

Taking Organ Transplantation to 2020

A detailed strategy



Acknowledgements

We are grateful to all those who contributed to the development of this strategy.

Our particular thanks go to the following groups and individuals, for their advice and support.

Within the UK

- British Transplantation Society
- College of Emergency Medicine
- Donor Family Network
- Faculty of Intensive Care Medicine
- Intensive Care Society
- Live Life Then Give Life
- National Black, Asian and Minority Ethnic Transplant Alliance
- National Kidney Federation
- Transplant 2013
- UK Donation Ethics Committee

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A collaborative UK strategy between



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Foreword

It is five years since the Organ Donation Taskforce published 'Organs for Transplants'¹, which set out a series of recommendations for increasing the UK organ donor rate and suggested that, if all the recommendations were implemented, then the deceased donor rates would increase by 50% by 2013.

The Taskforce report introduced a major programme of work to make sure that the right systems and support were in place to enable organ donation to become a more usual part of end-of-life care. We would like to thank the donor families, the NHS, and the professional organisations for rising to the Taskforce's challenge. Their support and commitment has led to dramatic improvements: by April 2013, there has been a 50% increase in the number of deceased donors and a 30.5% increase in transplants.

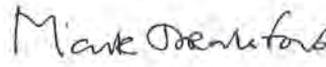
However, there is still more we can do. Currently there are over 7,000 people on the UK national transplant waiting list and, during the last financial year, over 1,300 people either died whilst on the waiting list or became too sick to receive a transplant. It is therefore vital that we continue to build on the current success and continue to make more progress.

In implementing the Taskforce report we learned much about what works well and where the obstacles remain. We have also spent the last year talking to our stakeholders about what more should be done to increase the transplant rate. We would like to thank the hundreds of people who provided their views on what steps should be taken.

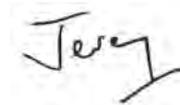
We have built on their knowledge and advice to develop a new strategy, which aims to enable the UK to match world-class performance in organ donation and transplantation.



Michael Matheson
Minister for Public Health



Mark Drakeford
Minister for Health and Social Services



Jeremy Hunt
Secretary of State for Health



Edwin Poots
Minister of the Department of Health,
Social Services and Public Safety



John Pattullo
Chair of NHS Blood and Transplant

¹ Organs for Transplants: a report from the Organ Donation Taskforce.

Section one

Summary

Five years of progress

The Organ Donation Taskforce published its report *Organs for Transplant* in January 2008, and made 14 specific recommendations that covered various aspects of donor identification and referral, donor coordination and organ retrieval. The five-year implementation programme for these recommendations, supported by all four health administrations, NHSBT and representatives of all relevant professional societies and Royal Colleges, has established a coherent UK-wide framework for deceased donation, and delivered the 50% increase in deceased organ donors called for when the Taskforce published its report. This achievement is a tribute to the commitment of healthcare professionals involved in the donation and transplantation pathway, but particularly to organ donors and their families.

These combined efforts have led to major changes in the infrastructure for organ donation in the UK, most notably the 250-strong centrally employed workforce of trained Specialist Nurses in Organ Donation (SN-ODs), a UK-wide network of Clinical Leads in Organ Donation (CLODs), and a National Organ Retrieval Service. The UK Donation Ethics Committee provides guidance to clinicians on ethical concerns regarding organ donation and the four UK Health Departments have clarified legal issues regarding donation. Twelve Regional Collaboratives have been established, which bring together intensive care consultants, SN-ODs, chairs of Donation Committees, retrieval surgeons and recipient co-ordinators to share innovative best practice and work out how to overcome local obstacles. The work to deliver change within the NHS is also supported by many in the voluntary sector and by faith leaders who have committed themselves to raising awareness and promoting organ donation and transplantation in the community.

These changes, together with other initiatives such as the NHSBT living kidney donor strategy, have further increased the transplant rate.

However, despite these improvements, there are still not enough donated organs to meet the current need. There are currently over 7,000 people on the transplant waiting list and, during the last financial year, over 1,300 people either died or became too sick to receive a transplant due to a shortage of available organs. With the changing population demographics, it is expected that the need for transplants will increase.

The increase in the number of donors since 2008 is almost entirely due to expansion of donation after circulatory death (DCD) programmes, not an improvement on family consent rates. Indeed, the UK continues to have one of the highest rates of family refusal in the Western world, with 43% of families declining permission for donation.

It must be clearly understood: the UK will never have a world-class donation and transplantation service if more than 4 out of every 10 families say no to donation.

This is a challenge for the whole of society, and represents our greatest opportunity to further increase donor rates.

A new strategy for the UK

NHSBT co-ordinated and oversaw a comprehensive stakeholder engagement exercise to seek advice on where the challenges remained and how to build on the current levels of success. A series of meetings and an online survey offered national and international experts in the field of organ donation and transplantation, donor families, transplant recipients, those on the transplant list, religious and community leaders and the general public the opportunity to give their views on what more needs to be done to increase the UK’s rates of solid organ transplantation.

The feedback from stakeholders highlighted the remaining challenges:

- The shift in making organ donation a usual part of NHS culture has not been mirrored in society as a whole, where 43% of families refuse to allow donation to go ahead, sometimes even overturning the recorded wishes of their loved one. Although this is particularly relevant for people from Black, Asian and Minority Ethnic (BAME) populations, who represent 27% of those on the waiting list but only 5% of organ donors, this applies to the whole of society. The biggest challenge in the UK is to increase the number of people from all parts of society who consent² to organ donation, either for themselves or on behalf of a loved one.

- Significant improvements have been made to end-of-life care practices to ensure that a patient’s wish to donate is met. However, opportunities for donation are still missed on some occasions.
- There is variation in practice within the medical community regarding the acceptance and transplantation of organs.

The Organ Donation Taskforce Report set out a series of recommendations that together provided the NHS with the necessary infrastructure to support organ donation across the UK. However, as outlined above, there are still challenges to be overcome. This strategy builds on the success of the Taskforce which – if its aims are achieved – will enable the UK to match world-class performance in organ donation and transplantation.

The Taskforce recognised that improvements in donation and transplantation were essentially dependent upon changing behaviours. This new strategy re-affirms this view, and presents a call to action directed towards the four key groups listed below. Should any of these groups fail to respond, then this strategy will not be fully achieved.

Call to action	
Who	Outcome
Society and individuals	Attitudes to organ donation will change and people will be proud to donate, when and if they can.
NHS hospitals and staff (donation)	Excellent care in support of organ donation will be routinely available and every effort made to ensure that each donor can give as many organs as possible.
NHS hospitals and staff (transplantation)	More organs will be usable and surgeons will be better supported to transplant organs safely into the most appropriate recipient.
NHSBT and commissioners	Better support systems and processes will be in place to enable more donations and transplant operations to happen.

² The Human Tissue Act 2004 provides the legal framework for organ donation in England, Wales and Northern Ireland, and uses the term ‘consent’. The Human Tissue (Scotland) Act 2006 covers practice in Scotland and uses the term ‘authorisation’.

Measure	Aim	Current level
Consent/authorisation for organ donation	Aim for consent/authorisation rate in excess of 80%*	57%
Deceased organ donation	Aim for 26 deceased donors per million population (pmp)	19.1 pmp
Organ utilisation³	<p>Aim to transplant 5% more of the organs offered from consented, actual donors</p> <p>Aim for:</p> <ul style="list-style-type: none"> • 85% of abdominal organs from DBD donors to be transplanted • 35% of hearts and lungs from DBD donors to be transplanted • 65% of abdominal organs from DCD donors to be transplanted • 12% of lungs from DCD donors to be transplanted 	<p>80%</p> <p>30%</p> <p>60%</p> <p>7%</p>
Patients transplanted	Aim for a deceased donor transplant rate of 74 pmp	49 pmp

* Figures for Wales should be measured separately after the implementation of the planned Wales Human Transplantation Bill in 2015.

The strategy

The new strategy has been developed by NHSBT and the four UK Health Departments. Organ donation and transplantation is delivered on a collaborative basis across the UK and organs donated by deceased individuals are considered a UK-wide resource. This ensures the most appropriate use of donated organs and that organs and expertise are shared throughout the UK. Although all UK Governments will continue to take individual approaches to aspects of policy and implementation in specific areas, strong collaboration will increase the benefits for both donors and recipients.

A collaborative approach to organ donation and transplantation

This strategy builds on the recommendations of the Organ Donation Taskforce. It is a strategy for the whole of society – for those who work in the NHS, for recipients, for donors and their families. It seeks to increase the pool of people who can and do donate their organs after death. It will strive to ensure that clinical practice throughout the NHS makes organ donation happen for every potential donor where donation is appropriate. It will seek to ensure that when consent has been given donation will happen and that all suitable organs are transplanted and survive as long as possible – delivering the greatest benefit for the greatest number of patients.

But society must also play its part. In support of the NHS's efforts, people need to accept organ donation as the normal and expected thing to do, both for themselves and their loved ones. Work will continue with all members of society, including people from those Black, Asian and Minority Ethnic communities (BAME) where the need for kidney transplants is high and organ donation is not part of culture or tradition.

³ These measures will be kept under regular review, as they will be subject to change as improved technologies and techniques for organ preservation become available.

Next steps

The actions to support the above priorities are outlined in this strategy. They are not easily achievable. All those with a role in organ donation and transplantation need to continue to work together. Politicians and civil servants will need to ensure that the NHS supports organ donation and transplantation wherever and whenever possible. Finally, and most importantly, society as a whole must recognise that without donation there can be no transplantation. Unless individuals and their families agree to donation, transplant rates cannot improve.

The four UK Health Departments will work in partnership with NHS Blood and Transplant (NHSBT) and the relevant professional bodies, charities, commissioners and regulators to develop a series of operational plans, which will provide the detail for each action. Namely:

- Who should be responsible for implementation
- How the strategy will be delivered
- What resource requirements (funding, skills and people) are needed
- How current resources could be better deployed
- When the work will be completed.

It is anticipated that work to implement the strategy will commence in September 2013.

Initially, no additional funding is likely to be needed to move forward: much of what needs to be done is about working differently rather than increasing resources. However, looking ahead, there are technological developments, pilot initiatives and other programmes which are capable of bringing improvements but which will require additional resource. An action plan together with the funding of such developments will require separate consideration. Detailed, costed implementation plans for all such changes will be produced and funding sought from the four UK Health Departments. This will include plans for an ambitious publicity campaign that will change public attitudes and behaviours, with similar outcomes to those in the areas of drink/driving and smoking cessation.

Section two

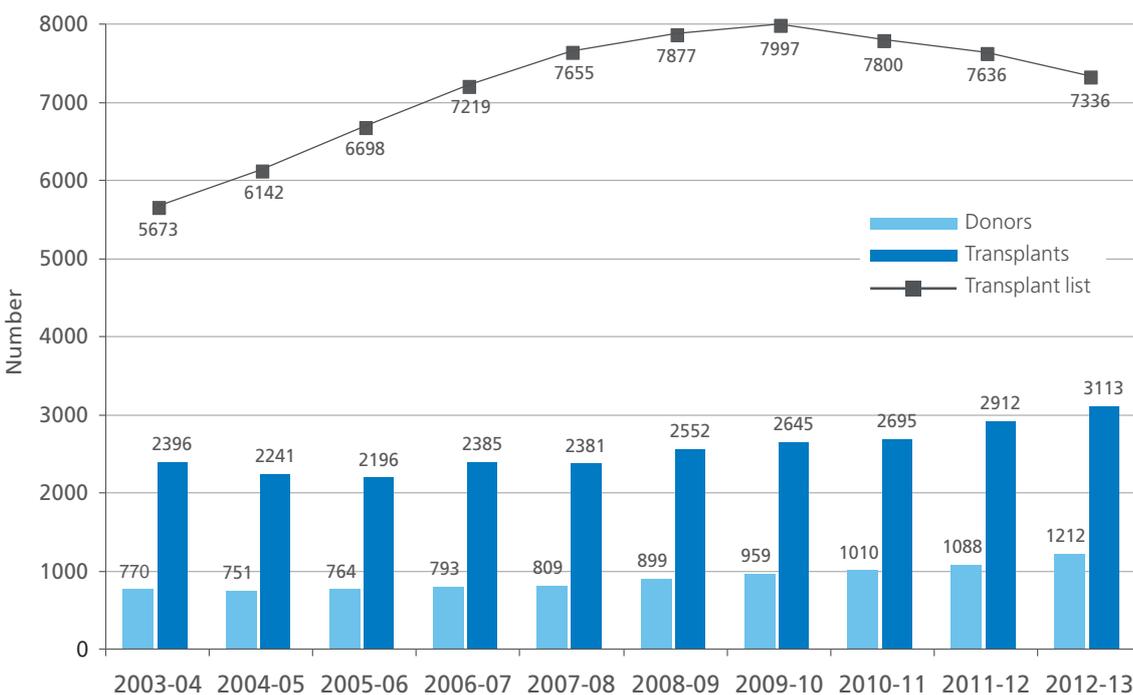
Background

The Organ Donation Taskforce highlighted three areas as barriers to organ donation: donor identification and referral; donor co-ordination; and organ retrieval arrangements. Since the Taskforce report was published in January 2008, the UK's approach to organ donation has been radically transformed – more donors are being identified and referred, donations are now co-ordinated by a centrally employed team of specialist nurses and organ retrieval is supported by a dedicated national organ retrieval service that is commissioned by NHSBT.

As a result, the number of people donating their organs after death increased by 50% between 2007/08 and 2012/13, as the Taskforce hoped. Consequently in 2012/13, transplant rates had increased by 30.5% and more people in the UK received an organ transplant than ever before.

However, more donor organs are needed. There remain over 7,000 people on the UK National Transplant Waiting List and the UK still lags behind many other Western countries (see figures below), both in terms of deceased donor numbers and also some types of transplants, notably heart and lung transplantation.

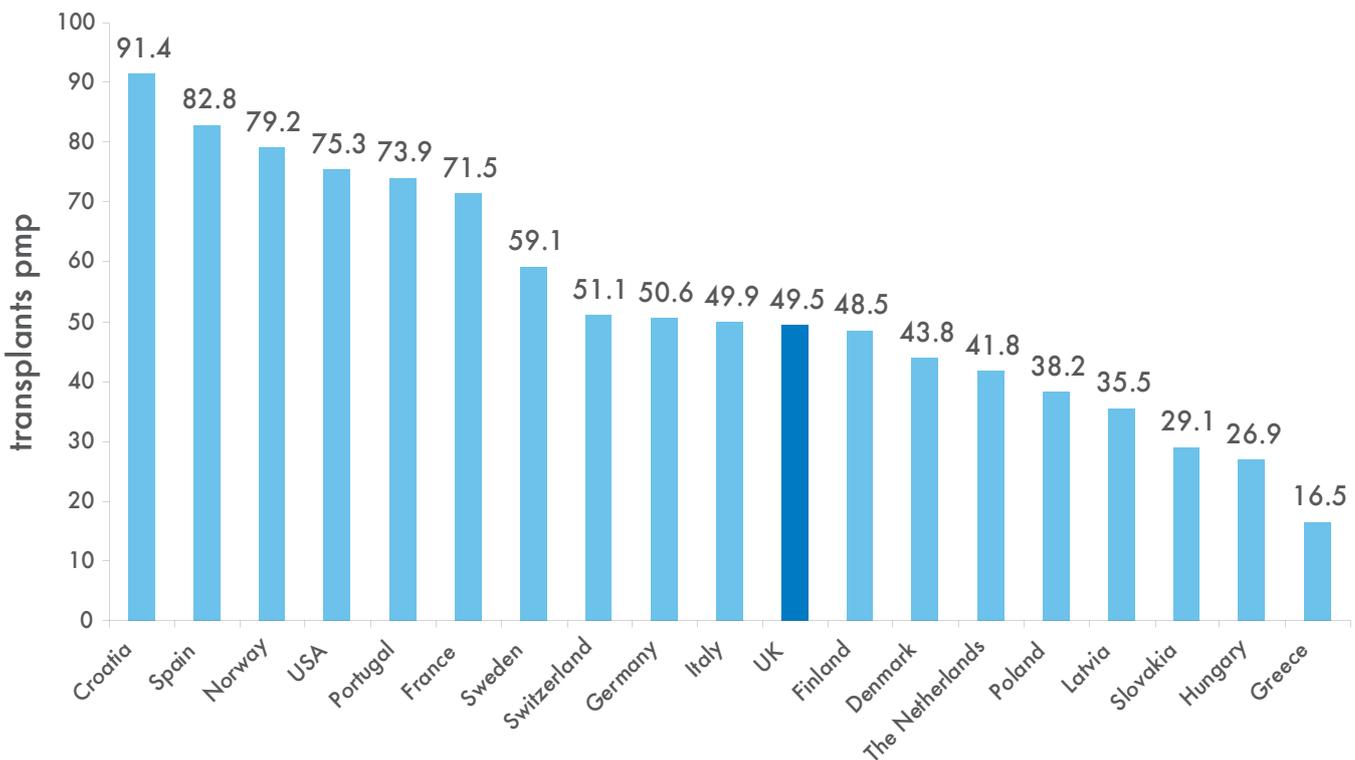
Deceased donors, transplants and transplant waiting list



The number of potential donors is also declining. People are living longer and fewer are dying in hospitals in circumstances where they can be organ donors. In the UK every year around 1,200 people die after death has been diagnosed on neurological criteria with a further 3,000 people dying after the withdrawal of treatment in circumstances where donation is possible. The UK's pool of potential brain-stem dead donors – donors who can donate hearts – is very small compared with some other countries. For example, in the UK 58% of all donation occurs following certification of death using neurological criteria (referred to as donation after brain-stem death – DBD). The remaining donations (42%) occur following cardiac arrest (referred to as donation after circulatory death – DCD). Unless there are significant changes to end-of-life care in the UK this picture is unlikely to change.

If the UK is to improve the availability of organs for transplantation, then transforming people's willingness to donate organs after they die will be critical. Just over 30% of the population – nearly 20 million people – have recorded their consent for organ donation on the NHS Organ Donor Register (ODR) and although most families will support their relative's wish, in 2012/13 115 families overruled their relative's consent.⁴ Even worse, when the wishes of the individual are not known, nearly 50% of families say no. This figure compares poorly with Spain, for example, where fewer than 20% of families refuse.

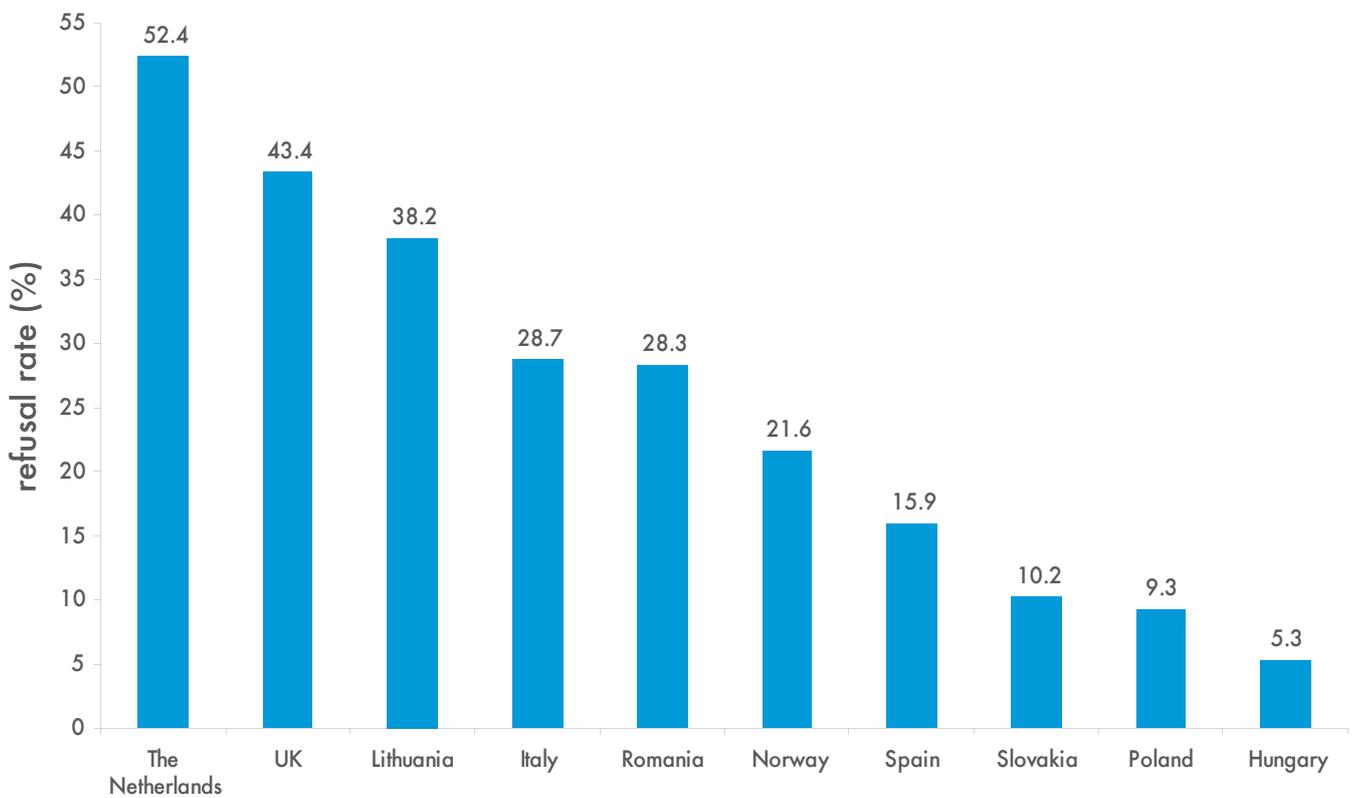
Total deceased donor transplant rates for Europe and the USA, 2011 (Transplants per million population)



⁴ Data from NHSBT Potential Donor Audit.

It must be stressed that, while solid organ transplantation is expensive, it saves the NHS money and improves the length and quality of recipient's lives. Economic analysis⁵ demonstrates that the transplant programme delivered an annual cost saving to the NHS of £316 million and that such savings have the potential to increase further as the number of transplant procedures rise.

Family refusal rates, 2011 (%)



⁵ West Midlands Specialised Commissioning Team: *Organs for Transplants: An analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation*, October 2010.

Section three

The detailed strategy

The new strategy, *Taking Organ Transplantation to 2020*, has been published as two documents. The first document, *A UK Strategy*, provides a very high-level explanation of what the UK should aim for in organ donation and transplantation. This document, *Detailed Strategy*, provides a more in-depth rationale for the strategy.

This document is focussed on a primarily clinical audience. Rather than follow each of the outcomes of the strategy, it is drafted to follow the clinical care pathway and covers:

- Increasing the number of potential donors
- Improving donor conversion rates
- Making the most of donor organs
- Increasing retrieval and transplantation of organs
- Resuscitation of retrieved organs
- Improving survival of transplant patients
- Systems to support organ donation and transplantation.

In doing so, it provides more detail regarding the actions that need to be taken and the supporting analysis and rationale. It is focused on a primarily clinical audience.

3.1 Increasing the number of potential donors

Donation as part of end-of-life care

The Organ Donation Taskforce was clear that every person in the UK should expect to be considered as a potential donor as part of his or her end-of-life care whenever it is medically possible. The General Medical Council has clearly defined the responsibilities of doctors in this regard.⁶ While there are many circumstances in which donation is not possible, there is good reason to believe that the number of people in the UK who might be considered as potential donors when they die – the potential donor pool – could be expanded. Such opportunities fall into two broad groups, defined by the way in which death occurs: either following a diagnosis of brain-stem death (where the heart is still beating) or following irreversible loss of the circulation.

End-of-life care practices and the potential of donation after brain-stem death (DBD)

Worldwide, deceased donation occurs most commonly after death that is diagnosed using neurological criteria (i.e. after brain-stem death). One of the striking features of UK deceased donation is the relatively low rate of brain-stem death. This is believed to be a direct result of clinical decisions to limit or withdraw treatments to patients with non-survivable brain injury before brain-stem death has evolved or can be diagnosed. It also remains the case that around a quarter of all patients who fulfil the pre-conditions for brain-stem death testing do not have such tests carried out. In other words, end-of-life care practices in the UK appear to limit the potential for donation after brain-stem death.

There is a pressing need to review to what extent these practices might be modified so as to promote donation after brain-stem death, particularly in circumstances where individuals have stated their wish to donate organs after death.

Actions to increase the potential for donation after brain-stem death

Specific Action	Responsibility
End-of-life care standards should promote brain-stem death testing as the preferred method of diagnosing death, where this can be achieved and is in the best interests of the patient.	Professional bodies, national legal and ethics organisations
End-of-life care practices should be reviewed to establish whether they might be adjusted so as to promote donation after brain-stem death.	Professional bodies national legal and ethical bodies
Publish hospital data to include brain-stem death testing rates.	NHSBT
Support Regional Collaboratives to lead local improvement in organ donation.	NHSBT, NHS
Develop training programmes to sustain and increase clinicians' organ donation understanding and expertise.	NHSBT, professional bodies
Explore how a requirement to confirm brain-stem death wherever possible might be incorporated into relevant professional standards of practice.	Professional bodies, NHSBT

⁶ General Medical Council guidance 'End-of-life Care: Organ Donation'. Available at: www.gmc-uk.org/guidance/ethical_guidance/end_of_life_organ_donation.asp

Promoting donation after circulatory death

While donation after brain-stem death is the mainstay of many deceased donation and transplantation programmes worldwide, confirmed brain-stem death is uncommon and accounts for less than 0.5% of all deaths in the UK. However, it is also possible to retrieve transplantable organs when death follows cardiac arrest. This is referred to as donation after circulatory death (DCD). The ways in which organ retrieval can take place following circulatory death are described in the Maastricht Classification.

Maastricht Category	Description
I/II	Organ retrieval after an unexpected cardiac arrest from a patient who cannot or should not be resuscitated. Sometimes referred to as uncontrolled DCD.
III	Organ retrieval after an anticipated cardiac arrest that follows the planned withdrawal of treatments that are considered to be of no overall benefit to a patient who is critically ill. Sometimes referred to as controlled DCD.

Maastricht III DCD

In contrast to DBD, the UK has comparatively high rates of Category III DCD, possibly because a high proportion of deaths in UK intensive care units follow decisions to limit or withdraw treatments that are of no overall benefit to a gravely ill individual. However, assessing a dying patient's suitability for Category III DCD is not always straightforward, particularly in older patients and/or those with complex medical histories, and this can impose time delays that are not always acceptable to the patient's family or the staff caring for them. As a consequence, not all of these possible donors are identified and referred, and there is widespread agreement that this would be promoted by streamlining the current referral, assessment and offering processes and by improving awareness of the possibility of organ retrieval from this group of patients.

Actions to promote the identification and referral of more Maastricht Category III DCD donors:

Specific Action	Responsibility
Publish hospital data to include variation in donor referral rates. This will include the publication of variation in referral of potential DCD donors on a hospital, regional and national basis	NHSBT
Establish a national referral service to improve support to hospitals and provide rapid triage of potential donors. This may include a service to triage potential Category III DCD donors rapidly.	NHSBT
Develop a system of peer review that is underpinned by a set of agreed standards for retrieval/transplant centres.	NHSBT, professional bodies
Develop training programmes to sustain and increase clinicians' organ donation understanding and expertise.	NHSBT, professional bodies

Maastricht Category I/II DCD

Several countries, most notably Spain, The Netherlands and France, support donation from patients who die after a sudden and unexpected cardiac arrest from which they cannot be resuscitated. This is referred to as Maastricht Category I DCD when death occurs outside of hospital and Category II when it happens in a hospital. Although the numbers of such donors are small, they nevertheless represent an important source of donor organs, principally kidneys. This form of donation has not been supported in the UK for several years, although a programme has recently been started in Edinburgh. If the experience in Edinburgh is favourable it is likely that several other transplant centres in the UK would follow its lead.

Actions to re-introduce Maastricht Category I/II across the UK:

Specific Action	Responsibility
Scope the potential for Maastricht Category I/II DCD in the UK, learning from the pilot programme in Scotland.	NHSBT, NHS

3.2 Improving donor conversion rates

The conversion ratio is the fraction of potential donors who become actual donors. For DBD, family refusal rates are the most important determinant of whether a potential donor becomes an actual donor, although additional factors exist for DCD. Key outcomes that would increase the proportion of potential donors who become actual donors are:

- An improvement in family consent rates
- A reduction in the objections to organ donation from Coroners and Procurators Fiscal
- Streamlining and greater consistency of other elements of the pathway for potential Maastricht Category III DCD donors, including:
 - referral, assessment and acceptance
 - decision to call off organ retrieval (stand-down).

Improving family consent

The UK has some of the highest family refusal rates for organ donation in the Western world. Furthermore, the increases in donation and transplantation reported following the publication of the Taskforce report in 2008 are a consequence of a significant expansion of DCD programmes, not because of any significant increase in family consent. Put plainly, the UK will never achieve its potential for donation and transplantation when over 40% of families refuse donation, sometimes against the known wishes of the patient.

There are two fundamental and complementary approaches to improving family consent rates. Firstly, as a society we need to get to a point where we believe it to be normal for families to be asked for consent and normal that they will give it. Secondly, families must be given the best possible support when asked to consider donation on behalf of a loved one.

The single most important objective of this strategy is to increase consent. Sustained and urgent attention must be given to improving the numbers of people in the UK who consent to donation. This will only be achieved if all key players – politicians, policy makers, healthcare professionals, professional bodies and the public – respond to the challenge.

Actions to increase society’s support for organ donation

Everyone in the UK must understand that without donation there can be no transplantation. Public awareness without action will not increase the numbers. Donation should be seen as a responsibility and a feature of good citizenship, regardless of background or community. Donation should be something of which people are proud.

Although there has been little improvement in family refusal rates elsewhere in the UK, consent rates for donation after brain-stem death in Scotland have improved substantially in recent years. It is hard to escape the conclusion that this is due to the success of television and media campaigns to promote Scottish society’s responsibilities towards donation, supported by an active and comprehensive schools education programme.

Much emphasis has been placed on the NHS Organ Donor Register (ODR) as a means of improving consent rates, and it is certainly the case that the knowledge that someone in life has consented to or authorised organ retrieval after death helps many families. However, there has been no overall improvement in consent since the introduction of the ODR in 1994.

Less than a third of actual deceased donors are registered on the ODR and as a result it is probably best viewed as a barometer of society’s support for donation and the effectiveness of interventions to engage the public, rather than a direct means by which family refusal rates might be reduced.

2012/13 potential donor audit (PDA)*				Organ donor register
Nation	DBD consent/authorisation rate (%)	DCD consent/authorisation rate (%)	Overall consent/authorisation rate (%)	% of population registered as at 31 March 2013
England	68%	52%	58%	30%
Northern Ireland	61%	45%	54%	30%
Scotland	78%	51%	60%	41%
Wales	65%	41%	50%	32%
UK	68%	51%	57%	31%

* based on PDA data as at 9 May 2013.

Several groups, including the British Medical Association, have long advocated the adoption of an 'opt-out' system of consent for organ donation. The Welsh Government is the first UK country to introduce legislation to bring in a soft opt-out system for consent to organ donation. Under the new arrangements, people in Wales will have the choice of either registering a wish to be a donor (opting in) or not to be a donor (opting out). Those who do neither will be deemed to have given their consent to donation. The new system will be preceded by a two-year communications campaign to promote the new law and choices available to people living in Wales. NHSBT is committed to ensuring the operational changes resulting from the new Welsh legislation are introduced safely and effectively.

In addition, the Department for Health, Social Services and Public Safety in Northern Ireland is consulting on attitudes towards organ donation, including the introduction of an opt-out system for organ donation.

The other UK countries will watch these changes with interest to see the impact on the consent and donation rates. NHSBT recognises its various responsibilities in supporting legislative change in Wales, and other parts of the UK, and is committed to fulfilling them.

Actions to increase society's support for deceased donation	
Specific Action	Responsibility
Develop national strategies to promote a shift in behaviour and increase consent and test progress with regular public surveys.	UK Health Departments, NHSBT
The relevant Government Health Departments should explore with Education Departments the possibility of incorporating donation and transplantation into schools curricula.	UK Health Departments
All Governments should provide regular reports to Parliament/Assembly on progress in their nation and Health Ministers should have a duty to promote organ donation and transplantation effectively leading to a significant improvement in public attitudes and consent for organ donation.	UK Health Departments
There should be national debates to test public attitudes to radical actions to increase the number of organ donors. For example, whether those on the Organ Donor Register should receive higher priority if they need to be placed on the Transplant Waiting List.	NHSBT, UK Government
Ensure that the introduction of a system of deemed consent to organ and tissue donation in Wales as described by the Human Transplantation (Wales) Bill is as successful as possible and learn from this experience.	Welsh Government, NHS Wales, NHSBT
Develop a community volunteer scheme to support Trust/Health Board donation committees to promote the benefits of donation in local communities', particularly amongst groups with little tradition of organ donation.	NHSBT, voluntary sector
Increase Black, Asian and Minority Ethnic communities' awareness for the need of donation, to benefit their own communities and provide better support for people in these communities to donate.	NHSBT, voluntary sector, professional bodies, UK Health Departments

Improving support for the families of potential donors

NHSBT data demonstrates that over the last three to four years, consent/authorisation rates for DBD have been fairly static at about 65%, while those for DCD have been static at around 50%. Family refusal rates in the UK are considerably higher than those reported from many parts of mainland Europe, where they are often less than 20%. They are also substantially higher than might be expected from the reported levels of public support for donation. It is particularly concerning that families continue to object to donation even though their loved one has given in life consent for it to happen by joining the NHS Organ Donor Register (ODR).

There is evidence that the way in which the possibility of donation is presented to a grieving family can have a critical impact – both positive and negative – upon the decision that they make. Families need to be approached at the right time, in the right way, and by someone with the right skills to support their decision-making. Few critical care clinicians have specific training on how to bring organ donation into an end-of-life care discussion, and organ donation will always be a relatively infrequent activity for the majority of critical care clinicians. However, it is a core activity of the teams of Specialist Nurses for Organ Donation (SN-ODs) who co-ordinate donation in the UK.

International evidence would suggest that co-ordinated approaches achieve higher consent rates, and the Potential Donor Audit demonstrates higher family consent/authorisation rates when SN-ODs are involved at an early stage. The National Institute for Health and Clinical Excellence (NICE) has made a clear recommendation that as a standard of care, SN-ODs should be involved as early as possible when approaching the families of potential organ donors.⁷ While this recommendation from NICE has no regulatory force in Scotland, SN-ODs need to be able to work closely with hospital teams throughout the UK to ensure that all families of potential donors are given the best possible support when donation is being considered.

Actions to improve the support for families of potential donors

Specific Action	Responsibility
Develop a workforce strategy for the organ donation service which will tailor the service to the needs of individual hospitals and seek to provide a workforce that is focused on supporting the potentially conflicting demands of providing a service to the donor family, donor management and donor co-ordination. This may be configured in one or more roles as the needs of the service dictate.	NHSBT, NHS
Following the experience in the USA, ensure everyone who has made a decision to donate during their life has their wishes honoured, if they die in circumstances where donation is possible.	NHSBT, NHS
Subject to variations in Government policy, agree a formal contract for organ donation with hospitals specifying how hospitals and the NHSBT donation service work together to achieve excellence.	NHSBT, NHS, UK Health Departments/Commissioners
Families of potential donors will only be approached by someone who is both specifically trained and competent in the role, and provide training packages and accreditation to those who wish to develop this competence.	Professional bodies, NHS, NHSBT
Pilot additional community support in a number of London hospitals to aid SN-ODs when they approach families from those Black, Asian and Minority Ethnic (BAME) communities where there are low levels of support for organ donation, and if successful expand to other key hospitals.	NHSBT

⁷ National Institute for Health and Clinical Excellence (December 2011). *Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation*. Available from: <http://guidance.nice.org.uk/CG135>

Reducing objections to organ donation from the Coroners and Procurators Fiscal

There are many occasions where a potential donor dies in circumstances that require involvement with the police and a referral to the Coroner or Procurator Fiscal. Although permission for organ donation is granted in the majority of cases, there are times when proceeding with donation may impede the police and Coroner/ Procurator Fiscal in their duties. In these cases, donation should not proceed.

Despite guidance being published in 2010, there is still variation in practice between what circumstances should prevent donation from proceeding. This needs to be addressed.

Actions to reduce objections to organ donation from the Coroner and Procurator Fiscal	
Specific Action	Responsibility
Work collaboratively to reduce instances of objection to organ donation from the Coroner and Procurator Fiscal service and the police.	NHSBT, UK Governments

Additional measures to increase the proportion of potential Maastricht Category III DCD donors who become actual donors

Although Maastricht Category III DCD makes substantial contributions to organ transplantation in the UK, a number of factors limit its overall impact, including:

- This type of donation requires that treatment withdrawal can only take place after initial assessments for donation have been made. This can take many hours, particularly when the patient is older and/or has a complex medical history. It also takes time for the surgical retrieval team to assemble and travel to the donor hospital. Families frequently cite these delays and the stress caused by them as a reason for not giving their permission for donation to proceed. As a result family consent rates for Maastricht Category III DCD in the UK are considerably lower than those for DBD.

- There are valid concerns that potentially transplantable organs suffer excessive ischaemic injury in the time interval between treatment withdrawal and death. This can mean that even when a patient has been accepted as a donor and family consent obtained, donation does not happen because the time interval between treatment withdrawal and death is too prolonged. However, as noted in the Consensus statement on DCD published in 2010, there is considerable variation in how long retrieval teams will wait and this unnecessarily restricts the number of actual DCD donations that occur.

Actions to increase the conversion of potential Maastricht Category III DCD donors	
Specific Action	Responsibility
<p>Reduction in time delays experienced by the families of potential DCD donors through the provision of:</p> <ol style="list-style-type: none"> 1. Develop a workforce strategy for the organ donation service, which will tailor the service to the needs of individual hospitals and seek to provide a workforce that is focused on supporting the potentially conflicting demands of providing a service to the donor family, donor management and donor co-ordination. This may be configured in one or more roles as the needs of the service dictate. 2. A national referral service to triage Maastricht Category III DCD donors in a more timely fashion. 	NHSBT
<p>Continued development of Maastricht Category III DCD retrieval and transplantation programmes to improve the consistency in decision-making, including decisions to accept or reject a potential DCD donor. This will be achieved by:</p> <ol style="list-style-type: none"> 1. Providing guidance on levels of acceptable risk in relation to offered organs, particularly from extended criteria donors, relevant to the individual recipient's needs and wishes. 2. Development of peer review systems, underpinned by a set of agreed standards for retrieval/transplant centres. 	NHSBT, professional bodies, Commissioners

3.3 Making the most of donor organs

Improving the function of donor organs prior to retrieval

People donate their organs in order to save and transform the lives of those who receive them. It is reasonable to assume that donors would wish the best possible good to come from their donation, and it is vital therefore that as many organs as possible are retrieved, and that they are retrieved in the best possible condition.

However, other factors must also be considered. The need for suitable organs must be balanced against the possible risks to the recipient, such as transplanting an organ that does not work properly or transmitting a serious disease from the donor to the recipient. While a significant risk of transmission of a serious disease usually contra-indicates the use of any organ, it is anxiety over the likely function of an organ that largely explains why it is only in a minority of cases that all the possible solid organs are used. Although there are usually valid clinical reasons for this, international comparisons suggest that there is room for improvement in UK practice.

Before accepting an organ, the transplantation team must be confident that the risks of implanting a specific organ into a particular patient are less than the risks of him or her remaining on the transplant waiting list. This decision in turn depends upon the team's assessment of the function of that organ. Sometimes, actions that could have been taken to improve the function of a retrievable organ are not taken, and the organ is declined. On other occasions, organs that were declined on the grounds of 'poor' function should have been accepted and implanted.

Improving the function of organs retrieved from DBD donors

Brain-stem death can result in significant physiological instability in the donor and although this instability is often reversible, such changes interfere with organ assessment and may result in organs being unnecessarily turned down. These difficulties have the greatest impact on heart and lung retrieval because it is these organs that suffer many of the adverse effects associated with brain-stem death, and their failure after grafting would have catastrophic consequences for the recipient. It is necessary therefore to continue or even to escalate critical care in the time between the diagnosis of brain-stem death and organ retrieval, so as to correct any physiological damage or disturbance to potentially retrievable organs. This is currently the responsibility of the clinical team caring for the patient in the donor hospital.

There is clear and readily available guidance on how donor management should be undertaken, including the guidance in NHSBT's 'donor care bundle'⁸ (clinical guidelines for donor optimisation). However, this guidance is not always applied as well as it might be, largely because it is an element of care that few ICU clinicians are required to deliver frequently. In contrast, cardiothoracic retrieval clinicians have such experience and competence, but are only rarely involved in the care of the brain-stem dead donor while the donor is on the ICU. There is considerable evidence that the number of hearts and lungs retrieved from DBD donors could be increased if:

- ICU clinicians initiate the core elements of donor optimisation quickly and effectively
- Cardiothoracic retrieval teams become more closely involved in the care of the consented cardiothoracic donors before they are transferred to the operating theatre.

Actions to increase organ retrieval from DBD donors

Specific Action	Responsibility
The promotion and support of early and effective physiological optimisation of the potential DBD donor through adoption of the 'donor care bundle' by hospital ICU staff, and support this process through audit and training.	NHSBT
Improve donor management for potential cardiothoracic donors, providing a 24/7 service to assist if pilot schemes prove effective. This will be part of a concerted effort to increase the number of thoracic organs retrieved from brain-stem donors, and will include a review of the duration of donor care, in light of evidence that better care of the donor's physiological health will lead to the retrieval of more thoracic organs, particularly hearts.	NHSBT, NHS

⁸ Available at: www.odt.nhs.uk/donation/deceased-donation/donor-optimisation/resources/

Improving the quality of organs retrieved from Maastricht Category III DCD donors

In Maastricht Category III donors, organ retrieval follows death that is diagnosed after cardiac arrest. The potentially transplantable organs may suffer ischaemic injury as the patient dies, and for this reason it is essential that every legitimate effort is made to limit the injury to which the retrievable organs are exposed. Theoretically at least, this might be achieved in various ways:

- Where minutes count, it is essential that all unnecessary delays in the donation process be avoided.
- It is possible that some drug treatments (e.g. heparin) might limit microvascular injury. However, these would need to be administered to the potential donor before death and this is prohibited by current UK guidance.
- It is possible that deterioration might be reversed after death by re-perfusing the organs with oxygenated blood before they are retrieved.

Actions to increase organ retrieval from DCD donors

Specific Action	Responsibility
Review what pre-mortem interventions could legally and ethically be undertaken to maximise the potential for organ donation (such as the antemortem administration of heparin).	UK Health Departments, National ethics organisations, professional bodies
Evaluate and effectively implement new techniques and technologies for the preservation of retrieved organs with a view to their use in the UK.	NHSBT, professional bodies

3.4 Increasing retrieval and transplantation of organs

Once consent for donation has been given, organs are offered to the transplant units according to the published protocols.⁹ From April 2013, offers will be made electronically to speed up the offering process and reduce the potential for error in transmission of essential information.

We know that opportunities for transplantation are lost during all stages of the pathway from offering to implantation. In most cases, there are clearly documented and valid clinical reasons for this loss of opportunity (such as a brain-stem death testing that cannot be done because the potential donor remains haemodynamically unstable, or has received sedation, or the organ may be unsuitable such as a fatty liver that would not function). However, in some cases, reasons why the surgeon declines some offered organs are not clear. There is some variation in the acceptance rates of offered organs both between and within units. For example, transplant units have different criteria for acceptance based on donor characteristics (such as donor age). In most cases, the reasons for decline are clear and appropriate (where the recipient is unwell for example), but in other cases the reasons for this variation in acceptance rates are not fully understood. Refusal of an offer leads to delay and so contributes to the likelihood of poor graft function or even non-use.

The retrieval team is responsible for retrieving those organs for which consent has been given and for which a suitable recipient has been identified or, when appropriate, for clinical research. There is variation in the number of organs retrieved from each donor. The median number of organs retrieved from a donor after brain death (DBD) is 3.9 with a mean of 2.6 organs being retrieved from a donor after circulatory death (DCD) for transplant purposes. It is also evident that some organs that are retrieved from a donor are not transplanted. Again, there are many potential reasons why not all organs are retrieved, including perceived poor function of the graft if transplanted or disease in the organ and, rarely, no suitable recipient in the UK or elsewhere.

⁹ Available at: www.odt.nhs.uk/transplantation/policies

Reduce the rates of decline of organs where consent has been given

Organs may be declined because of donor or organ factors. Donor factors that may preclude organ donation include bacterial or viral infection or malignancy in the donor that would be transmitted to the recipient, with a high probability that the infection or cancer would jeopardise the recipient’s survival following transplant. Guidance on risks associated with the acceptance of donors comes from a variety of sources, including international bodies (such as the Council of Europe), national bodies (such as the Advisory Committee on the Safety of Blood Tissues and Organs {SaBTO}) and professional bodies (such as the British Transplantation Society {BTS}). However, national and international guidelines are not always consistent.

The recipient transplant surgeon makes the final decision on the basis of the evidence available and should ensure that the recipient has given informed consent. The surgeon has to balance the risks of proceeding with the transplant against the risks of declining the offer (which includes the risk of the patient’s death while awaiting another offered organ). As the number of marginal donors increases, surgeons are working increasingly at the extremes of what is acceptable and where there is little or no evidence based on which to make an informed decision.

Supporting the surgeon on understanding donor risk

There is variation both between and within centres about those donor characteristics that may preclude transplantation for a given recipient. In many cases, this variation is a consequence of the lack of a robust evidence base. Clinicians (transplant surgeons or physicians) will use their judgement, based on the current national and international evidence, to draw up criteria for non-acceptance. It should be recognised that those centres that have fewer exclusions do not invariably accept all the extended offers and wider acceptance criteria may not always be associated with better outcomes.

Actions to support the surgeon to take appropriate risk assessment	
Specific Action	Responsibility
Provide guidance on levels of acceptable risk in relation to offered organs, particularly from extended criteria donors, relevant to the individual recipient’s needs and wishes.	Professional bodies, NHSBT

Reducing risk-averse behaviour

One of NHSBT’s roles is to monitor outcomes after transplantation. When outcomes from a centre fall outside accepted ranges, NHSBT, working in conjunction with expert clinicians and a representative who acts on behalf of the commissioners of transplant services and the relevant Government Health Department will investigate further. Studies in the US and elsewhere have suggested that too much focus on outcomes can encourage risk-averse behaviour in clinicians and lead to worse outcomes for the patient.

While it is accepted that NHSBT, in partnership with Commissioners, will continue to monitor outcomes to ensure quality and safety, clinicians must be supported to take appropriate risks. Patients listed for a deceased donor kidney transplant at those centres which have a higher rate of decline of kidneys that are then used elsewhere, have tended to have longer waiting times. There are many valid potential reasons for the variation in acceptance rates, including the risk/benefit balance for the recipient as well as the experience of the team.

Improving utilisation of retrieved organs

Retrieval surgeons will remove appropriate organs deemed suitable for transplantation. However, it is not always possible to transplant retrieved organs. In 2012/13, approximately 250 kidneys, 100 livers, 200 pancreases and 50 lungs were removed but not transplanted.¹⁰ All retrieved hearts were transplanted. Failure to use retrieved organs could be due to one or more of several factors, including:

- Uncertainty that the organ will function
- Risk-averse behaviour
- Damage to organs during retrieval, transportation, preparation or implantation
- Failure to resuscitate the retrieved organ
- Recipient’s decision.

Action to reduce risk-averse behaviour and improve utilisation

Specific Action	Responsibility
Publish centre-specific risk-adjusted patient survival from listing as well as from transplantation.	NHSBT
Provide guidance on levels of acceptable risk in relation to offered organs, particularly from extended criteria donors, relevant to the individual recipient’s needs and wishes.	Professional bodies, NHSBT
Ensure clinicians are aware of and follow, best practice to increase patient and graft survival.	Commissioners, NHSBT, professional bodies

10 Exact numbers: 272 kidneys; 212 pancreas; 107 livers; 43 lungs.

Improving certainty about organ function

While there are some validated models that can be used to predict the organ function, these models are relatively crude and surgeons’ confidence in them varies. Donor and organ characteristics that are associated with poor outcomes are well described but much still depends on the judgement and experience of the surgeon. More and clearer information would help the surgeon decide how best to use donated organs: for example, whether to implant both kidneys into the same recipient if function is likely to be insufficient if transplanted separately, or whether to split a liver to allow one donated organ to help two recipients.

Biomarkers¹¹ and histological¹² characteristics are of help but there are few valid and easily accessible biomarkers currently available and histological assessment of retrieved organs is not readily accessible to surgeons.

Greater understanding of the probability of the graft functioning will not only prevent inappropriate risk of harm to the recipient by transplanting an organ that will not function but will reduce the risk of surgeons inappropriately discarding an organ that might well function. Criteria that will help the decision whether or not to graft an organ will help reduce the inappropriate variation in decline rates amongst surgeons and so lead to greater equity of access. In many cases, knowledge of the histopathology will help the surgeon decide whether to use a kidney, transplant both kidneys into one recipient or use or split a liver. A robust 24/7 histopathology service with expert histopathologist support would also allow accurate identification of incidental tumours that may preclude transplantation.

Action to improve certainty about organ function	
Specific Action	Responsibility
Research is supported that will lead to better biomarkers that will identify organs that are associated with good or poor function and lead to new pharmacological approaches to improve organ function.	NHSBT, UK Health Departments, professional bodies
Investigate the feasibility and implications for the provision of a 24/7 provision of expert histopathology advice.	NHSBT, Commissioners, Health Administrations
Review the current processes for donor characterisation (especially for microbiology and tissue typing).	NHSBT, Commissioners

Damage to organs during retrieval, storage, preparation and implantation

A small proportion of organs are damaged prior to or during the retrieval, transport, and preparation or implanting processes. In some cases, the damage is a result of the illness or incident that led to the donor’s death or to poor donor perfusion. The retrieval process is complex and it must be done speedily (within minutes for organs from DCD donors). In most cases, when damage does occur, it is minor and can be readily corrected by surgical techniques. However, very rarely this damage can result in loss of an organ. Every case where there has been surgical damage that results in non-use of the organ or harm to the recipient is listed as a Serious Adverse Event (SAE). These are reported under the EU Organ Donation Directive (EUODD), investigated by NHSBT and the appropriate corrective action taken.

Actions to reduce damage to donated organs	
Specific Action	Responsibility
Develop and implement a training and accreditation programme for all retrieval surgeons and extend this to supporting post-mortem technologies when these are introduced.	NHSBT, Professional bodies

¹¹ An indicator of a biological state.

¹² The microscopic anatomy of cells and tissues of plants and animals.

3.5 Resuscitation of retrieved organs

In the past decade, there have been advances in the preservation of organs following retrieval. These approaches are being increasingly used, including improvement in the preservation fluid and technologies to improve organ function. An analysis by NICE in 2009¹³ did not formally recommend machine perfusion. Since then new data has been generated and new approaches introduced to improve organ function. Newer devices allow assessment of organ function to be made before deciding whether to implant.

Actions to improve resuscitation of retrieved organs

Specific Action	Responsibility
Evaluate new techniques and technologies for the preservation of retrieved organs with a view to their use in the UK.	NHSBT, professional bodies

Lack of suitable recipient

In a very few cases, there is no suitable recipient in the UK (usually because of an inability to match recipient size or blood group) so the organ is exported to another country. Rarely, organs have been deemed too high risk for use in the UK but used effectively elsewhere. It should be noted that the UK shares unused organs with other countries and there is a fair balance of exchange. Nonetheless, it is preferable that the organ is retrieved and used in the UK to keep the wait time short and so maintain graft function.

Action to address lack of suitable recipient

Specific Action	Responsibility
Increase the number of organs that can be transplanted safely.	NHSBT

3.6 Improving survival of transplant recipients

Outcomes after transplantation in the UK are as good as or better than in other European and North American countries, which reflects well on the clinical services in the UK.^{14,15} Ten years after deceased donor transplant, over 70% of kidney transplant recipients and 60% of liver transplant recipients are alive with functioning grafts. NHSBT, in collaboration with partners, also monitors and reports outcomes by centre. Any centre with unusual adverse outcomes is investigated and remedial action identified and implemented.

However, in the UK, as elsewhere, both graft and patient survival may be limited by factors that could in some cases be mitigated. Improved outcomes of retrieved organs will not only improve the length and quality of life of recipients but will also reduce the need for re-grafts and so make those organs that are donated available for more recipients.

Survival after transplantation is improving both in quality and in quantity. However, despite developments in surgical, medical, anaesthetic and microbiological practice and introduction of new drugs to induce and maintain immunosuppression and promote tolerance in recipients, survival after transplantation is less than that expected in an otherwise healthy individual. Recipient death and/or graft loss may be due to many factors, including immune-destruction of the graft, recurrent disease and premature death from some infections, some malignancies and cardiovascular disease. Once implanted, grafts may fail for one or more of several reasons.

Patient and graft survival may be increased by several approaches:

- Better matching of donor with recipient
- Reduction in premature graft failure rates
- Reduction in premature mortality.

13 TA165 <http://guidance.nice.org.uk/TA165/ReviewProposal>

14 Survival after liver transplantation in the United Kingdom and Ireland compared with the United States. Dawwas MF, Gimson AE, Lewsey JD, Copley LP, van der Meulen JH. GUT, 2007 Nov; 56(11):1606-13

15 A comparison of disease severity and survival rates after liver transplantation on the United Kingdom, Canada and the United States. Stell DA, McAlister VC, Thorburn D. Liver Transplant. 2004 Jul; 10(7):898-902

Better matching of donor with recipient

There remains ongoing discussion amongst both the lay community and healthcare professionals about the most appropriate use of the limited number of organs from deceased donors. The rationale for both selection and allocation is based on a combination of utility, benefit and need. The relative importance of these different factors will vary for different organs. NHSBT has developed models to predict outcomes after transplantation for kidney and for liver. With changing donor and recipient demographics, better immunosuppressive agents and interventions, allocation policies need regular review.

Reduction in graft failure rates

Grafts may fail for one or more of several reasons, including technical problems, non-function, immune-mediated mechanisms and recurrence of disease. Reduction in rates of graft failure will not only improve the length and quality of life for the recipient but also, by reducing the need for a re-graft, make donated organs available to more people.

Actions to improve matching of donor with recipient to reduce graft failure rates	
Specific Action	Responsibility
Improve transplant recipient survival by improving understanding of the donor organ/recipient compatibility.	NHSBT, professional bodies

Reduction in premature mortality

The UK maintains a comprehensive registry of transplant recipients. Use of the registry data has driven up standards and led to the UK’s position as an international leader. Analysis of the registry provides huge benefit for patients, professionals and healthcare managers. Potential transplant recipients are given the right information to make a fully informed choice, while donor families can be reassured that donated organs save or improve as many lives as possible and clinicians can ensure good outcomes and learn from experience.

Studies in the UK and elsewhere show that the life expectancy of transplanted patients are better than if the patient had not received an organ transplant. However, life expectancy is still shortened in comparison with the general population. Causes of premature death include an increased risk of some infections, some cancers, cardiovascular events and recurrent (or persisting) disease.

Actions to reduce premature mortality	
Specific Action	Responsibility
Ensure clinicians are aware of and follow, best practice to increase patient and graft survival. This could include appropriate monitoring and treatment of cardiovascular risk factors and screening for malignancies, to increase patient and graft survival.	Professional bodies, Commissioners, NHSBT

3.7 Systems to support organ donation and transplantation

The UK's organ donation and transplant support systems need updating and improving, so there is greater clarity about what is expected and available and the process works more smoothly.

It is anticipated that the demand for intensive care resources will increase during the lifetime of the strategy, regardless of the expected increase in donation. Commissioners should keep the demand for intensive care beds under review and, if necessary, take steps to ensure that ICU capacity is not a barrier to donation. Other options for resourcing the management of donors may need to be identified, such as giving hospitals flexibility to increase staffing to care for a donor, including an anaesthetist on retrieval teams or creating dedicated donor capacity in major cities.

Excellence in organ donation and transplantation

Improvements need to be made throughout the transplant pathway so that the desired outcomes can be achieved. The IT, which the organ donation and transplantation process depends on, is out of date and making changes is time-consuming, expensive and risks destabilising the process.

Recent improvements have included the development of web pages to make information more readily available to healthcare professionals, patients and other interested parties (www.odt.nhs.uk), and electronic offering through the electronic offering system (EOS mobile).

NHSBT will introduce a national offering system for bowels in mid-2013 and for kidneys from DCD donors from late 2013. The move to national allocation schemes for other solid organs is being discussed by clinicians in collaboration with professional and lay groups.

Actions to deliver excellence in organ donation	
Specific Action	Responsibility
Optimise the processes, timescales, resources and supporting IT at every stage of the pathway from donor identification to long-term survival.	NHSBT, NHS Commissioners
Review the current processes for donor characterisation (especially for microbiology and tissue typing).	NHSBT, Commissioners

Developing the workforce

A workforce of up to 251 whole time equivalent Specialist Nurses in Organ Donation (SN-ODs) are trained to provide the donor service to over 300 hospitals across the UK. The SN-ODs spend over 60% of their time in the hospitals they support, covering four main areas of work: approaching families about donation; managing and co-ordinating the donation and offering process; hospital development (supporting the clinical lead and donation committee in improving hospital processes); and carrying out the potential donor audit.

However, the visibility of the SN-ODs on the intensive care units and in emergency departments is too low: the large number of clinicians in these units, their shift patterns, the clinical priorities and the primacy of the need to spend time with the patients, all mean that the ability of the SN-ODs to engage with the clinicians is limited. The donation process may take many hours and the SN-OD needs to balance the support of the family with managing and co-ordinating a very complex donation and offering process. This can be challenging and lead to conflicting demands.

Currently, every hospital receives a broadly similar level of service. However, hospital needs vary considerably and it is widely felt that the donor service will be more effective if it is better aligned to the individual needs of the hospital.

The National Organ Donation Service, which supports families and co-ordinates organ donation, will be amended to meet the needs of different types of hospitals and will support donor families separately from caring for the donor, where appropriate.

Actions to develop the workforce

Specific Action	Responsibility
Develop a workforce strategy for the organ donation service which will tailor the service to the needs of individual hospitals and seek to provide a workforce that is focused on supporting the potentially conflicting demands of providing a service to the donor family, donor management and donor co-ordination. This may be configured in one or more roles as the needs of the service dictate.	NHSBT, NHS

Developing Donation Committees and Regional Collaboratives

Each UK hospital appoints its own Donation Committee Chair (sometimes these are shared by several hospitals) and its own Clinical Lead for Organ Donation (CLOD). NHSBT ran a professional development programme for Chairs and Clinical Leads and continues to provide training and development through Regional Collaborative meetings and annual refresher training. It is apparent that Donation Committee Chairs and CLODs still have different expectations about their roles and the expectations and distinctions need to be made much clearer if the full potential of these roles is to be met.

Over the last two years, NHSBT has supported the development of twelve forums across the UK – known as Regional Collaboratives – whose role is to support the local Donation Committees and organ donation teams. These forums bring together Clinical Leads, Specialist Nurses in Organ Donation, and Donation Committee Chairs and increasingly involve clinicians from the retrieval service and local transplant surgeons. Led by the Regional Clinical Lead and Regional Manager, the Collaboratives review audit data, share learning, provide support to people leading change in hospitals and drive improvement.

Regional Collaboratives will be the focal point for translating much of the strategy into action and will increasingly involve clinicians from the transplant service, to enable them to develop local solutions to the interface between donation and transplantation. Collaboratives will be provided with identified hospital data to help them understand local and national variations in performance. Some regions are already matching international levels of donation and by reducing variation more can be achieved. As a first step all hospitals should be seeking to improve to the level that the top 25% are already achieving.

Action to support Regional Collaboratives	
Specific Action	Responsibility
Support Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practices and in local promotion of donation and transplantation.	NHSBT, Commissioners, professional bodies

Transplant capacity and surgical expertise

Transplant services are commissioned by the commissioning bodies (or their equivalents) of the four UK nations. Renal transplant services are provided by 26 UK hospitals, there are 7 liver transplant centres and 6 cardiothoracic transplant centres. Each country organises its provision of transplant services differently but as the number of transplants continue to rise, the four countries will need to work together to make sure that there is sufficient capacity and surgical expertise to meet demands. A recent examination of cardiothoracic transplantation across the UK co-ordinated by English Commissioners has provided a useful model for planning for future transplant services.

Action to meet transplant capacity and expertise requirements	
Specific Action	Responsibility
Ensure that transplant centres have the capacity, surgical expertise and other clinical skills to meet the demands for transplantation as donor numbers increase.	Commissioners

Commissioning a shared donation service – NORS

The National Organ Retrieval Service (NORS) was developed following the Organ Donation Taskforce (ODTF) recommendations. The service has been commissioned since April 2010 and ensures there are fully staffed retrieval teams who are available 24/7 to retrieve donated organs from any hospital within the UK. The current service configuration works well, but, as the new strategy is implemented there is a need to continue to commission an effective and cost-efficient service that is responsive to the needs of the donor hospitals and transplant centres. It will be important to ensure that the retrieval service can respond to increasing numbers of donors but does not include underutilised capacity. The service will be reviewed to ensure it remains fit for purpose.

Actions for configuration of NORS	
Specific Action	Responsibility
Implement the recommendations from the forthcoming Cardiothoracic Examination of Issues.	Commissioners, NHSBT
Review the NORS service to ensure that there is sufficient capacity and flexibility within the retrieval teams to meet any increase in donation.	NHSBT

Research and Development

As with every aspect of healthcare, best practice should be based on a robust evidence base. The UK is very competitive in many aspects of research in both organ donation and transplantation. Much research is done by scientists and clinicians working in their respective university and clinical departments and supported by local, national and international funding. However, NHSBT has been actively involved in both initiating and supporting clinical research and, since 2008, staff at NHSBT have been authors in publications in peer-reviewed journals.

Over the past five years, NHSBT has actively supported research through project funding and clinical trials, and has funded clinical research fellows, and supported honorary fellows to work on projects that are directly aligned with NHSBT’s strategic aims. Furthermore, in the last two years, NHSBT has funded QUOD (Quality in Organ Donation, a bioresource and basic laboratory support, based in the University of Oxford) which will provide a unique resource to support translational research focusing on quality in organ donation. NHSBT has also funded a Clinical Trials Resource that will provide advice and practical support for clinical trials that will not only help clinicians with specialist knowledge in transplant trials but, because of the close links with the Registry, provide an efficient and cost-effective trials unit.

Despite these developments, NHSBT needs to do more to increase organ donation and transplantation research and development, within the resources available, to identify best practice, and support new research initiatives that are in line with our strategic aims.

Actions for improvement in Research and Development

Specific Action	Responsibility
Develop a programme of sponsoring systematic reviews to assess the current evidence base in aspects of donor identification, consent, donor and organ characterisation and retrieval.	NHSBT
Review and further improve ability to support clinical research studies that are in line with strategic goals of increasing the availability, quality and outcomes of donated organs.	NHSBT
Develop an integrated programme to support clinical fellows in healthcare to undertake or support clinical studies and reviews.	Professional bodies, NHSBT

Contracts

Hospitals with 40 or more potential donors annually receive a similar organ donation service to hospitals with fewer than ten potential donors a year. Specialist Nurses work long hours trying to meet the needs of the donor family, caring for the donor to improve organ quality, gathering information about the donor and offering organs to the transplant community. Clinical Leads for Organ Donation (CLODs) and Donation Committee Chairs work hard to change hospital systems and practice but may find themselves doing so with little support from within their organisation. Learning from the experience in the US, systems will be established to specify the levels of service that hospitals and NHSBT should provide in relation to organ donation. Subject to regional variations in Government policy, this will involve the development of contracts with hospitals, clarifying how the donor service, provided jointly by the hospital and NHSBT staff, will work.

The contract will be developed with the Regional Collaboratives and individual hospitals and, utilising funding currently available to the hospital through donor reimbursement, would be a vehicle for a range of performance management targets and incentives, such as:

- Fixed levels of funding for predicted donor activity
- Marginal rates of funding for donations above target
- Implementation of NICE guidelines and other appropriate standards to ensure timely identification, referral and assessment of potential donors.

This approach would mean that the level of service to be provided by both hospitals and NHSBT is clear and underpinned by contractual arrangements which support performance improvement and encourage all hospitals to achieve their full potential for organ donation and transplantation. Information about individual hospital performance in organ donation and transplantation is routinely available to both hospitals and the public.

Action to improve contractual arrangements

Specific Action	Responsibility
Subject to variations in regional policies, establish formal contracts between NHSBT and hospitals, specifying how hospitals and the NHSBT donation service work together to achieve excellence.	NHSBT, NHS, UK Health Departments/Commissioners

Section four

Measuring success

Achieving the aim of the strategy for the UK to match the best in the world will require focus and sustained collaborative effort by both individuals and organisations. It is important to be able to understand whether the sum of these actions is having the expected impact. A number of measures will be used to track improvements in performance and to compare with international benchmarks. It is likely to take longer than seven years to achieve these measures fully, but they represent world-class performance and should be the aspiration for the UK.

Measure 1 Consent/authorisation for organ donation

Aim for consent/authorisation rate in excess of 80% (currently 57%)¹⁶

Rationale: Improving consent/authorisation rates is our most important strategic aim and is fundamental to the success of the strategy. Spain achieved an 84% consent rate in 2011, based primarily on potential DBD donors. In the UK it has proved more difficult to obtain consent for DCD donors, which make up an increasing proportion of our deceased donor pool. Using Spain as a benchmark but taking account of differences between UK and Spanish donor pools, achieving a measure of at least 80% consent would compare very favourably with European counterparts. This will be very challenging to achieve, particularly for Black, Asian and Minority Ethnic communities where family refusal rates are 66% but rewards for donors, their families and for organ transplant recipients are enormous.

¹⁶ Figures for Wales should be measured separately after the implementation of the planned Wales Human Transplantation Bill in 2015.

Measure 2 Deceased organ donation

Aim for 26 deceased donors per million population (pmp) (currently 19.1 pmp)

Rationale: The deceased donor rate in the UK has increased by seven donors pmp over the last five years. Another such increase would mean a deceased donor rate of 26 pmp in the UK and would bring all regions up to the standard of the best performing team in the UK. Given the considerable changes in the UK over the last five years, this aim is very challenging and will not be achieved without a change in public attitudes and behaviour and an improvement in consent/authorisation rates. Such a rate should compare very favourably against the benchmark countries of Spain, Portugal, Croatia, USA and France (the top performing countries in 2011), with the UK aiming to be one of the top five of comparator countries.

Measure 3 Organ utilisation

Aim to transplant 5% more of the organs offered from consented, actual donors

Aim for:

- 85% of abdominal* organs from DBD donors to be transplanted (currently 80%)
- 35% of hearts and lungs from DBD donors to be transplanted (currently 30%)
- 65% of abdominal organs from DCD donors to be transplanted (currently 60%)
- 12% of lungs from DCD donors to be transplanted (currently 7%).

* Kidney, liver and pancreas.

These measures will be kept under regular review, as they will be subject to change as improved technologies and techniques for organ preservation become available.

Rationale: An efficient organ offering, retrieval and transplant system will use: (i) suitable triage arrangements such that offers of unsuitable organs are minimised; (ii) effective donor optimisation; perfusion and preservation techniques so that organ quality is maximised, and (iii) efficient organ-offering processes so that organs can be directed to suitable recipients as quickly as possible. Transplant rates of organs from deceased donors will increase as such systems develop. 5% more organs transplanted in each of these groups means that 5% more patients would receive a transplant rather than risk death on the transplant list.

Measure 4 Patients transplanted

Aim for a deceased donor transplant rate of 74 pmp (currently 49 pmp)

Rationale: The ultimate aim of this strategy is to increase the number of patients who are transplanted and give everyone on the transplant list a realistic chance of receiving the life-saving or life-enhancing transplant that they need. If all the steps in the donation and transplantation pathway work as well as possible and more people donate their organs then deceased donor rates of 74 pmp should be achievable.

Currently, in the UK there are 39 deceased donor transplants for every 100 patients on the transplant list at year end. An increase in the transplant rate to 74 pmp would mean 58 transplants per 100 patients on the transplant list at year end (based on current transplant list figures). This figure compares much more favourably with current international benchmarks: 70 per 100 in Spain, 45 per 100 in France and 32 per 100 in the US, although different rates of underlying disease and different listing practices make it difficult to achieve a meaningful comparison.

Aiming for 74 transplants pmp is challenging, but achieving it will provide life-saving transplants for many more patients and would match world-class performance.



A collaborative UK strategy between

