

Taking Organ Transplantation to 2020

A UK 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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www.nhsbt.nhs.uk/to2020

A collaborative UK strategy between



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Foreword

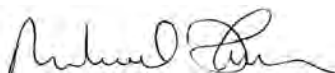
It is five years since the Organ Donation Taskforce published 'Organs for Transplants'¹, which set out a series of recommendations for increasing the UK organ donor rate and suggested that, if all the recommendations were implemented, then the deceased donor rates would increase by 50% by 2013.

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.

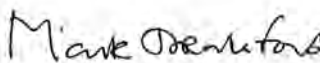
However, there is still more we can do. Currently there are over 7,000 people on the UK national transplant waiting list and, during the last financial year, over 1,300 people either died whilst on the waiting list or became too sick to receive a transplant. It is therefore vital that we continue to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

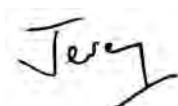
We have built on their knowledge and advice to develop a new strategy, which aims to enable the UK to match world-class performance in organ donation and transplantation.



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 Organ Donation Taskforce, *Organs for Transplant. A report from the Organ Donation Taskforce*. January 2008. Department of Health.

Taking Organ Transplantation to 2020: A UK strategy

The UK can and must do more to save and improve lives through organ donation and transplantation. The NHS still does not support some people who want to donate and more can be done to ensure that donated organs are used.

The NHS needs to build on the excellent progress achieved in the past five years, pursue consistently excellent practice in the care of every potential donor and maximise the use of every available organ. Getting it right every time in hospital, however, will not be enough. Unless people in the UK are prepared to donate their organs when and if they can and families are proud to agree to donation when their relative's wish is unknown, these aims cannot be achieved. The UK needs a transformation in donor and family consent to match the transformation already underway in NHS organ donation and transplantation services.

The aim is to match world-class performance in organ donation and transplantation.

Three groups (society and individuals, NHS hospitals and staff, NHSBT and Commissioners²) need to act for this strategy to be successful and achieve the desired outcomes. Action from Government, professional bodies and the voluntary sector in support will be essential too. Should any of these groups fail to respond the aims of this strategy will not be fully achieved.

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 term Commissioners is used to cover those who are responsible for planning and funding transplantation, recognising that there are different systems across the UK

More needs to be done

Despite five years of progress and a 50% increase in the number of deceased organ donors since 2008, the UK still faces a shortage of donated organs and people waiting for a transplant still die. Over half a million people die each year in the UK but fewer than five thousand people a year die in circumstances or from conditions where they can become donors.

Evolution in the NHS

Government and the NHS need to explore whether there are potential donors who are overlooked or whether changes to end-of-life care might allow more people to donate. Although there have been big improvements in hospitals with respect to organ donation, there is still considerable variation in practice between different regions and hospitals. If every region performed at the level of the best, it is estimated that there would be over 500 (45%) more donors than the 1,212 who actually donated organs last year.

Variation in organ usage

Once consent for donation is given, there are considerable variations in how organs are used. The decision on whether a particular organ is suitable for a particular recipient is difficult to make and involves a balance of risk and benefit with consideration given to both donor and the potential recipient.

In future, with more support and information, surgeons should be confident to use more of the available organs. Sometimes donation does not go ahead because of timing and logistical issues. Families of donors who die following circulatory death³ can find the time it takes to evaluate the donor and retrieve and implant their relative's organs too stressful and so they withdraw consent. Streamlining systems may reduce the difficulties families face and improve support to clinicians too.

This strategy is intended to provide the UK organ donation and transplantation community with what it needs to match the best in the world. An evolution of NHS services and a revolution in public behaviour are required to achieve this.

A revolution in consent

The revolution in public behaviour is needed in one key area – consent⁴ if the UK is to match those countries that perform best – such as Spain. Although more people have agreed to donate organs over the past five years, this is because more people have been asked to do so. The proportion of families who refuse to allow their relative's organs to be used, sometimes even when they are informed that their relative wanted to be a donor, has not changed in most parts of the UK. Most people in the UK would accept an organ from someone else, if they needed one, but the majority have not signed up to donate their own organs. Those who do join the NHS Organ Donor Register (ODR) often do not tell their families, who then may feel unable to support that wish.

Although there are over 19.5 million people on the ODR, most will die in circumstances or from conditions where organ donation is not possible. Ideally, everybody should be prepared to donate if they are able to do so and families should support their relative's wishes.

Without organ donation there can be no transplantation

As a society we need to recognise that without organ donation there can be no transplantation. Indeed, when a family refuses to support a relative's wish to donate or is unwilling to make the decision on his or her behalf, someone else will die. This strategy aims to provide the leadership, education and recognition that will make UK citizens proud to donate. This is particularly relevant for people from Black, Asian and Minority Ethnic (BAME) communities, who represent 27% of those on the waiting list but only constitute 5% of organ donors.

The Welsh Government has made a bold move 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 may 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.⁵

³ Donation may follow the declaration of death according to neurological criteria known as Donation after Brain Death (DBD) or it may follow circulatory death known as Donation after Circulatory Death (DCD).

⁴ Where the term consent is used, this should also be taken to refer to 'authorisation', the term used in the legislation in Scotland.

⁵ The Welsh Government's view is that international evidence suggests it could see a 25% increase in the donation rate.

What will organ donation and transplantation look like in 2020?

Outcome 1

Action by society and individuals will mean that the UK's organ donation record is amongst the best in the world and people donate when and if they can.

Society will expect that donation will be the natural outcome for individuals who die in circumstances where donation is a possibility. More people in the UK will actively support donation and will have pledged to donate their organs using a range of different mechanisms (such as joining the NHS Organ Donor Register, carrying a card and via prompted choice schemes such as the DVLA) and told their families and friends of their wish to donate. Families will be better prepared to play their crucial role in the organ donation process. They will be aware of their relative's wishes, expect to be asked about organ donation if this is a possibility and be prepared to support their relative's wish to be a donor. It will be very rare for a family to override a pledge to donate. In the increasingly small number of instances where their relative's views are unknown, families will be proud to donate on their behalf. As a consequence, society as a whole will be proud of its record and the life chances offered to patients who previously would have died.

All UK countries will have a higher rate of consent. In Wales the Government has brought forward legislation to introduce a soft opt-out system for consent to organ donation from 2015. The expectation of the Welsh Government is that this will increase the proportion of people who donate organs. This change will be watched carefully to see the effect on the donation and transplantation programme.

People from BAME communities will understand that they are more likely to need a transplant than the wider population, will recognise the benefits of donation and donation rates from these communities will more closely match those of the wider population.

Outcome 2

Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.

Every hospital will routinely identify and refer everyone with the potential to donate, regardless of where they die or whether death is determined using neurological or cardio-respiratory criteria. Critical care clinicians will be provided with clear standards of practice that underpin an expectation that a neurological determination of death is made wherever this appears to be a likely diagnosis, even should this require a period of stabilisation and observation or ancillary investigation. Following a Scottish pilot, more centres will be able to offer donation following unexpected witnessed cardiac arrest and failed resuscitation. Each potential donor's eligibility will be assessed rapidly, and where donation is an option, all families will be approached by a trained and skilled clinical team and provided with the advice and support they need to make an informed decision about organ donation.

Every eligible, consented donor will be cared for to make sure that their wish to donate benefits as many people as possible and no opportunity to use the organs is lost. Coroners, Procurators Fiscal, their officers and the police will support donation where this does not impede their responsibilities.

There will be greater clarity for hospital staff about what interventions are legal and ethical to support good organ function. Where donors have given express consent for donation, their end-of-life care will be managed to enable their wishes to be fulfilled. In Wales and any other UK country that may have introduced an opt-out scheme for organ donation new legislation will result in more families supporting donation where their relative had expressed or deemed consent. There will be good evidence on which to debate whether the legal system should be changed elsewhere in the UK.

Society and individuals

Attitudes to organ donation will change and people will be proud to donate, when and if they can.



Martyn was only 23 when his life ended suddenly in a road traffic accident. Yet in the middle of their tragedy, only hours after his death, his family decided to let others be helped through the donation of his tissues.

Outcome 3

Action by NHS hospitals and staff means that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.

Retrieval will be planned to make sure that as many organs as possible are used and retrieval surgeons will have a better range of options for preserving organs after retrieval.

Transplant surgeons will have more information and guidance to help them decide which organs can be safely and effectively transplanted into which recipients.

There will be greater consistency in the acceptance of offers of organs between transplant centres and surgeons, a greater proportion of organs will be transplanted safely and more lives will be saved or dramatically improved. The UK will transplant more organs, particularly more hearts and lungs, where this is the best option for the patient.

Patient selection for the transplant waiting list and organ allocation policies, underpinned by research, will support and enable a reduction in graft failure rates thereby reducing avoidable premature mortality.

Outcome 4

Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

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

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.

Clinicians and other staff involved with organ donation, retrieval and transplantation are trained, skilled and motivated to achieve excellence and receive regular feedback to enable them to monitor their achievements.

A national referral service will support the donation and transplant process, through accessing donor wishes, rapid triage to determine whether a patient is a potential donor and co-ordination of resources, including specialist nurses and retrieval teams.

An efficient information technology service supporting every element of the organ donation and transplantation pathway is designed to meet the needs of clinicians and other users and reduce inefficiencies. This will include a newly built register for recording organ donation wishes.

A co-ordinated and sustainable programme of research will provide an evidence base for clinicians and policy makers to continue to ensure that successful, innovative techniques are identified and used to benefit organ donors, their families and those on the transplant waiting list.

How will these outcomes be achieved?

Outcome 1

Action by society and individuals will mean that the UK's organ donation record is among the best in the world and people donate when and if they can.

Outside the NHS, knowledge of organ donation remains low and while most people would accept an organ if they needed a transplant, only a third of the population indicates a wish to donate after death by putting their names on the ODR. Although over half a million people die every year in the UK, fewer than five thousand people die in circumstances where they can become an organ donor. The UK needs a shift in behaviour comparable to the changes achieved in preventing drink-driving or smoking cessation. There is evidence that education and publicity campaigns highlight the importance of organ donation and increase willingness to donate. The four UK countries, with the support of NHSBT and in the context of their own legal frameworks, will develop strategies for changing the behaviour of their citizens and NHSBT will regularly monitor public attitudes in each country.

Making a positive decision to donate

Families of people who have the potential to donate organs are faced with making decisions for which they are often unprepared. Where people have made an explicit decision in life to be a donor, it is much easier for their family to know what to do. Education programmes can encourage more people to consent in life but it is naive to assume that everyone will make a decision and tell their family what they want. If families are to be confident to consent in the absence of knowledge of their loved ones' wishes, then they must feel that this is a positive decision, one which they can be proud of and one for which their community and country honours them.

In Wales, the Government has brought forward legislation to introduce a soft opt-out system for consent to organ donation from 2015. The expectation is that this will increase the proportion of people who donate organs. This change will be followed with interest to see if the expected increases are delivered.

Where individuals have given express consent, it is important that this consent is honoured and that families accept their relative's intention. In 2012/13 there were 115 (13%) families who refused to support express consent compared with 799 families who supported their relative's wish. The UK will review, in the light of American experience, systems where families are not permitted to override pre-existing consent so people can be confident their pledge will be respected.

BAME communities

People from BAME communities are up to three times more likely to need a transplant than the wider population. They also wait longer for their transplant and those waiting for a kidney transplant are more likely to die before the right organ match can be found for them. A good organ match is important because it results in better outcomes for the transplant recipient. These inequalities will only be addressed when BAME families routinely consent to organ donation. In partnership with the National Black Asian and Minority Ethnic Transplant Alliance (NBTA), as well as targeted engagement in the other UK countries, work will continue to engage with BAME communities to promote the importance and benefits of donation. Further training and support will be provided for those who approach BAME families to discuss donation.

To achieve Outcome 1 the UK should:

- **Develop national strategies to promote a shift in behaviour and increase consent.**
- **Ensure that it is easy to pledge support for organ donation and once a pledge has been given, to honour the individual's wish.**
- **Increase Black, Asian and Minority Ethnic communities' awareness of the need for donation to benefit their own communities and provide better support for people in these communities to donate.**
- **Learn from the experience of legislative change in Wales.**

Outcome 2

Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.

The Organ Donation Taskforce (ODTF) made it clear that every person in the UK can expect to be considered as a potential donor as part of his or her end-of-life care where it is medically possible. The General Medical Council (GMC) has set out doctors' responsibilities to make this happen. Hospitals identify and refer 68% of the small group of people (fewer than five thousand a year) who die in circumstances which allow them to donate but more can be done to increase the total group of donors.

It should be possible to increase the numbers of people who are able to donate their organs by exploring three areas. Firstly, by reviewing the impact of end-of-life care practices on the potential for donation after brain-stem death (DBD). There are relatively low numbers of potential DBD donors in the UK compared with other countries and this appears to be a direct result of clinical decisions to limit or withdraw treatment to patients with non-survivable brain injury before death of the brain has occurred or can be diagnosed. Even where brain-stem death testing is possible this often does not happen. Clinical practice in end-of-life care needs to be reviewed to promote donation, particularly for those who have pledged to donate.

Secondly, there is a significant proportion of people who may be able to donate after clinicians decide to withdraw or limit treatment (DCD donors). Currently, only 63% of these potential donors are referred. More people will have the opportunity to donate by making it easier and quicker to assess these patients' eligibility for donation.

Thirdly, a pilot in Scotland seeks to give the option of donation to people following unexpected witnessed cardiac arrest and failed resuscitation – as happens in Spain. If successful this option should be developed in other major centres.

A planned approach to organ donation

Donor identification and referral is only part of the story. The NHS needs to offer an excellent, caring service to potential donors and their families. This involves a planned approach to the subject of organ donation which ensures that families are supported by people with the right skills and knowledge and given time to consider the benefits of donation. Good practice in this area is essential to increasing the numbers of families who support their relative's wish to consent or who feel able to consent on their behalf when their wishes are unknown.

The care a person receives at the end of their life can have a significant impact on the functioning of their organs and without the right support, otherwise transplantable organs may become unusable. It will be important to ensure that clinicians have the expertise and help to make sure that as many organs from deceased donors as possible can be used.

Professional bodies will develop standards of care, based on existing and emerging national guidance, which would lead to increasing BSD testing and therefore increasing numbers of potential donors following brain death.

Hospitals will be held to account for the quality of their organ donation practice using a variety of mechanisms. Comparative data will be published showing performance by each Trust or Health Board.⁶ NHSBT will develop formal contracts with major donor Trusts/Boards establishing what is expected and how this will be funded and performance managed. Practice should follow the National Institute for Health and Clinical Excellence guideline CG135. Organ Donation and Organ Donation Committees will audit practice against this guideline.

To achieve Outcome 2 the UK should:

- **Increase adherence to national standards and guidance.**
- **Increase the number of people who are able to donate following circulatory death and learn from the Scottish pilot on donation after failed resuscitation.**
- **Provide hospital staff with the support, training, resources and information they need to provide an excellent organ donation service.**
- **Ensure every donor's care, prior to retrieval, optimises organ quality.**

⁶ The format for publication will depend on the different types of hospital organisation across the UK.

NHS hospitals and staff

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.



Outcome 3

Action by NHS hospitals and staff means that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.

Once consent has been given for the use of the donor's organs for transplantation, the organs need to be retrieved expertly and transported efficiently to the transplant centre for implantation. The timing of retrieval will depend on the type of donor (DBD or DCD) and which organs are to be retrieved. After brain death, the functioning of some organs (such as hearts and lungs) may be improved by extending the care of the donor enabling an increase in the number of transplants and better outcomes for the recipients. Organ retrieval is a very intricate procedure and has to be undertaken quickly in DCD donors so as to minimise organ deterioration. A new training and accreditation programme will ensure high levels of skills are maintained.

New technologies, such as specialist perfusion machines, which aim to preserve and improve the quality of organs after removal and evaluate which organs should or should not be used are being explored. If successful, it is estimated that 5% more organs which currently prove to be unusable, could be transplanted.

Opportunities for transplantation are lost at all stages of the process from offering to implantation and while there is a valid clinical reason for this in most cases, there are some instances when variation in practice is unexplained. A range of measures such as evidence-based risk assessment guidance, peer review and comparative data will support surgeons to assess the risk/benefit of using an organ. Research will lead to better biomarkers of organ function and help clinicians decide which organ will be best for which recipient and improve graft survival, reducing the need for re-transplantation later.

To achieve Outcome 3 the UK should:

- **Increase the number of organs that are retrieved from both DBD and DCD donors.**
- **Increase the number of organs that can be transplanted safely, and provide surgeons with the information and guidance to make decisions about organ suitability.**
- **Improve transplant recipient survival by improving understanding of the donor organ/recipient compatibility.**

Outcome 4

Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

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

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 of Organ Donation (CL-ODs) 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. 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.

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.

The Regional Collaboratives

The development of twelve Regional Collaboratives, led by Regional Clinical Leads and Regional Donation Service Managers, has been successful in providing a supportive environment for Clinical Leads, Chairs and Specialist Nurses to work together on how best to increase organ donation. However, they often gain only limited involvement with the retrieval teams and transplant centres that implant the organs. Organ donation, retrieval and transplantation teams need to work more closely together, so as to build trust and support improvements, particularly in donor management and organ offering. Regional Collaboratives will now bring everyone together to focus on improvements throughout the clinical pathway.

The entire donation and transplantation pathway has developed over time and can be unnecessarily complex and lengthy. Learning from 'lean' techniques that have been used successfully elsewhere in the NHS, it should be possible to simplify and speed up processes and improve the service offered to clinicians and families. Advantage needs to be taken of the benefits of recent technological advances, for example moving from laptops to tablets or mobile phones where these can help staff work more safely and efficiently. IT systems and applications will be re-developed to meet modern standards, making support systems more efficient, effective and easier for the clinicians who rely on them.

Over the last five years, NHSBT has provided training to Clinical Leads for Organ Donation, Donation Committee Chairs and Specialist Nurses for Organ Donation. General training in organ donation now needs to be available to more key staff working in intensive care and emergency departments and training in planning and approaching families should be more widely available to consultant staff in hospitals (this model has already been implemented in Scotland). A specialist training scheme for retrieval surgeons is planned to standardise and accredit their training.

To achieve Outcome 4 the UK should:

- **Support Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practice and promote organ donation.**
- **Review and improve the workforce, IT, systems and processes which operate throughout the donation and transplant pathway.**
- **Build a sustainable training and development programme which can be tailored to meet local needs, so as to support organ donation and retrieval.**

Measuring success

Focus and sustained collaborative effort by individuals and organisations is required for the UK to achieve the aim of matching the best in the world. It is important 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 UK aspiration.

Measure 1

Consent/authorisation for organ donation

Aim for consent/authorisation rate above 80% (currently 57%)⁷

Improving consent/authorisation rates is the single most important strategic aim and fundamental to the success of the strategy as a whole. 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, who 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. It will be a challenge to achieve this, particularly for Black, Asian and Minority Ethnic communities where family refusal rates are 66%. But the challenge could not be more worthwhile given that the rewards for donors, their families and for organ transplant recipients are enormous.

Measure 2

Deceased organ donation

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

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. This rate would compare very favourably against the benchmark countries of Spain, Portugal, Croatia, USA and France (the top performing countries in 2011), and aims for the UK to be among the top five of comparator countries.

⁷ Figures for Wales should be measured separately after the implementation of the planned Wales Human Transplantation Bill in 2015.

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%), and
- 12% of lungs from DCD donors to be transplanted (currently 7%).

* Kidney, liver and pancreas.

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

An efficient organ offering, retrieval and transplant system will use: (i) suitable triage arrangements so that there are minimal offers of unsuitable organs; (ii) effective donor optimisation and organ 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 further as such systems develop. However, the UK's rate of organ utilisation already compares well with other countries and 94% of actual donors result in at least one transplant compared with 86% in Spain and 87% in the US. Nevertheless, 5% more organs transplanted 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)

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.

It will be challenging to aim for 74 transplants pmp but achieving this figure would provide life-saving transplants for many more patients and would mean the UK matches world-class performance.

NHS hospitals and staff

More organs will be usable and surgeons will be better supported to transplant organs safely into the most appropriate recipient.



Appendix 1

Background to organ donation and transplantation in the UK and the development of the strategy

Five years of progress

The Organ Donation Taskforce was charged with identifying how the UK should improve its organ donation performance, which was lagging behind many other Western nations. The Taskforce reported in January 2008 and made 14 recommendations.⁸ It suggested that full implementation of the recommendations might lead to a 50% increase in the number of deceased organ donors. Since then, all the recommendations have been implemented and deceased donor numbers have risen in line with expectations. This is a great tribute to all the donors, their families and the doctors and nurses who made this possible. There are people alive today following a transplant who would otherwise have died.

Organ donation in the NHS has been transformed: there are more Specialist Nurses in Organ Donation to support families, every hospital has access to a dedicated Clinical Lead and is supported by a Donation Committee and there are dedicated organ retrieval teams serving the entire UK, 24 hours a day. Clinicians now have access to ethical and legal advice to help them facilitate donation, the National Institute for Clinical Evidence has published best practice guidelines and training and development programmes have improved knowledge and skills. Regional Collaboratives bring together leaders in organ donation, to promote the need for donors and provide support for service improvement. Clinicians increasingly view organ donation as a normal part of end-of-life care.

Organ donation in the UK

Although attitudes to and support for organ donation in the NHS have changed considerably, some outcomes were unexpected. The Taskforce anticipated that most donors would be people in intensive care units who had been declared dead according to neurological criteria, that is, donors after brain death (DBD). In fact, the numbers of people dying in this way has fallen in most parts of the UK.

Patients with non-survivable brain injuries are assessed in emergency departments and when doctors determine that further treatment is futile, these patients and their families are also now offered the option of organ donation via established referral pathways. UK hospitals are now able to offer donation to this group of people, known as donors after circulatory death (DCD). At present, DCD donors cannot donate their hearts and this contributes to the low levels of heart transplantation in the UK. It has taken time to build confidence in the process for DCD donation and therefore transplant numbers have not risen at the same rate as donor numbers. Further developments in DCD donation are likely: Spain⁹ for example, now offers donation to people who have died following an unexpected cardiac arrest where resuscitation has failed. A pilot in Scotland seeks to replicate the Spanish experience.

The UK has developed living donation in part to attempt to meet the demand for transplants. Living donation is when a relative or friend or, in exceptional circumstances, an anonymous individual, gives a kidney (and more rarely part of a liver) to another person. Living donation is the subject of a separate strategy launched in January 2012.¹⁰

In the UK 58% of all deceased donors are DBD and 42% are DCD. This compares with Spain where in 2011, 91% of deceased donors were DBD and 9% were DCD. Unless there are significant changes to end-of-life care in the UK this picture is unlikely to change.

⁸ Organs for transplants: a report from the Organ Donation Taskforce, Department of Health, January 2008.

⁹ Spain has the highest number of deceased donors per million population and is useful comparator.

¹⁰ The NHSBT UK strategy for living donor Kidney Transplantation 2010-2014. Formally launched January 2012. NHS Blood and Transplant.

The demand for transplantation

Evidence suggests that changes in UK lifestyles and disease prevalence will mean that the need for cardio-thoracic and liver transplants will continue to increase in the future. There are wide-ranging prevention programmes underway across the UK to persuade people to live healthier lives and reduce the incidence of diseases such as diabetes and heart failure which lead to organ failure. These health improvement measures to reduce lifestyle-related disease are welcome but are unlikely to reverse the increasing trend within the next seven years. Even if this were not the case, the number of people who would benefit from transplantation, particularly heart transplantation, far exceeds the numbers of organs available. We can say with some confidence that the UK waiting list considerably under-represents the true number of people who could benefit from an organ transplant. The prevalence of renal disease, however, appears to have stabilised, but there are still not enough donated organs available to meet the current requirements.

Resourcing the strategy

At a time of financial austerity some people may be concerned that increasing transplantation will take resources from other areas of NHS care. On the contrary, work undertaken in 2010¹¹ identified that the transplant programme delivered a cost saving to the NHS of £316 million and that savings have the potential to increase further as the number of transplant procedures rise.

Initially, no additional funding is likely to be needed to move forward: the need is to work differently rather than increase resources. However, looking ahead, there are technological developments, pilot initiatives and other programmes capable of bringing improvements. 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 ambitious publicity campaigns which will work to shift public attitudes and gain similar outcomes to those achieved from public information campaigns aimed at stopping drink-driving and smoking cessation.

How the strategy was developed

Organ donation and transplantation is a complex process involving dying patients, their families, clinical staff in many hospitals (up to nine hospitals may be involved in any single donation and transplantation process) and laboratory staff. Many other people have an interest: those waiting for transplants and their families, transplant recipients, donor families, voluntary sector organisations, people who have pledged to donate by joining the ODR and the general public.

NHSBT is co-ordinating this strategy on behalf of the four UK Health Departments and the NHS and has consulted with hundreds of people about what should be done to address the shortage of organs for transplantation. As well as listening to partners and stakeholders, a portfolio of evidence¹² about UK performance compared with other countries was considered. Clinicians also considered the clinical and technological developments that might affect donation and transplantation over the next seven years. A group of international and national experts met to assess the strategic priorities and planned actions and to assure NHSBT that the proposals would deliver the expected outcomes. It has not been possible to include every suggestion but a companion report outlines the ideas that are not being taken forward as part of this strategy.

¹¹ 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.

¹² Portfolio of Evidence available at: www.nhsbt.nhs.uk/to2020

Appendix 2

Actions of the detailed plan

Aim to match world-class performance in organ donation and transplantation

Outcome 1 Action by society and individuals will mean that the UK’s organ donation record is amongst the best in the world and people donate when and if they can.

- Develop national strategies to promote a shift in behaviour and increase consent.
- Ensure that it is easy to pledge support for organ donation and once a pledge has been given, honour the individual’s wish.
- Increase Black, Asian and Minority Ethnic community awareness of the need to donate, to benefit their own communities and provide better support for people in these communities to donate.
- Learn from the experience of legislative change in Wales and elsewhere.

Specific Actions	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 issues into schools curricula.	All 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.	All UK Governments
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.	UK Government, NHSBT
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 and 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
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



Susan Lee Clarke received a liver transplant in 2007, she is pictured here with her son Harry at the opening of the donor memorial wall at the Royal Free hospital, London.

Outcome 2 Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.

- Increase the number of people who are able to donate following brain death.
- Increase the number of people who are able to donate following circulatory death and learn from the Scottish pilot on donation after failed resuscitation.
- Provide hospital staff with the support, training, resources and information they need to provide an excellent organ donation service.
- Ensure every donor's care, prior to retrieval, boosts organ quality.

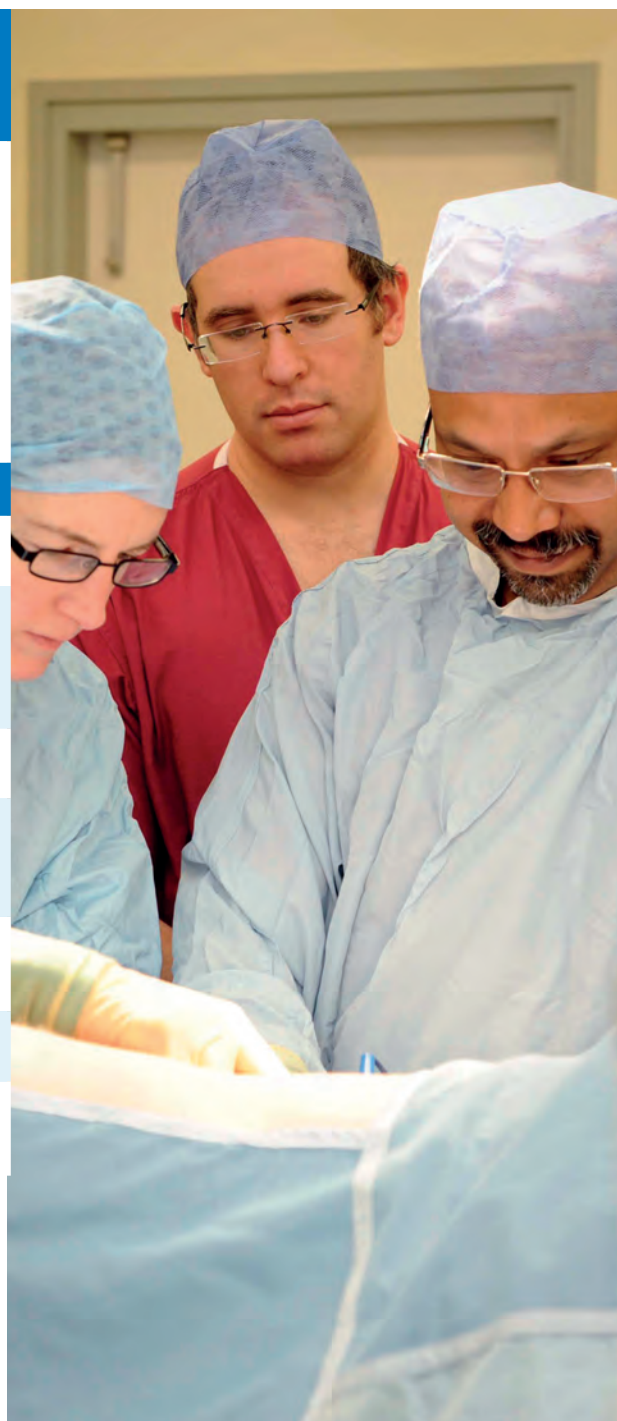
Specific Actions	Responsibility
End-of-life care standards should promote BSD testing as the preferred method of diagnosing death, where this can be achieved and is in the best interests of the patient.	Professional bodies, national legal and ethics organisations
End-of-life care practices should be reviewed to establish whether they might be adjusted so as to promote donation after DBD.	Professional bodies, national legal and ethics organisations
Establish a National Referral Service to improve support to hospitals.	NHSBT
Scope the potential for donation following unexpected cardiac arrest in the UK, learning from the pilot programme in Scotland.	NHSBT, NHS
Families of potential donors will only be approached by someone who is both specifically trained and competent in the role, training packages and accreditation will be provided to those who wish to develop this competence.	Professional bodies, NHS, NHSBT
Work collaboratively to reduce instances of objection to organ donation from the Coroner and Procurator Fiscal service and the police.	Governments, NHSBT
Publish hospital data to include: brain-stem death testing rates, donor referral rates, family approach rates, Specialist Nurse involvement and other key areas.	NHSBT



Outcome 3 Action by NHS hospitals and staff will mean that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.

- Increase the number of organs that are retrieved from both DBD and DCD donors.
- Increase the number of organs that can be transplanted safely, providing surgeons with the information and guidance to make decisions about organ suitability.
- Improve transplant recipient survival by improving understanding of the donor organ/recipient compatibility.

Specific Actions	Responsibility
Improve donor management for potential cardiothoracic donors, providing a 24/7 service to assist if pilot schemes prove effective.	NHSBT, NHS
Review what pre-mortem interventions could legally and ethically be undertaken to maximise the potential for organ donation (such as the administration of heparin, elective ventilation etc.).	UK Health Departments, UK Donation Ethics Committee, professional bodies
Evaluate new techniques and technologies for the preservation of retrieved organs with a view to their use in the UK.	NHSBT, professional bodies
Develop a system of peer review that is underpinned by a set of agreed standards for retrieval/transplant centres.	Transplant Commissioners, NHSBT, professional bodies
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
Publish centre-specific risk-adjusted patient survival from listing as well as from transplantation.	NHSBT
Ensure clinicians are aware of and follow, best practice to increase patient and graft survival.	Commissioners, NHSBT, professional bodies



Outcome 4 Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

- Support Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practice and promote organ donation.
- Review and improve the workforce, IT, systems and processes which operate throughout the donation and transplant pathway.
- Build a sustainable training and development programme to support organ donation and retrieval.

Specific Actions	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
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
Regional Collaboratives to lead local improvement in organ donation, retrieval and transplant practices and in local promotion of donation and transplantation.	NHSBT, NHS
Ensure that transplant centres have the capacity and surgical expertise and other clinical skills to meet the demands for transplantation as donor numbers increase.	Commissioners
Develop training programmes to sustain and increase clinicians' organ donation understanding and expertise.	NHSBT
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
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
Investigate the feasibility and implications for the provision of a 24/7 provision of expert histopathology advice.	Commissioners, NHSBT





A collaborative UK strategy between

