator arrangements that will help to ensure comprehensive recognition and referral of all potential organ donors.

1.38 The national Organ Donation Organisation envisaged by the Taskforce would be responsible for the employment, training and management of DTCs.

1.39 It is also recommended that the process of donor registration with UKT, and the offering of donor organs to transplant teams, should be improved and streamlined through the introduction of electronic (web-based) real-time IT systems in line with the DonorNet system that has recently been introduced in the USA.

1.40 It is estimated that improved donor co-ordination services could increase the consent rate for donation from 60% to at least 70% over five years.

Recommendation 9

The current network of DTCs should be expanded and strengthened through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded within critical care areas, should be employed to ensure a comprehensive, highly skilled, specialised and robust service. There should be a close and defined collaboration between DTCs, clinical staff and Trust donation champions. Electronic on-line donor registration and organ offering systems should be developed.

Organ retrieval teams

1.41 Donor numbers need to increase, but organ retrieval arrangements are already stretched. Specialist teams from several different transplant centres may be required for a single donor, and delays in responding to a referral cause distress to the donor's family and impose an extra burden on the ICU. On occasions the donor's haemodynamic state (ie their blood pressure and other vital signs) becomes unstable, threatening the viability of some or all of the organs. Teams vary in size, composition and level of experience, while their funding comes from various, often obscure, sources. Few members of a team are available specifically for organ retrieval, with most having other clinical commitments that limit their ability to respond quickly. The teams all rely on significant help from the donor hospital. Changes to consultant contracts and the effects of the European Working Time Directive will further erode their viability. In addition, few teams are able to provide early expert assistance in donor management to donor hospitals, and this adversely affects the number and quality of organs removed.

1.42 Organ retrieval teams should be virtually self-sufficient and not require anaesthetic, theatre or surgical staff from the donor hospital (other than minimal local liaison). They should be available 24 hours a day without other elective commitments during their time on call. They should be able to respond appropriately if there is more than one donor on the same day

and be able to provide opportunities for training. They should also be responsible for working with critical care staff in the donor hospital to ensure optimal donor care to maximise the number and viability of organs retrieved. A working party of the British Transplantation Society is considering these issues in more detail, and is due to report its recommendations in the near future.

Recommendation 10

A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high-quality organ removal from all heartbeating and non-heartbeating donors. The Organ Donation Organisation should be responsible for commissioning the retrieval teams and for audit and performance management.

Training, education and continuing educational support

1.43 Organ donation is an infrequent occurrence in all but the largest Trusts and many critical care staff may go through their training without ever having been involved in the care of a single potential organ donor. This can lead to a lack of expertise amongst professionals. This contrasts with the situation in Australia, where one of the mandatory components of critical care training relates to organ donation. There is a need to reinforce training in organ donation and to provide regular refresher training and continuing professional development. This would further support the notion of organ donation being usual rather than unusual. The UK-wide Organ Donation Organisation could play a major role in ensuring that appropriate multidisciplinary training is commissioned and available, including that for all DTCs.

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.

Honouring the gift of donation

1.44 Appropriate public recognition of donors and their families should be established. The Taskforce considered a range of options, from the most public acknowledgement through a 'roll of honour' in a public place, to a private letter of thanks from a senior figure such as the Chief Medical Officer. Many donor families find great comfort in hearing about the benefit derived by recipients as a consequence of their relative's donation. Other possible forms of public recognition that could be considered include a memorial garden, an eternal flame or a web-based register. Research is needed to establish the means of recognition that most donor families would appreciate.

Recommendation 12

Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. These approaches may include national memorials, local initiatives and personal follow-up to donor families.

Promoting donation

1.45 Promotion of organ donation to the general public has been a great success story, with nearly 15 million people now registered on the NHS Organ Donor Register. This promotion should continue, particularly since registration on the Register now constitutes valid agreement to donation under the Human Tissue Acts, which give primacy to the wishes of the individual, if known.

1.46 During the preparation of this report the Taskforce was unable to consider legislative changes such as presumed consent, as this fell outside its terms of reference. However, in September 2007 the Secretary of State asked the Taskforce to consider whether a change to presumed consent would increase the number of organ donors and to submit a report in 2008.

1.47 There are particular concerns related to donation from people of black and minority ethnic (BME) origin. These groups are under-represented amongst actual organ donors, with only 3% of deceased organ donors coming from BME communities, who in the 2001 census made up 8% of the population.

Currently, 23% of patients waiting for a kidney transplant are from BME groups – people from Asian or African-Caribbean backgrounds are three to four times more likely to need a kidney transplant than are white people. It is also the case that whilst, overall, families of 40% of potential donors refuse consent at the critical time, this figure is 75% for potential donors from a BME background. More work is needed to understand the different reasons for non-donation and to establish how best to encourage engagement with the option of organ donation after death.

Recommendation 13

There is an urgent requirement to identify and implement the most effective methods through which organ donation and the 'gift of life' can be promoted to the general public, and specifically to the BME population. Research should be commissioned through Department of Health research and development funding.

1.48 If the death of a potential organ donor occurs in circumstances that require notification to the coroner, it is necessary to obtain their agreement (or that of the procurator fiscal in Scotland) before donation can take place, even where the donor has explicitly stated a wish to donate. The Taskforce was made aware that there is considerable variation in the practice of individual coroners. Whilst understanding the responsibilities that rest with coroners, and their autonomy, the Taskforce felt that clearer national guidance should be developed. Considerable work towards this was undertaken several years ago, and the Taskforce recommends that the Department of Health and the Ministry of Justice should work together to build on previous discussions and to develop formal guidelines for coroners.

Recommendation 14

The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.

1.49 One major issue outside the direct remit of the Taskforce was recognised as important. Transplant units may not have adequate resources to perform the increased number of transplants that this report expects, not only in terms either of staffing (consultants, juniors and nursing) or of infrastructure (beds, operating theatres etc) but also, crucially, in terms of the support services upon which transplantation depends. For kidney transplants (and for an increasing number of heart and lung transplants) the services of histocompatibility and immunogenetics laboratories are essential. The Taskforce was made aware that even the recent modest increase in kidney transplant numbers has stretched these resources in some places almost to breaking point. Commissioners of transplant services must ensure that donated organs are not wasted as a consequence of infrastructure constraints. This is an area of concern for all forms of solid organ transplantation, but particularly so for renal transplant units, which are currently commissioned on a local basis. The Taskforce recommends that consideration should be given to a national basis for the commissioning of all transplant services, to build on the robust commissioning arrangements currently in place for liver, pancreas and cardiothoracic transplantation through the National Commissioning Group.

1.50 **These recommendations are radical, wide-ranging and essential. Their implementation will not be without difficulty, but the potential prize is significant. The involvement of all key stakeholders will be essential to their successful implementation. The Taskforce feels that it is crucial that progress is reviewed on an annual basis, and all its members are both willing to reconvene for this purpose and committed to doing so.**

2. Current complexities and limitations

Background

2.1 The UK has one of the lowest organ donation rates in the developed world. It was in recognition of this that the Organ Donation Taskforce was established, at the request of the Government. The terms of reference and membership are given in Appendix 2. Membership of the Taskforce was deliberately wide-ranging to ensure that expertise was available from critical care, donor co-ordination, transplant surgery, senior NHS management (at Trust and Strategic Health Authority level), commissioners, donors and donor families, patients and the media. Representatives of the UK's devolved health administrations were in attendance from an early stage. An academic ethicist joined the Taskforce after two meetings, and a researcher with specific expertise on issues of donation amongst ethnic minority communities was recruited.

2.2 The UK has not always been at the bottom of the league table for organ donation. Although comprehensive international data has only been available more recently, the Council of Europe newsletter has published donation rates for selected countries for over a decade. In 1995 the UK and Ireland donor rate of 15.8 per million population (pmp) was comparable with the 15.1 pmp rate reported by Eurotransplant (the Netherlands, Belgium, Germany, Luxembourg, Austria, Slovenia and Croatia) and the 15.5 pmp rate in France. Now the UK rate is 12.9 pmp, while Spain has achieved 35.5 donors pmp (see Figure 2 on page 28).

2.3 The first UK-wide attempt to increase organ donation was the establishment of UK Transplant (UKT) in 2000, which was given specific responsibilities and funding. These responsibilities were taken over by NHS Blood and Transplant in 2005. Since 2000, improvements have been made both in increasing organ donation and identifying obstacles to further increases. Several of the initiatives have been very successful – particularly in increasing living donor kidney transplants and donation after cardiac death (DCD). Success has been achieved through additional targeted funding for Trusts and transplant units, together with very considerable efforts on the part of clinical staff throughout the NHS (particularly in critical care) and specifically those working in transplant donor co-ordination and in transplant units.

2.4 However, there are some areas in which efforts have not been successful. The bedrock of organ donation has historically been donation after brain stem death (DBD), and since 2001/2 there has been a 9% fall in the number of such donors. This has had a particular effect on liver, heart and lung donation and transplantation, for which organs from donation after cardiac death (DCD) donors are either unsuitable or are associated with significant concerns about recipient outcomes.

2.5 A further stimulus to the establishment of the Taskforce was the need to review progress in the light of recent changes in Government policy and new legal developments. The Department of Health published the Transplant Framework in 2003. This was followed by the Human Tissue Act 2004 and the Human Tissue Act (Scotland) 2006 (both Acts came into effect in September 2006).

2.6 Prior to this there had been many reviews and reports into individual aspects of organ donation over the previous ten years, and common themes emerge from them. Many of those themes are echoed in the recommendations of this Taskforce. Although the additional funding provided through UKT has been helpful in some regards, there has been no systematic attempt to analyse the wide range of obstacles to increasing organ donation in order to provide a coherent series of recommendations and to implement them.

2.7 The many reviews, and their many recommendations, have failed to resolve the problems that result from the unstructured and fragmented arrangements that are currently in place for organ donation and, to a lesser extent, for organ transplantation – particularly kidney transplantation. These problems fall into three categories:

1. donor identification and referral
2. donor co-ordination
3. organ retrieval.

Whilst problems remain, the tremendous dedication and high quality service that is provided by many individuals must be acknowledged – but it has to be recognised that this is often provided despite, rather than as a result of, current arrangements.

Donor identification and referral

2.8 All patients who are potential organ donors are in hospital under the care of clinicians whose primary objectives and responsibilities are to provide the best possible treatment, in the best interests of the patient, in the hope or expectation that the patient will survive. The change of emphasis to possible organ donation can only occur when death of the patient is to be confirmed following clearly defined tests of the brain stem, in which case Donation after Brain Death (DBD) may be possible, or when a decision has been taken – again in the best interests of the patient – that no further treatment options are available or appropriate and active treatment should be withdrawn, in which case Donation after Cardiac Death (DCD) may be possible once death has been certified following cardio-respiratory arrest. That change of emphasis can only occur when critical care staff have complete confidence in the means by which death is certified, and a clear framework that ensures that there is – and is seen to be – no conflict of interests and that their actions are clearly lawful. However, it should be emphasised that the diagnosis of death following tests of the brain stem is recognised as good practice for all appropriate patients – regardless of their suitability as a potential organ donor.

2.9 When these conditions are satisfied, there has to be an acceptance by all staff responsible for the care of potential donors that organ donation is a normal part of end-of-life care and that the option of donation must be explored in all suitable circumstances. Thus the early (and appropriate) identification of potential donors, and their referral to the donor co-ordinator network, should be the norm. It should also be the norm that the wishes of the individual concerning donation are established (most reliably by checking whether the individual has registered on the NHS Organ Donor Register), and an approach be made to the donor's family by an individual with all the necessary training and skills.

Donor co-ordination

2.10 The first donor transplant co-ordinators (DTCs) were appointed by renal transplant units in the late 1970s, and over the 20 years that followed there was a steady increase in the number of co-ordinators. As liver and heart and lung transplantation developed, these units also began to employ co-ordinators. However, there was no structured approach to co-ordination in many areas of the country. Many individuals combined the role of recipient co-ordinator (ie having responsibility for individual potential or actual recipients within the transplant unit) with the DTC role, and therefore the focus on improving organ donation and providing the necessary support to hospitals in the local area was potentially diluted.

2.11 Working practices of DTCs are considered unsustainable. Typically over a 12–18 hour period, a DTC is called to a hospital; assesses the suitability of a patient; is involved in approaches to the family and the gathering of information about the donor that leads to the offering and allocation process; arranges surgical teams to come in from the transplant units; offers advice, where required, in the physiological and haemodynamic management of the patient, ie the vital signs such as pulse and blood pressure; attends the organ removal procedure; and arranges the last offices. Some of these steps need to be carried out simultaneously and it is not possible for one individual to do them all well. Moreover, a co-ordinator may frequently work continuously for over 24 hours as a result of the current arrangements.

Organ retrieval

2.12 As with co-ordinators, organ retrieval arrangements have evolved and developed over many years. During the 1960s and early 1970s there were an increasing number of kidney transplant units, and each unit retrieved kidneys from donors in local hospitals. As liver transplantation developed in the 1970s and early 1980s, and heart and lung transplantation subsequently, the arrangements for retrieval of these organs became the responsibility of the individual transplant centres. For many years there was little in the way of integration – at each multi-organ donation the local kidney team would be present together with a team from one of the liver

units and a third team from a cardiothoracic transplant unit. The situation became absurd – a liver team from London could be in Yorkshire at the same time as a team from Leeds was in Kent.

2.13 During the 1990s, liver and cardiothoracic retrieval was reorganised, and each centre now has primary responsibility for retrieval from organ donors within a defined geographical zone, although there are still occasions when teams travel to other zones for organ retrieval. Further rationalisation has led to the situation where the liver teams usually, but not invariably, remove the kidneys, with the local renal transplant unit no longer providing a retrieval team.

2.14 However, two recent developments have – to some extent – taken things backwards. DCD has developed during the past eight to ten years as a result of improved surgical and organ preservation techniques. Initially, such donors almost exclusively donated only the kidneys, and responsibility for retrieval therefore reverted to the local renal transplant units. Within the last two years all liver teams have started to retrieve and transplant livers from donors after cardiac death and history is repeating itself. Some of these donors are suitable for both liver and kidney donation and the zonal liver teams provide the service. Other donors are kidney-only donors, and so kidney retrieval teams provide the service.

2.15 Kidney-pancreas transplantation has grown remarkably since 2004, when it gained recognition from the former National Specialised Commissioning Advisory Group (NSCAG) as a national service. Indeed, retrieval of the pancreas is the only aspect of organ retrieval for which specific funding is identified by NSCAG's successor organisation, the National Commissioning Group. However, the expertise required to perform pancreas retrieval is not available in all liver-based retrieval teams and so once again another team from another unit may attend the retrieval operation.

2.16 The only concerted attempt to streamline organ retrieval has taken place in Scotland. A single, multi-organ Scottish Organ Retrieval Team (SORT) was established, and was funded for a year (2004/5). In addition to reducing the number of surgeons from different teams that attended the retrieval operation, SORT included a consultant anaesthetist who was able to travel

to the donor hospital at an early stage to optimise donor care. The anaesthetist was able to ensure that, in particular, the function of the donor's heart and lungs was assessed and improved. Evaluations of the one-year SORT pilot were favourable, on both clinical and cost-effectiveness grounds.

2.17 The Taskforce offers a critically important opportunity to review progress in the light of these clearly identified, widely accepted deficiencies in current practice and to provide constructive recommendations in the light of recent policy and legal developments. It is based on a thorough review of existing information and knowledge in the UK, builds on a detailed assessment of progress in other countries and takes as its starting point the principle that the whole NHS must play a part. It has been a 'systems failure' that has led to the current situation rather than failings on the part of the many people working in all areas of the NHS who are dedicated to making improvements. None of them can achieve their maximum impact working in isolation, but – if provided with the necessary structure and support within which to contribute – very real progress can and will be made.

2.18 The national Potential Donor Audit (PDA) started by UKT in 2003 is providing a detailed and ongoing picture of the various practical steps that lead to organ donation. The PDA is currently being revised to give more accurate information about some of the steps, including the identification of potential donors, referral to the co-ordinator network, the approach to obtaining consent for donation, the consent rate (and factors that influence it) and organ retrieval.

2.19 However, the focus on organ donation needs to extend beyond the traditional hospital areas – intensive care units – where donation is considered. Other hospital areas where critically ill patients are cared for – emergency medicine, high dependency units and others – have a role. Refocusing should begin with recognition by all acute Trusts of the role that they can play, and their responsibility to do so.

2.20 The current consent rate for donation (the proportion of potential donors whose relatives agree to organ donation) – approximately 60% – means that 40% of transplantable organs are not donated because no consent has been given. Therefore the public as well as the NHS have a major role to play.

2.21 Organ donation can only be appropriate and successful within a secure and accepted legal, ethical and professional framework. It must be recognised that, despite clinical guidelines, there remain uncertainties and debate about what is and is not acceptable or appropriate, and whilst the Taskforce has sought further advice and clarification from the GMC and the BMA, legal advice should be taken and, if necessary, a legal opinion obtained. The Human Tissue Act (2004) and the Human Tissue Authority's Codes of Practice set out clearly many of the processes involved in organ donation but it is essential that outstanding issues are resolved.

3. The approach of the Taskforce

3.1 The Taskforce started with a review of current donation and transplant activity in the UK and the trends over the past ten years, using UK Transplant (UKT) data. Data from Europe, the USA, Australasia and South America was also available. The need to increase the donation rate, and the very low ranking of the UK in the international comparison 'league tables', were immediately apparent (see the Figures on the following page).

3.2 A systematic review of all relevant reports and reviews since 1997 was undertaken. It was clear from the outset that the production of realistic and practical recommendations was essential, that these would build on much of the earlier work, and that successful implementation of the recommendations would be of paramount importance.

3.3 In addition to topics discussed at Taskforce meetings, a number of work streams were commissioned on behalf of the Taskforce. These included:

- an analysis of the donation and transplantation pathway;
- the health economic case for increased donation and transplantation;
- the possible impact of future demographic and epidemiological changes within the UK on the need for transplantation;
- the impact of an increased kidney transplant rate on future demand for dialysis (currently predicted by the Department of Health to grow by 6–8% per annum);
- the most appropriate way in which the need to increase organ donation could be brought to the attention of Strategic Health Authorities, Trusts and others;
- the ethical issues surrounding donation;
- the problems and difficulties in organ donation for people from black and minority ethnic communities.

The detailed reports on these work streams are published as a supplement to this report.

Figure 1: Number of deceased donors and transplants in the UK, 1 April 1997–31 March 2007, and patients on the active transplant lists at 31 March (of each year)

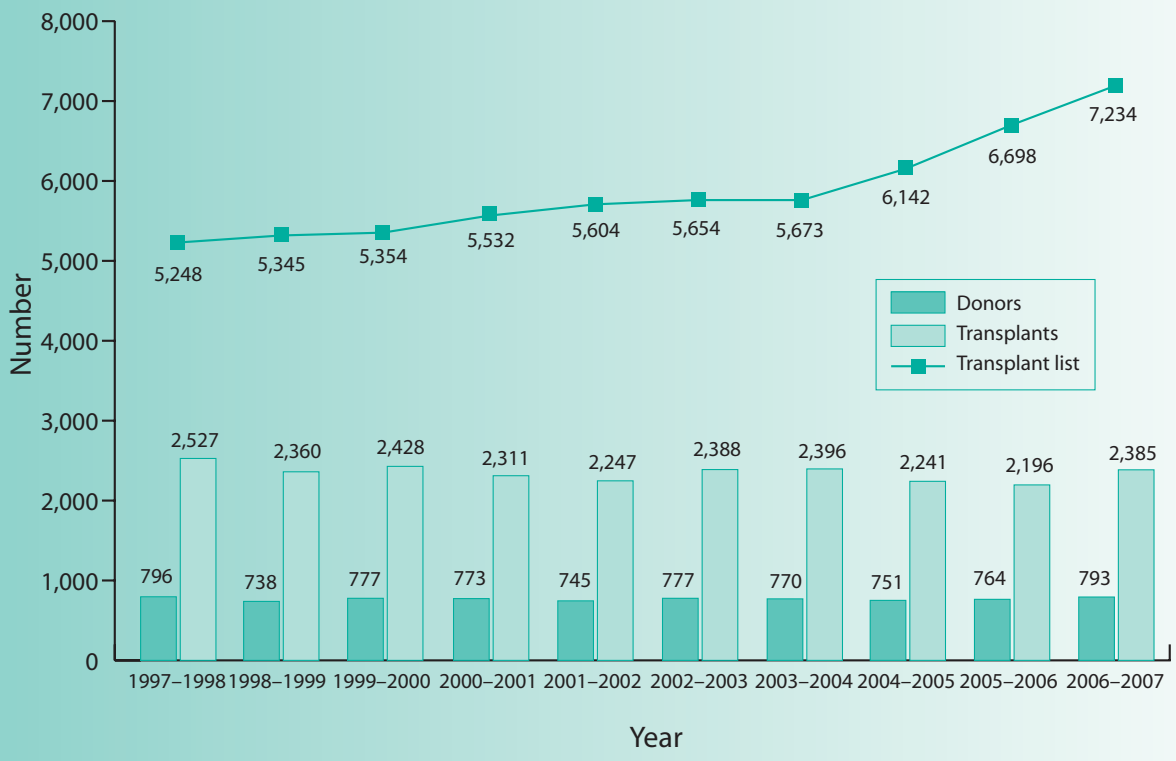


Figure 2: Deceased organ donor rates for Europe and the USA, 2006

3.4 Additionally and simultaneously the British Transplantation Society established a working party to build on earlier work identifying the necessary structure for robust organ retrieval arrangements.

3.5 The second meeting of the Taskforce was of particular importance. It was attended by the then Minister for Health Rosie Winterton MP, and was devoted primarily to two topics.

3.6 The first was the experiences of other countries that have introduced successful programmes to increase donation. By far the most dramatic and sustained achievements over many years have been made in Spain, and Dr Raphael Matesanz, the architect of the 'Spanish model', presented a comprehensive overview of its introduction and the lessons learnt over the last 15 years. The Spanish model has been introduced more recently into northern Italy and several South American countries, with similar encouraging results. Dr Frank Delmonico from the USA described the crucial support and impetus given by the Secretary of Health Tommy Thompson in 2003, that led to the introduction of Organ Donation Breakthrough Collaboratives. These have been associated with significantly increased conversion rates (the proportion of potential donors that become actual donors), which is considered to be one of the most appropriate comparative measures of donation success. The number of potential donors will vary from country to country depending on the road traffic mortality rates, the incidence of fatal cerebral trauma of all causes, the availability of intensive care facilities and other factors.

3.7 Improvements in deceased organ donation rates have been seen within a year of the implementation of these programmes in the USA and South American countries, but the full effects are felt over a longer time period – five years or more. The conclusions from these two presentations are presented in the rationale for the individual recommendations that follow in Section 4, and a more detailed description will be found in the supplement.

3.8 The second topic discussed at the meeting concerned legal and ethical concerns. These were eloquently expressed by clinicians responsible for the care of patients who had the potential to become organ donors. They focused principally on the steps that could be taken to facilitate donation after death, particularly donation after cardiac death, and on the potential for an actual or perceived conflict of interests, together with concern about the ambiguity of the law relating to some of the procedures that are involved.

3.9 Subsequent meetings of the Taskforce continued to review the issues outlined above, and included a brief presentation from Dr Jeremy Chapman, who is currently chair of an organ and tissue taskforce established by the Australian government.

4. Recommendations – rationale and detail

4.1 The recommendations cover five broad aspects of donation, based on one overriding principle – that there should be a UK-wide Organ Donation Organisation.

4.2 The five aspects are:

i. legal and ethical issues;

ii. the role of the NHS;

iii. organisational aspects of co-ordination and retrieval;

iv. training;

v. public recognition of donors and their families and public promotion of donation.

4.3 Each recommendation is presented below, followed by further details of the background and the rationale that led the Taskforce to its conclusions.

A UK-wide Organ Donation Organisation

Recommendation 1

A UK-wide Organ Donation Organisation should be established.

Recommendation 2

The establishment of the Organ Donation Organisation should be the responsibility of NHS Blood and Transplant.

4.4 There have been many reviews and recommendations concerning co-ordinators and the need for a more national structure has long been recognised. The quinquennial review of the United Kingdom Transplant Support Service Authority in 1999 recognised this but did not recommend national employment of co-ordinators, opting instead to give the new UK Transplant (UKT) responsibility for professional leadership of

co-ordination whilst leaving employment and managerial responsibilities at a more local level. Whilst significant progress has been made in some areas – most specifically in the increasing separation of the recipient and donor aspects of the posts – the service remains vulnerable to local pressures and has recently come close to collapse in several areas of the UK. The reasons for this have included threats to funding, inconsistent Agenda for Change outcomes and, most importantly, the fact that no one organisation has had the managerial responsibility and authority to respond to concerns about the weaknesses of the service.

4.5 In terms of organ donation, all acute Trusts serve the interests of all patients in the country who need a transplant. Organ donation is a 'local' activity, but transplantation can only be successful on a UK-wide basis. Quite literally, patients may be dying in one area of the country as a result of local failings in another part of the country. Because the local availability of the right organ at the right time can never be relied upon to meet the needs of local patients, transplantation can only function in a satisfactory and successful way as a UK-wide integrated service. It is this that leads the Taskforce to its recommendations about co-ordinators, while recognising that they go against the general policy of moving resources and decision-making closer to the communities that local hospitals serve.

4.6 For this reason, and although the Taskforce was established by the Department of Health in London, representatives of the devolved health administrations were in attendance from a very early stage, and the Taskforce strongly urges that its recommendations should be implemented throughout the UK in an integrated fashion. This process must have due regard to devolved autonomy and the different structures and systems in place in both the NHS and the health administrations in Scotland, Wales and Northern Ireland. Where terms are used in this report that relate primarily or exclusively to England, there are almost invariably equivalent organisations within the devolved administrations that could carry out the same, or very similar, functions.

Legal and ethical issues

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.

4.7 Modern medical ethics places a high premium on individual consent, and the importance of consent in the context of organ donation should not be underestimated. Any process by which people register their willingness to donate must be judged in terms of whether that process allows individuals to make a valid and ethically defensible statement of consent. Furthermore, any move away from a system relying on expressed consent must be shown to be a justifiable exception to the current ethical norms.

4.8 Amongst clinicians there is a certain amount of concern that the carrying of a donor card, or even registration with the donor register, falls short of what would usually be defined as consent in a medical setting. Furthermore, in the absence of independent evidence of a persisting wish, the passage of time between registration and death is seen by some to weaken the ethical force of the action. These concerns cannot be ignored, and when seeking to increase the number of registered donors agencies must ensure that sufficient and appropriate information is provided to be sure that consent is valid and robust.

4.9 In the case of post-mortem donation, a person only becomes a potential organ donor having first become a patient, albeit for a short time in some cases. This fact is ethically and legally significant. Death marks the transition from patient to donor, and donation will only commence after death is confirmed following clearly defined tests of the brain stem, or when cardiac death has irrefutably occurred.

4.10 Certain basic legal and ethical requirements hold in all cases. For example, if the death of the patient follows on from the withdrawal of life-sustaining treatment, the decision to withdraw must be made purely in the interests of the patient, without reference to their potential donor status. Similarly, if a decision is made to withhold treatment from the patient, it must be justified in terms of the interests of the patient. When withdrawing or withholding treatment, clinicians must be confident that their decision relates to the futility of that treatment and/or the known wishes of the patient not to be treated by certain means.

4.11 Having made a decision to withdraw treatment from a patient who is known to be a potential donor, one faces the ethical question of whether it is morally acceptable to manage the process of treatment withdrawal (as opposed to the decision to withdraw) and the death of the patient in the interests of ensuring the best possible retrieval of the organ or organs. Similarly, in the case of non-heartbeating donors one could ask whether it is justified to carry out tests and procedures prior to death, in the interests of avoiding deterioration of the organ or organs. These are difficult ethical questions which genuinely trouble staff working with this group of patients.

4.12 **If** we take registration as a donor to be a valid instance of consent, and further interpret it as a clear statement of an important wish on the part of the patient, we might argue that anything we do to facilitate the patient having that wish fulfilled is in his or her best interests. However, if we are unclear about the value of the consent, or where no wishes have been stated, we would have to concede that some of the actions taken to facilitate donation may not necessarily be in the interests of the donor.

4.13 Thus, once a decision has been made to withdraw or withhold treatment, or once death is seen as inevitable within a short space of time, the question arises as to whether or not it is justified to treat the patient as a potential donor. This change of emphasis must be recognised as extremely challenging and potentially problematic for staff and a sensitive issue to communicate to families. Furthermore, in the case of potential non-heartbeating donors, there is a lack of legal clarity around how, if at all, a patient close to death can be treated differently in order to facilitate donation, particularly if their wishes to donate are not expressly recorded.

4.14 Staff will only be reassured that it is possible to treat potential donors in a manner that is not clearly in their medically defined best interests if there is a clarification of the legal situation. However, it is important to acknowledge that some clinicians will still feel a moral tension arising from what they believe to be a mismatch between what is in the patient's best interests and what they know to be necessary to facilitate donation.

4.15 Given the complexity of the ethico-legal issues involved and the genuine concerns expressed by clinicians, the Taskforce believes that steps should be taken to engage with relevant clinicians on an ongoing basis, and where appropriate to facilitate opportunities for cross-speciality discussion of ethical issues.

4.16 Donation after brain stem death (BSD) is supported by, and takes place within, very clear professional guidelines – principally the statements of the Academy of Royal Medical Colleges on the diagnosis of death, the most recent revision of which is due for publication as this report is being prepared. This document defines the steps that must be taken to establish destruction of the brain stem in all circumstances, regardless of organ donation, and allows organ donation after death to take place within a well-established framework. Professional clinical guidelines on organ donation from intensive care have been published by the Intensive Care Society (ICS) and are also to be updated in 2008. There has not until recently been a detailed description of the diagnosis of death after cardio-respiratory arrest, although it is understood that the Academy of Royal Medical Colleges' revised report will address this issue, and it is also covered in the ICS guidelines referenced above.

4.17 The Human Tissue Acts of 2004 (and 2006 in Scotland), together with the Codes of Practice of the Human Tissue Authority (HTA), set out the legal framework under which donation must occur, but inevitably there are details of practice where the Acts and Codes of Practice cannot cover every possible scenario. However, it should be noted that the spirit of the legislation is to allow organ donation to occur if at all possible.

4.18 Discussions with the British Medical Association and the General Medical Council confirmed their views that brain stem testing of all appropriate patients, whether they are potential organ donors or not, should be

normal practice as it is in the patient's best interests. Continued treatment of a patient whose brain stem is dead is not in the patient's best interests.

4.19 There is currently no single authoritative forum in which the ethical issues surrounding organ donation and transplantation can be discussed and which can provide resolution of difficult issues for clinical staff. It is recommended that an independent Donation Ethics Group should be established with a wide membership.

The role of the NHS

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.

4.20 The Taskforce recognises that, for many of the 250–300 acute Trusts from which organ donors may be referred, donation is an infrequent event. However, data from the Potential Donor Audit (PDA) suggests that a significant number of patients for whom BSD is a possible diagnosis do not undergo formal tests of brain stem function. It is not known why this is the case, whether indeed brain stem tests were appropriate for these patients, or whether they would have met the criteria had they been tested. However, there is a prima facie case that BSD tests are not undertaken in all suitable situations. The PDA also shows that for 15% of patients certified dead after BSD testing – ie 15% of current potential donors after BSD – there is no record of a discussion with the family concerning organ donation. There are occasions in some Trusts where donation could be an afterthought or an optional extra. The Taskforce strongly recommends that organ donation should become usual, rather than unusual – ie a standard part of end-of-life care for suitable patients.

4.21 The NHS Organ Donor Register should be accessed routinely as nearly 25% of the population have now registered their wish to donate organs

after their death. If the patient is registered, their wishes are paramount (and now enshrined in law) and should be respected whenever possible. If the patient is not registered, the opportunity to donate should be discussed with the family. National policy – the HTA Codes of Practice and the ICS guidelines on organ donation from intensive care – should be used to develop and implement local protocols which can be agreed with the Trust donation committee.

4.22 Whilst much of the focus has been on intensive care units (ICUs), such protocols should also be in place wherever potential organ donors may be treated – including emergency medicine, high dependency units and other areas.

4.23 International experience – particularly of the Spanish model – has demonstrated the value of the formal appointment of clinical 'champions' – typically consultant-level clinicians – and it is recommended that such appointments should be made in every acute Trust that treats potential donors. Clinical champions should be employed for 4–12 hours per week, depending on the size and donor potential of the Trust, and will be responsible for developing and implementing local policies to maximise donation, ensuring that all appropriate staff receive necessary training, and reporting donation activity to the Trust donation committee (see below). Every acute Trust should establish a donation committee, chaired by a non-clinical donation champion who could be a patient, and accountable to the Trust Board through the clinical governance arrangements. The Trust's chief executive and medical director should be responsible for the Trust's donation performance.

4.24 As part of that implementation, the Taskforce further recommends that each Strategic Health Authority (SHA) or equivalent authority should hold a formal, preliminary meeting of those who may be involved in donation. This would include critical care staff, Trust or health board chief executives and medical directors, transplant teams, co-ordinators and commissioners (both local and national). The objective of the meeting would be to identify the current situation and the desired end-point in the region, along with the obstacles and, most importantly, the solutions to reaching that end-point. Such meetings should develop local action plans and should be repeated at a minimum on an annual basis.

Recommendation 5

Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis. These criteria should be reviewed after 12 months in the light of evidence of their effect, and the comparative impact of more detailed criteria should also be assessed.

Recommendation 6

Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent to donation should be reported. The Trust donation committee should report to the Trust Board through the clinical governance process and the medical director, and the reports should be part of the assessment of Trusts through the relevant healthcare regulator. Benchmark data from other Trusts should be made available for comparison.

Recommendation 7

BSD testing should be carried out in all patients where BSD is a likely diagnosis, even if organ donation is an unlikely outcome.

4.25 The Taskforce was particularly impressed with the various oversight systems that have been introduced in a number of other countries, in particular in the USA, and with their effectiveness.

4.26 As mentioned above, it is not appropriate simply to monitor the number of organ donors, or to expect an automatic increase in donor numbers in response to any particular changes. An additional and important measure is the conversion rate of potential to actual donors. Each stage of the process that leads to organ donation is amenable to measurement. The first stage is the performance of brain stem tests in all appropriate patients – not just because they may become organ donors, but because the professional guidelines emphasise that this is the best way to care for such patients.

4.27 It is also felt that all patients whose condition is such that it should normally lead to BSD testing, and also those whose active treatment is to be withdrawn, should be notified to the donor transplant co-ordinator (DTC) network; that the wishes of all such patients concerning donation should be identified where known (by consulting the NHS Organ Donor Register); and that if their wishes are not known their family or next-of-kin should be approached in line with the HTA Codes of Practice. The consent rate for donation should also be monitored.

4.28 The Taskforce discussed at length whether clear and specific clinical criteria could be developed that would identify, with the necessary specificity and sensitivity, all patients in whom the diagnosis of death by neurological tests was appropriate. In other words, whilst the timely identification of all potential organ donors is a key feature of successful organ donation programmes it was recognised that the acceptability of such criteria is dependent on notification only of patients whose death was felt to be inevitable.

4.29 The Donation Advisory Group of UKT was asked to develop a model that would guarantee comprehensive potential donor identification in UK ICUs, in consultation with the ICS. The group produced two proposals, which were endorsed by the Taskforce:

> 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.

> 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 cardiac death might be contra-indicated or inappropriate.

4.30 The group discussed in detail the incorporation of a clinical 'trigger' but concluded that **at this stage** this was not appropriate. It was also recognised that for many intensive care clinicians the agreed proposals recommended in paragraph 4.29 represent a substantial change in practice.

4.31 The Taskforce endorsed the group's proposals as an acceptable but minimum description of what is necessary. They should be implemented in full in all acute Trusts.

4.32 The Taskforce also believes that where clinicians in individual Trusts can agree more specific and detailed notification criteria they should be encouraged to introduce them. It is essential to monitor the impact both of the agreed basic notification criteria and of alternative, more detailed approaches. This should be done as a research-based project with the aim of assessing the effectiveness and clinical feasibility and acceptability of more detailed criteria. Within one to three years evidence should be available that may support more detailed criteria, if necessary, that could be recommended and accepted on a national basis. For example, the Taskforce heard a presentation on an agreed protocol that has recently been introduced in Birmingham, with clearly defined clinical criteria for the notification of possible organ donors. This could serve as a model for wider use as a comparison with the agreed basic criteria.

4.33 Taken together these measures identify the number of potential donors and the proportion that become actual donors. They will also identify the points in the process which stall conversion and which hinder potential donation. Most of this data is currently collected through the PDA and imminent changes to the data set will improve the validity of the data. Further resources will be required to establish a secure and effective web-based updated version of the PDA.

4.34 This data, and the comparative data from other Trusts, should be reported to, and reviewed by, the Trust donation committee and the Trust Board. It should be incorporated into the health regulator's standards and be part of each Trust's assessment. The information should be placed in the public domain through Trusts' annual clinical governance reports. Each SHA should have a designated accountable officer responsible for oversight of these processes and for identifying and resolving any issues of concern.

4.35 Extra resources will be required by Trusts in order to achieve the measures set out in Recommendations 4, 5 and 6 and it is proposed that these are provided through the revised co-ordinator arrangements set out below.

Recommendation 8

Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.

4.36 The funding mechanisms throughout the NHS are evolving and there is a need to bring the funding of donation into line with these changes. Financial incentives for organ donation are felt by the Taskforce to be unacceptable but the removal of financial disincentives is necessary. The introduction of national tariffs and Payment by Results (in England) provides a suitable mechanism through which the additional costs to the donor hospital of all aspects of donor management could be funded. Such payment should be provided for all potential donors who are referred, regardless of whether donation occurs, as additional costs are incurred whether organ retrieval occurs or not. This is particularly true in the case of potential donors after cardiac death, since some such patients die after an extended period of low blood pressure that means their organs are no longer suitable for donation and transplantation.

Organisational aspects of co-ordination and retrieval

Recommendation 9

The current network of DTCs should be expanded and strengthened through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded within critical care areas, should be employed to ensure a comprehensive, highly skilled, specialised and robust service. There should be a close and defined collaboration between DTCs, clinical staff and Trust donation champions. Electronic on-line donor registration and organ offering systems should be developed.

4.37 The current co-ordination system in the UK has developed in an ad hoc and unsystematic way over many years, although there have been attempts more recently to provide a more integrated system. At present there are approximately 100 DTCs in the UK, working in 18 teams, and the majority of DTCs are employed within Trusts – typically those with a transplant unit. There are two teams with different employment arrangements – those in North Thames and South Thames. The details of the employment arrangements, grades and line management of the 18 teams vary and governance arrangements are inconsistent or undefined. Professional, although not managerial, leadership for DTCs is provided through the five regional managers employed directly through UKT, who in turn report to the UKT Director of Donor Care and Co-ordination. In addition, there are currently 12 'in-house co-ordinator' posts funded by UKT with a further 10 to be established in 2007/8. These are fully trained DTCs employed in individual Trusts who are an integral part of the critical care teams but who also play a role in the DTC teams. Virtually all DTCs and in-house co-ordinators come from a nursing background, and it is recognised that in the future this may not always need to be the case, particularly as the different roles that are carried out become more clearly identified and potentially separate.

4.38 A number of reports in the UK have shown this system to be unsatisfactory and it contrasts unfavourably with the systematic co-ordinator network in Spain, that is seen as being fundamental to the success of the Spanish model. It is also increasingly unsustainable, being susceptible to local pressures such as cost savings and redeployment of nursing staff that threaten the integrity of the national network. Nor is the current working practice of DTCs sustainable. At present a DTC is called to the hospital at which the potential donor is being cared for. They assess the suitability of the donor, are typically (but not always) involved in the approach to the potential donor's family, and are then involved in the detailed process of obtaining all the relevant information about the donor that leads to the offering process and allocation of donated organs. Arrangements for an operating theatre for organ removal must be made, and a surgical team from the transplant unit must be arranged to travel to the donor hospital. The physiological and haemodynamic (vital signs) condition of the donor may call for intervention. Finally, the DTC attends the organ removal procedure, continuing to ensure that all necessary arrangements for organ allocation and transplantation are in place, and ultimately carries out the last offices and ensures that any specific requests of the donor family are met. This entire process typically lasts 12–18 hours and can on occasions take longer. As a result it is not uncommon for a DTC to work continuously for periods in excess of 24 hours. It is not acceptable for one individual to undertake this entire process. Indeed, it is not possible for any one individual to devote adequate attention to each of the stages mentioned above – several of which may be happening simultaneously.

4.39 A working party of the Taskforce reviewed the current working practices and the requirements to provide the necessary service in the optimum fashion. From this review, and in line with practice elsewhere (most impressively in the USA) it became clear that there are in fact three distinct roles that need to be fulfilled when a potential donor is identified, and there was clear evidence that each role could be achieved in different and better ways than at present. These roles are:

- the approach to, and assent process with, the potential donor's family, together with support of the family. The assent process requires expertise and time. A complete understanding of the legal and ethical issues surrounding consent is needed, together with sufficient knowledge of donation and transplantation. Training in the approach to bereaved families and consent for donation is essential. It is not appropriate for the individual involved in detailed, difficult and sensitive discussions with the donor's family to be simultaneously responsible for the donor registration and organ allocation process;
- the process of obtaining and recording all the clinical information required for the organs to be allocated, and liaison with UKT and individual transplant centres in order to achieve this. During this time it is also essential that the clinical management of the donor is optimised whilst the arrangements for organ retrieval are made. Co-ordination of this process requires a detailed understanding of the needs of UKT, the transplant units, the retrieval teams and donor management;
- the organ retrieval process itself and the last offices. This can take up to six hours or more, during which further organ allocation arrangements may be necessary, all the necessary documentation must be completed and transmitted to UKT and any final wishes of the donor's family must be respected.

4.40 As a consequence of this analysis the Taskforce recommends that there should be a UK-wide Organ Donation Organisation responsible for the employment, training and management of DTCs. The Organ Donation Organisation would have responsibility for the provision of a high-quality co-ordination service through a number of teams (approximately 12) to meet the needs of critical care units, donor families, donor hospitals and

retrieval teams. It is envisaged that up to three DTCs may attend a single organ donor – each with a specific area of responsibility and appropriate skills and training – in order to meet the requirements and fulfil the roles set out in 4.39.

4.41 In order to support all critical care teams on a day-to-day basis, the DTCs should all be made available to be embedded within a designated critical care team, managed by a team leader from a regional office. The Taskforce recommends that there should henceforth be a much closer working relationship between DTCs and local ICUs, and furthermore believes that such collaboration between embedded DTCs and Trust donation champions is key to the success of these recommendations.

Recommendation 10

A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high-quality organ removal from all heartbeating and non-heartbeating donors. The Organ Donation Organisation should be responsible for commissioning the retrieval teams and for audit and performance management.

4.42 Current organ retrieval arrangements are not sustainable in many areas of the country and are not able to support the required increase in donor numbers. Whilst the teams in the six designated English and one Scottish liver transplant units now perform the majority of liver and kidney removals, a number of renal units also play a role – predominately in kidney removal in the case of donation after cardiac death. The seven designated pancreas transplant centres in the UK are largely responsible for pancreas removal, although three of them are co-located with the liver units. Removal of cardiothoracic organs remains the responsibility of the six adult and two paediatric designated cardiothoracic transplant centres. The teams vary in size and composition, their funding is often obscure and their level of experience and expertise is variable. The smaller teams rely almost exclusively on consultant staff, and few of the teams are available specifically for organ retrieval – many team members have elective clinical commitments that restrict their ability to respond quickly. The teams all rely, to a greater or lesser extent, on significant

help from medical and nursing staff from the donor hospital. Changes to both junior and consultant contracts, and the effects of the European Working Time Directive, are all threatening the sustainability of the current service, and there are considerable concerns on grounds of clinical governance.

4.43 Finally, few teams are able to provide early, expert assistance in donor management to donor hospitals and this can adversely affect both the number and quality of organs that are removed. A donor may donate up to eight organs (including small bowel) but inadequate donor management will reduce the number of viable and transplantable organs.

4.44 It was recognised in 2003 that there was a need to review the arrangements for organ retrieval and to develop proposals that would strengthen existing services and help them develop into the service that is needed. Building on that earlier work, the British Transplantation Society (BTS) established a working party in 2006/7 whose detailed recommendations should be available in 2008. There has been regular contact between the Taskforce and the working party to ensure a consistent approach. The key principles that have led to the BTS recommendations are also the key principles identified by the Taskforce. They are that organ retrieval teams should be:

> virtually self-sufficient and not require anaesthetic, theatre or surgical staff from the donor hospital (other than the minimum needed for local liaison);

> available 24 hours a day, without elective commitments during their time on call for retrieval;

> able to respond appropriately if there is more than one donor in the same region on the same day;

> able to provide opportunities for training.

Training, education and continuing educational support

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.

4.45 Organ donation occurs infrequently in all but the largest ICUs and Trusts. Many critical care staff may go through their training without being involved in the care of a single potential organ donor. It is not surprising therefore that there is a lack of awareness of donation and of the criteria, procedures and practices of donor referral and donor management that are appropriate. The Taskforce was particularly interested to hear that in Australia organ donation is one of the mandatory components of critical care training. Not only is there a need for initial training in donation, there is also a need for regular refresher training and for the appropriate dissemination of updated regulatory requirements and professional advice and guidelines. An understanding of donation should start at undergraduate level and the Taskforce would strongly support schools of medicine, nursing and professions allied to medicine in the introduction of organ donation into their curricula. Steps such as these would reinforce the principle that donation should be the norm rather than the exception. The UK-wide Organ Donation Organisation could play a major role in ensuring that appropriate multidisciplinary training is commissioned and available, and could also ensure that training is available for all DTCs and Trust donation champions.

Public recognition and promotion of donation

Recommendation 12

Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. These approaches may include national memorials, local initiatives and personal follow-up to donor families.

4.46 Individuals vary in their wish for public recognition of a gift, and this may also be true as a generalisation of individuals from different cultural backgrounds. In the case of organ donation, some families may want to forget and to put the past behind them. Other families may shun public acknowledgement of donation but welcome recognition in the form of a personal letter, for example from the Chief Medical Officer. Others may gain comfort and satisfaction from a public memorial to donation in general, whilst there may also be families of organ donors who would welcome public recognition of the individual donor's action through a 'roll of honour' in a public place. The Taskforce considered options such as a memorial garden, an eternal flame and a web-based register. However, it felt that it did not have the evidence or expertise to make specific detailed recommendations, although it felt strongly that appropriate recognition of donation should be established and provided.

Recommendation 13

There is an urgent requirement to identify and implement the most effective methods through which organ donation and the 'gift of life' can be promoted to the general public, and specifically to the BME population. Research should be commissioned through Department of Health research and development funding.

4.47 Much work has been done to promote organ donation to the general public. The NHS Organ Donor Register currently includes nearly 15 million names, representing nearly 25% of the public who have registered their wish to donate organs after their death. Approximately one million

names have been added to the register in the last year. Much information is available to inform public campaigns and it is encouraging that over 90% of the public are, in principle, in favour of organ donation.

4.48 People of Asian or African-Caribbean descent are three to four times more likely to develop end-stage renal failure and need a kidney transplant. Biological differences between ethnic groups – the frequency of different blood groups, the frequency of Human Leucocyte Antigens (the 'tissue type' of an individual), and the particular combinations of HLA antigens found in different ethnic communities – result in difficulties in identifying suitable organs (mainly kidneys) for patients from Asian and African-Caribbean backgrounds. Recent UKT data has shown dramatic differences in the proportion of such patients on the UK kidney transplant waiting list (23%) and those who actually receive a kidney (13%). Another measure of the problem is the waiting time to kidney transplantation – a median of 719 days for white patients, 1,368 days for Asian patients and 1,419 days for black patients. Organ donation from these communities is low, and whilst there is an increasing body of research into the reasons for this, much further work remains to be done. In 2003/4 only 3% of deceased organ donors came from black and minority ethnic (BME) communities, who in the 2001 census made up 8% of the UK population. Campaigns to promote organ donation amongst the black and South Asian communities have been ongoing for a number of years, and there is a need to develop a more detailed understanding of the barriers to donation within BME communities and the most effective ways to overcome them.

4.49 It is still the case that nationally, the relatives of 40% of potential donors refuse consent for donation (75% in the case of potential donors from a BME background). The refusal rate in Spain has for many years been less than 20%, and steps to achieve a similar refusal rate in the UK are essential. These should include better training and more time for those involved in requesting assent to organ donation, and may be informed by the results of the ACRE study – a current randomised trial of 'collaborative requesting' (which involves both an intensive care clinician and a DTC).

4.50 The Taskforce realises that much more work is needed to identify the most appropriate and successful methods of promoting awareness and understanding of donation, of identifying the different reasons for non-donation, and most importantly of understanding how best to encourage consent for donation from all sections of the community, particularly from the BME population.

The role of the coroner

Recommendation 14

The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.

4.51 The coroner (or in Scotland the procurator fiscal) may refuse permission for organ removal in a variety of circumstances, principally those in which a post-mortem examination is required to establish the cause of death. This will be most clearly the case if the death is not natural and if criminal actions may be relevant. However, coroners vary widely in their interpretation of this requirement, with some willing to agree to donation in all but the most extreme circumstances, while others refuse donation more frequently. Some but not all coroners agree that their requirements can be met if an appropriate pathologist is present during organ removal. This variation in approach causes a degree of discontent to donor families, clinicians and co-ordinators out of all proportion to its frequency, but is clearly an issue that should be resolved.

5. The economic case for increased donation

5.1 To implement the recommendations of this Taskforce will undoubtedly require additional resources. Increased donation will save lives, and that alone could be seen as adequate justification. However, the Taskforce wished to explore the overall effect on the NHS of increased investment in organ donation and the consequent increase in organ transplants. The detailed analysis is presented in the Supplement Report, but a number of points should be made here.

5.2 Transplantation of the liver, heart or lung are of themselves expensive, albeit life-saving, treatments for which there is no alternative. There is limited data on which to base any estimate of cost savings that may follow transplantation of these organs. There is some evidence that the care of patients with life-threatening organ failure – eg liver failure – may involve many days or weeks of in-hospital care, including significant time in intensive care (which is very expensive), that would be avoided if transplantation had taken place.

5.3 The most obvious and significant economic benefits are shown by an analysis of the costs of renal replacement therapy – dialysis – compared with the costs of kidney transplantation. Current indicative costs suggest an average annual cost for dialysis of £23,177, compared with an initial cost of £42,025 for a transplant followed by annual maintenance costs of £6,500.

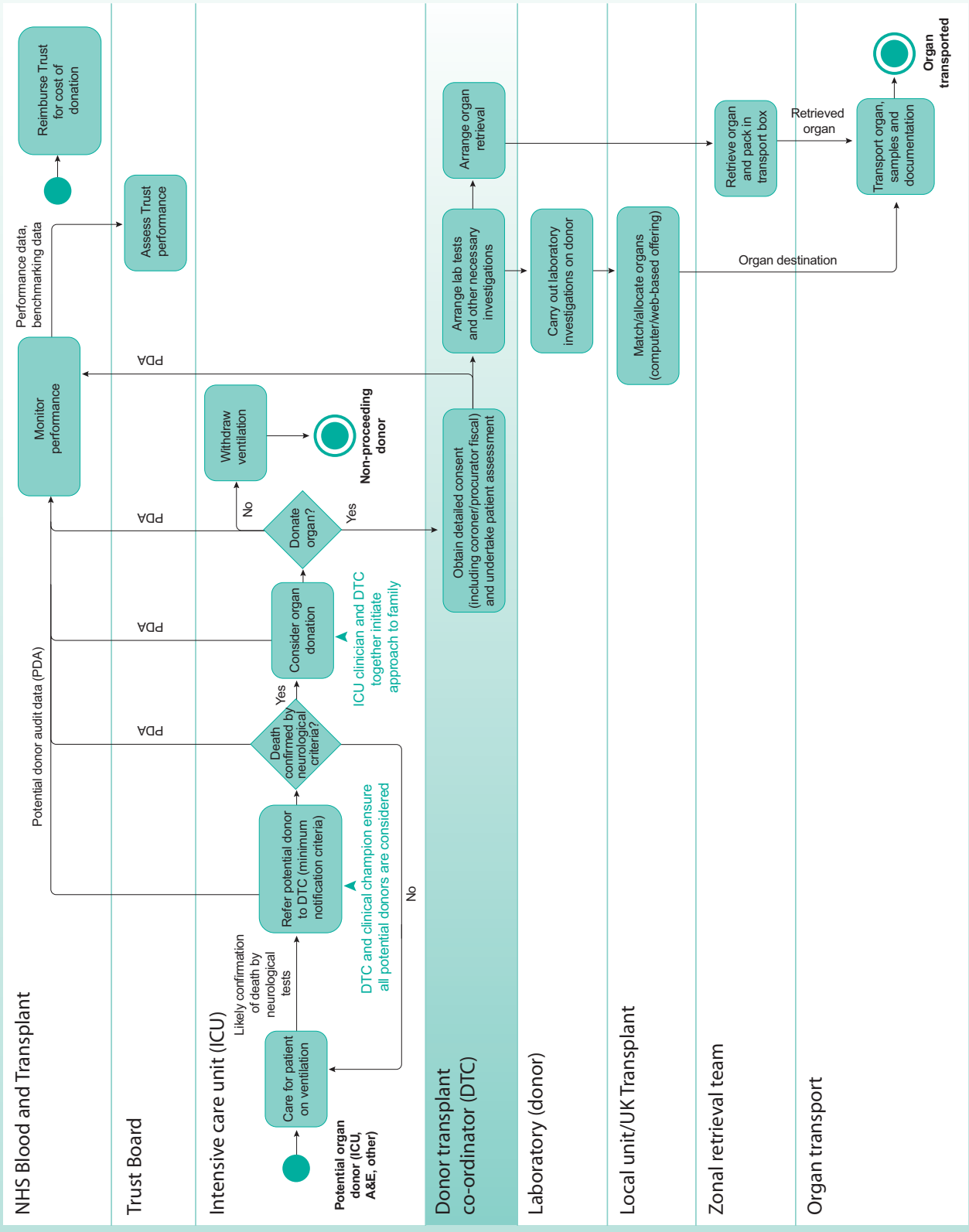
5.4 It is sometimes thought that this is a false argument – that no dialysis savings follow transplantation of an individual patient because another patient immediately fills their dialysis place. This is to misunderstand the situation. If patient A is receiving dialysis and patient B presents to the renal unit in need of dialysis, either a new dialysis place is established – requiring more machines, nurses, etc – or patient B dies. If, however, patient A receives a kidney transplant, patient B can receive dialysis at no extra (dialysis) cost. As maintenance costs for a transplant recipient are markedly lower than dialysis costs, transplantation can either be seen as allowing more patients to live without expanding dialysis capacity, or as treating the same number of patients with end-stage kidney failure more cheaply – in addition to providing a much better quality of life.

6. Conclusion

6.1 The 14 recommendations in this report, taken together, would create a structured and systematic approach to organ donation in the UK. The Taskforce believes their implementation would save the lives of at least 1,000 people each year and dramatically improve the quality of life for hundreds more, and for their families.

6.2 The three key fundamentals – donor identification and referral, donor co-ordination, and organ retrieval – need to be addressed in an integrated way. The changes proposed will ensure that donation is considered every time a possible organ donor dies; that the wishes of the potential donor or their family are ascertained and respected; and that every opportunity is taken to maximise the number of organs that can be transplanted successfully. Each recommendation has an important contribution to make in building the donation service that is so urgently needed.

Appendix 1: How donation is to be organised



Appendix 2: Terms of reference and membership of the Taskforce

Terms of Reference

To identify barriers to organ donation and transplantation and recommend solutions within existing operational and legal frameworks.

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

Members

Elisabeth Buggins CBE (Chair)	Non-Executive Director of NHS Blood and Transplant and Chair of West Midlands Strategic Health Authority
Helen Bevan	Director of Service Transformation, NHS Institute for Innovation and Improvement
Robert Bonser	Director of Thoracic Transplantation, Queen Elizabeth Hospital, Birmingham
Simon Bramhall	Consultant Liver Transplant and Hepato-pancreatic-Biliary Surgeon, Liver and Hepatobiliary Unit, Queen Elizabeth Hospital, Birmingham
Mark Britnell	Director General for Commissioning and System Management in the NHS, Department of Health
Robert Dunn	National Advocacy Officer, National Kidney Federation
Christine Elding	Donation Nurse Specialist, Brighton and Sussex University Hospitals NHS Trust
Bobbie Farsides	Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School
Michael and Kathryn Lewis	Donor family
Julie Moore	Chief Executive, University Hospital Birmingham NHS Foundation Trust
Karen Morgan	Donor Transplant Co-ordinator Regional Manager (South West)

Paul Murphy	Consultant Neurointensivist, Leeds General Infirmary
Vivienne Parry	Writer and broadcaster
Gurch Randhawa	Professor of Diversity in Public Health, University of Bedfordshire and Chairman of Luton Primary Care Trust
Martin Smith	Consultant in Neurointensive Care, National Hospital for Neurology and Neurosurgery, University College London Hospitals
Chris Watson	Consultant Liver, Kidney and Pancreas Transplant Surgeon, Addenbrooke's Hospital, Cambridge

In attendance

NHS Blood and Transplant/UK Transplant

Kathy Cardwell (Secretary), UKT

Sue Falvey, UKT

Martin Gorham, NHSBT

Terry Male, NHSBT

Chris Rudge, UKT

Rob Warwick, NHSBT

Department of Health

Edmund Jessop
(National Commissioning Group)

Gareth Jones

Neil Moors

Triona Norman

Hugh Whittall

Dan Wood
(Economic Operational Research)

Representatives from devolved administrations of Scotland, Wales and Northern Ireland

Jennifer Armstrong (Scotland)

Caroline Lewis (Wales)

Siobhan McKelvey (Northern Ireland)

Will Scott (Scotland)

Appendix 3: Glossary

ACRE
A research study in intensive care units designed to establish the most successful way to seek consent for organ donation from the relatives of potential organ donors.

Active transplant waiting list
The list of patients who are waiting for a transplant and who are in a suitable condition to have a transplant if a donated organ becomes available. At any one time some patients who need a transplant are temporarily 'suspended' from the active list for short periods as a result of other medical events.

Acute irreversible heart failure
Sudden and unexpected failure of the heart, often as a result of viral infection, which may lead to the death of the patient within days or weeks without a heart transplant.

Acute Trusts
The NHS bodies responsible for the management of hospitals that provide acute services to patients.

Agenda for Change
The system that grades most staff working within the NHS and establishes the pay-bands and terms and conditions applicable to each individual.

Brain stem death (BSD)
Death diagnosed and certified following neurological tests of brain stem function. The diagnosis of death can be made whilst the body of the person is attached to an artificial ventilator, and thus whilst the heart is still beating.

Brain stem
The critical part of the brain that is responsible for consciousness, breathing and other functions that are essential for life.

Brain stem tests
A series of clearly defined tests used to establish whether or not the brain stem still has any function.

British Medical Association
The professional association for doctors.

British Transplantation Society (BTS)
The professional society for clinicians, scientists, co-ordinators and others involved in transplantation.

Cardiac death
Death certified by a doctor after the heart has irreversibly ceased to beat.

Cardio-respiratory
Relating to the heartbeat and breathing.

Cardiothoracic
Relating to the heart and lungs.

Coroner
An independent legal officer whose responsibilities include, in certain circumstances, establishing how people came to their death.

Dialysis
The use of an artificial kidney machine or techniques to keep alive a patient whose kidneys have failed.

Donation Advisory Group
An advisory group of UK Transplant, with wide representation from critical care clinicians, nurses, and co-ordinators, that provides professional advice to UK Transplant.

Donation after brain stem death (DBD)
The donation of an organ or organs after death has been certified following tests confirming absence of brain stem function.

Donation after cardiac death (DCD)
The donation of an organ or organs after death has been certified following permanent cessation of the heartbeat.

Donor co-ordination
Donor transplant co-ordinators are the crucial link between staff caring for a potential donor and the transplant teams and organisations.

Donor hospital
Any hospital where a potential or actual organ donor is cared for.

Donor identification and referral
The recognition that someone who has died or is expected to die in hospital could potentially donate their organs, and the notification of this to the donor co-ordinator system.

Donor management
The process that ensures that the organs of a potential donor function as well as possible after death has been certified by brain stem tests, until organ removal takes place.

DonorNet
The online system of donor registration introduced in the USA in 2006.

Donor Transplant Co-ordinators (DTCs)
Specially trained clinical staff, usually from a nursing background, who play a crucial role in providing a link between critical care staff and the transplant organisations and units.

Epidemiological
Relating to diseases in the population, and the impact of changes within the population on the incidence of diseases.

Eurotransplant
An independent Foundation that is responsible for organ allocation in seven European countries – the Netherlands, Belgium, Luxembourg, Germany, Austria, Slovenia, and Croatia.

General Medical Council
The regulatory and disciplinary body responsible for ensuring that doctors work within the law and within accepted standards of clinical practice.

Healthcare Commission
The independent regulator and inspector of the provision of healthcare by the NHS.

Heartbeating donor
A donor whose organs are removed after death has been certified following neurological tests of the brain stem.

High-dependency unit
An area of a hospital that provides more complex treatment than can be given in a standard hospital ward, but less complex than full intensive care.

Histocompatibility and immunogenetics
The study of the Human Leucocyte Antigens system and its role in organ transplantation, also known as 'tissue-typing'. A necessary service to match organs and patients for many, but not all, organ transplants.

Human Leucocyte Antigens
The proteins on cell surfaces that define a person's 'tissue type'. They allow the body to recognise as 'foreign' an organ from another individual, and this may lead to the process of rejection of a transplanted organ unless drugs to modify the immune system are used.

Human Tissue Acts
The Human Tissue Act 2004 applies in England, Wales and Northern Ireland and the Human Tissue Act (Scotland) 2006 applies in Scotland. Both Acts came fully into force in September 2006. The Acts are very similar but not identical, and cover (amongst other issues) the removal, storage and use of organs from dead people for transplants.

Human Tissue Authority (HTA)
The regulatory authority established under the Human Tissue Acts that, amongst many functions, defines the consent process (authorisation in Scotland) required for organ donation.

In-house co-ordinators
Fully trained donor transplant co-ordinators who are based in single critical care teams with the role of promoting organ donation.

Intensive Care Society (ICS)
The professional body for critical care staff.

Intensive care unit (ICU)
A special unit within a hospital where the most complex care and life support for severely ill patients is provided.

Living donation
Donation of an organ or part of an organ for a transplant by a healthy volunteer – usually for someone with whom the donor has a close family or emotional relationship.

Mental Capacity Act 2005
The Act that describes, amongst many other things, what can and cannot be done to a person or patient who lacks the capacity to give consent themselves.

National Blood Service (NBS)
An operating division of NHSBT responsible for ensuring that there is a safe and secure supply of blood and most blood products for England and North Wales. It also has responsibility for some, but not all, tissue donation, banking and supply.

Neurological
Relating to the nervous system – specifically, in this report, to the functions of the brain stem.

NHS Blood and Transplant (NHSBT)
A Special Health Authority within the NHS, established in 2005, that incorporates both UK Transplant and the National Blood Service, together with Bio Products Laboratory.

Non-heartbeating donor
A donor whose organs are removed after death has been certified following cessation of breathing and the heartbeat (cardiac death).

Organ donation
The process of allowing organs (including kidneys, liver, heart, lungs and pancreas, and occasionally other organs) to be removed after death and used for transplants.

Organ Donation Breakthrough Collaboratives
The initiatives introduced in the USA since 2003 that bring together all parts of the healthcare system to promote organ donation.

Organ Donor Register
The NHS computer register of those who have recorded their wish to donate their organs and/or tissues after death.

Organ retrieval
The surgical removal after death, in an operating theatre, of organs for transplants.

Physiological
The normal way in which organs such as the heart, liver and kidneys function.

Potential Donor Audit (PDA)
A UK-wide audit of patients who die in intensive care units. It was established in 2003 and provides information about the number of potential organ donors and whether they became actual donors or not.

Procurator fiscal
The Crown Office and Procurator Fiscal Service (COPFS) is responsible for the prosecution of crime in Scotland, the investigation of sudden or suspicious deaths and complaints against the police.

Renal failure
The failure of kidney function, leading to death unless the patient receives dialysis or a kidney transplant.

Royal College of Anaesthetists
The professional college responsible for training and standards within anaesthesia.

Severe acute liver failure
Sudden and unexpected liver failure, often the result of a viral infection or drug toxicity, which may lead to the death of the patient within hours or days without a liver transplant.

Strategic Health Authorities (SHAs)
The 10 NHS authorities in England responsible for the overall healthcare provision for the population they serve.

Transplant
Replacement of a failed organ with an organ from a human donor.

Type 2 diabetes
A form of diabetes that is more common in older patients than Type 1 ('insulin-dependent') diabetes, and which can cause kidney failure.

UK Transplant
An operating division of NHS Blood and Transplant with responsibility for managing the transplant waiting lists, allocating organs for transplants, collecting all necessary information about donors and transplants and promoting organ donation.

285565 1p 0.35K Jan 08 (Asset)
Produced by COI for the Department of Health

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