



Blood and Transplant

Information for Organ Donation Committee Chairs

April 2019



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Introduction

Organ donation and transplantation is one of the greatest success stories of modern medicine. Since its introduction in the UK in the 1960s, transplantation has saved and transformed tens of thousands of lives. Whilst the benefits to patients with kidney failure on dialysis can be quantified in terms of improved quality of life, improved life expectancy and even considerable financial savings, the benefits for those with end stage liver, lung or heart failure need much less analysis, because the alternative to transplantation is death.

Since 2008 and the implementation of the Organ Donation Taskforce recommendations¹ the UK has seen a welcome increase in organ donation and transplantation with a resulting eight consecutive year decrease in patients waiting for a transplant (**Figure 1**). Despite the 95% increase in organ donors, it is still estimated that an average of three people die every day in the UK through lack of a suitable donor organ, whilst many more never even get onto the transplant waiting lists because there is no realistic prospect of them ever receiving the offer of an organ.

Significant progress is still possible along the organ donation pathway. Using the comparative measure of deceased donors per million of population per year, UK rates of donation, although improving, still remain below those reported from many parts of mainland Europe and North America (**Figure 2**). There are also significant disparities between ethnic groups in the UK in terms of access to waiting lists, waiting times before transplantation (**Table 1**), and likelihood of a transplant.

The primary role of an Organ Donation Committee is to ensure that deceased organ donation national policies, guidelines and best practice are implemented and followed consistently in the Trust / Health Board. Secondary roles include championing deceased donation (both organ and tissue) in hospitals and to hospital staff and visitors, overcoming local barriers to donation, promoting donation to the wider local community and advising the local hospital on the best way to utilise NHS Blood and Transplant's (NHSBT) annual donor recognition funding.

¹ Organs for Transplants: A report from the Organ Donation Taskforce. London: Department of Health, 2008. Available from <http://www.nhsbt.nhs.uk/to2020/resources/OrgansfortransplantsTheOrganDonorTaskForce1streport.pdf> accessed January 2015

Figure 1. Number of deceased donors and the number of transplants from deceased donors each year, together with the number of patients on the active transplant waiting list on March 31st each year.

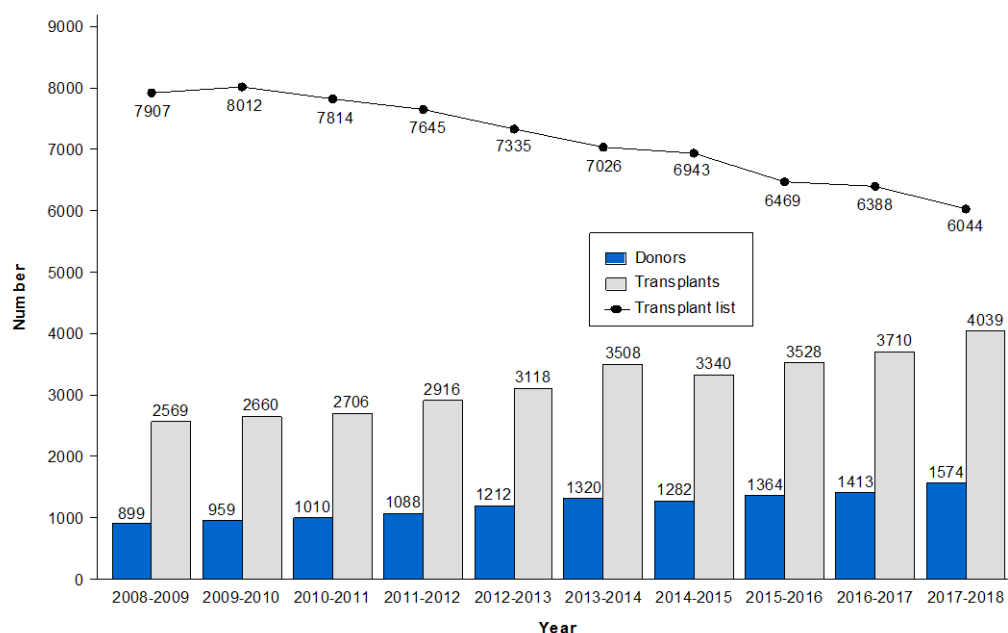


Figure 2. International deceased organ donation rates in 2017 expressed as donors per million of population (pmp).

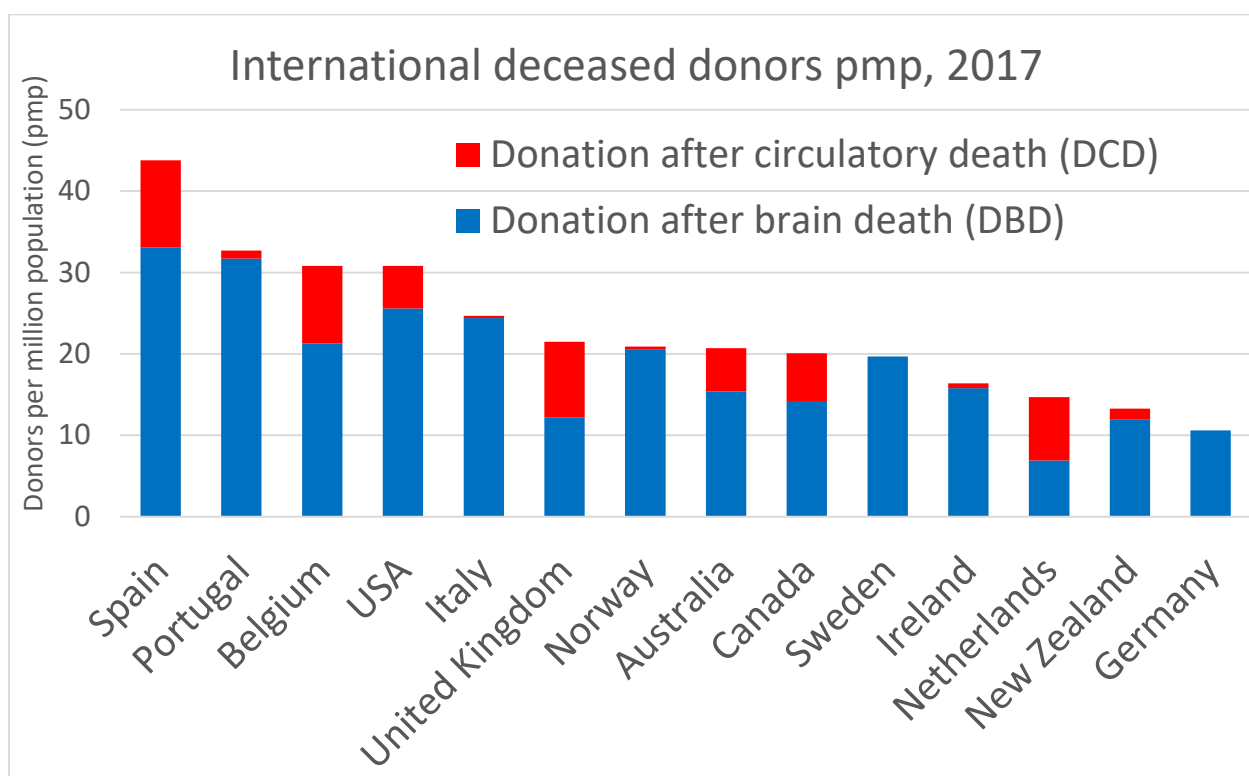


Table 1. Median waiting time to kidney only transplant in the UK for all adult and paediatric patients registered for transplant between 1 April 2011 – 31 March 2015, by ethnicity.

Ethnicity	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Adult			
White	6492	723	703 - 743
Asian	1515	891	846 - 936
Black	879	985	926 – 1044
Other	274	871	796 - 946
TOTAL¹	9303	782	764 - 800
Paediatric			
White	143	228	176 - 280
Asian	68	366	209 - 523
Black	18	323	0 - 668
Other	10	498	181 - 815
TOTAL²	243	277	212 - 342

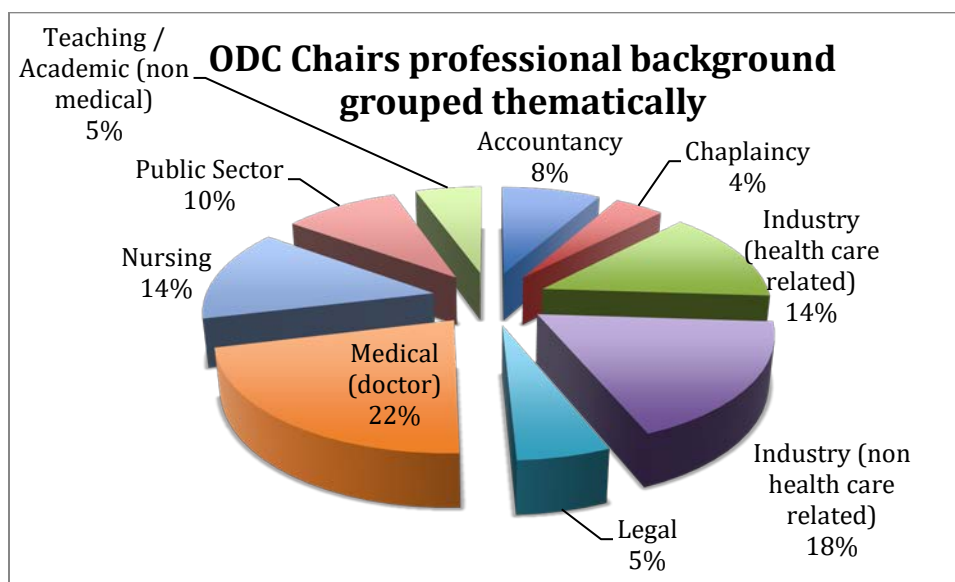
¹ Includes 143 patients whose ethnicity was not reported

² Includes 4 patients whose ethnicity was not reported

The role of the Organ Donation Committee Chair

The chair of a Trust or Health Board's Organ Donation Committee is an integral and important part of the deceased organ donation team whose other principal members are the Clinical Lead(s) and Specialist Nurse(s) for Organ Donation (CLOD and SNOD). The Committee Chair role is a voluntary one and is undertaken by a wide variety of people from many different backgrounds (**Figure 3**).

Figure 3. Organ Donation Committee Chairs' professional background (2014 ODC Chair Survey)



While many chairs are associated with the hospital in another capacity (for example as non-executive directors), others are lay people drawn from the local community. Some chairs have personal experience and/or extensive knowledge of organ donation while others take on the role with little or no understanding of donation at the outset.

There is also a great deal of variety in hospitals' experience of donation: for some organisations it is a reasonably common occurrence whereas other hospitals may only have two or three donors each year at most. This variability means that no two organ donation committees are the same and committees will tend to focus on different issues depending on their individual circumstances.

Nevertheless, regardless of all these variable factors, there are common aspects to the role of the organ donation committee chair.

Your key role as Chair is to:

1. Lead an effective and functioning hospital organ donation committee to champion and promote the value of organ donation.
2. Establish effective working relationships with key stakeholders throughout the hospital and within the wider community.
3. Provide constructive challenge where the potential donor audit (PDA) data demonstrates there have been missed opportunities for donation and identify action(s) to be taken for improvement.

Expanding upon this, it will be important as Chair to:

- Establish a good working relationship with the CLOD(s) and SNOD(s), communicating between meetings about any issues that arise and agreeing in advance the business of forthcoming meetings.
- Take time to understand as much about organ donation as possible, how donation works within your own organisation and where issues are most likely to arise which will need the attention of the organ donation committee.
- Monitor the Potential Donor Audit (PDA) for your organisation and provide constructive challenge where the data demonstrates that the hospital is underperforming.
- Support the CLOD(s) and SNOD(s) in their roles.
- Chair regular (quarterly) meetings of the Organ Donation Committee, ensuring as far as possible that there is representation from all the appropriate and relevant departments of the hospital at the meetings.
- Consider and agree with your Organ Donation Committee how best to use the funding available to you. This funding will consist principally of the donor recognition funding paid by NHSBT (see the section on Financial Support) but some committees may also have access to charitable or other funding.
- Where interest and resources permit, take a leading part in the promotion of organ donation both in your hospital and within your local community. It is hoped and expected that every Organ Donation Committee carries out some form of promotion activity during the annual Organ Donation Week.
- Represent, with the CLOD and SNOD, your Trust / Health Board at Regional Collaborative meetings.

To summarise, the FOUR big tasks of an Organ Donation Committee are to drive forward:

1. **Performance** – work to ensure there are no missed donation opportunities in your hospital.
2. **Policy** – ensure the hospital policies and guidelines support organ donation, are up to date and are in line with national guidance.
3. **Education** – ensure that any staff who may care for a potential donor are adequately trained.
4. **Promotion** – engage the public through opportunities within both the hospital (like the annual Organ Donation Week) and your local community.

Your role as the Organ Donation Committee Chair is not to deliver these tasks on your own. It's a team endeavour with your CLOD, SNOD and the other Committee members.

An Introduction to Organ Donation and Transplantation

Types of organ and tissue donation

Four types of donation (living and deceased) are possible from a human body (**Table 2**). Organ Donation Committees are primarily concerned with deceased organ donation but are encouraged to monitor tissue donation. Living donation and transplantation (eg kidneys and liver) is outside the recommended scope of most Committees, but links to living donation and transplantation could be established, if transplants of this nature are occurring in the Trust / Health Board.

Donation after Circulatory Death (DCD), where donation occurs after the heart has stopped beating, was the original type of deceased organ donation. Once the determination of death using neurological criteria became accepted in the 1960s and 70s, donation after brain (stem) death (DBD) became possible.

In DBD, deceased donors are maintained on a ventilator after death has been confirmed and the heart, lungs and other organs are supported, optimised and remain functioning up to the point that the donor's organs are retrieved. By contrast in DCD, damage (warm ischaemia) will occur to the donor's organs in the final stages of the donor's life once the donor has been taken off the ventilator and as their circulation fails and death occurs.

DCD donation was effectively abandoned in the UK for 25 years due to the challenges of this type of donation and was replaced with DBD. However, because of both the continuing unmet need on the transplant waiting list and requests from families in intensive care advocating organ donation for their relatives who did not meet neurological criteria for death, DCD programmes recommenced in the 21st century and were supported by the structural changes in donation and retrieval practice introduced after 2008.

DCD in the UK involves a mechanically ventilated patient with overwhelming single organ failure, usually the brain, where a prior decision has been made to withdraw life-sustaining treatment. This decision is made when the patient's medical team judge that on-going treatment is not to the overall benefit of that person, that the patient's death is inevitable and therefore that life sustaining treatment will only prolong the dying process.

The independent UK Donation Ethics Committee, which ran from 2009-2016, recommended that two senior doctors be involved in making the decision to withdraw life-sustaining treatment. If there is a clinical expectation that the circulation will cease imminently (that is within 4 hours) upon the withdrawal of life-sustaining treatment, DCD may be possible.

If consent/authorisation for organ donation is obtained during discussion with the family by the Specialist Nurse for Organ Donation (SNOD), a surgical retrieval

team is mobilised. Withdrawal of treatment only commences once the surgical team is prepared in theatre and recipients for the organs have been identified. This type of DCD is called controlled DCD because the death is expected, and the surgical team are already prepared. The SNOD supports the family throughout this process. In DCD the time from family consent to withdrawal is usually a minimum of 16 hours, and this timeframe can occasionally lead some families to revoke their consent.

Table 2. The four types of organ donation. Source: NHS Blood and Transplant Statistics 2017-2018

Type	Requires	Donated
Living	Consenting living donor; donating a non-vital part of the human body.	Kidneys (1,020 transplants) Liver lobe (20 transplants) Intestine (1 transplant) Lung lobe (0) - internationally performed Bone marrow Blood (Approximately 2 million donations)
Tissue donation	Deceased in mortuary ideally within 4 hours of death; donation usually within 24 hours.	Cornea donors (> 3,000) Heart valves Skin Bone and ligaments
Donation after Brain death (DBD)	Organ retrieval in theatre with circulation maintained in a mechanically ventilated patient where death has been confirmed using neurological criteria.	955 donors resulted in transplants: Kidney (1,436) Liver (692) Pancreas (133) ^a Intestine (25) Lung (163) Heart (172)
Controlled donation after circulatory death (DCD)	Organ retrieval commencing in theatre ideally within a maximum of 15 minutes after death diagnosed using circulatory criteria following the withdrawal of life-sustaining treatment.	619 donors resulted in transplants: Kidney (943) Liver (200) Pancreas (52) ^a Lung (38) Heart (25) ^b

Some additional, multi-organ transplants are not accounted for in this table.

^a Includes kidney and pancreas or pancreas alone.

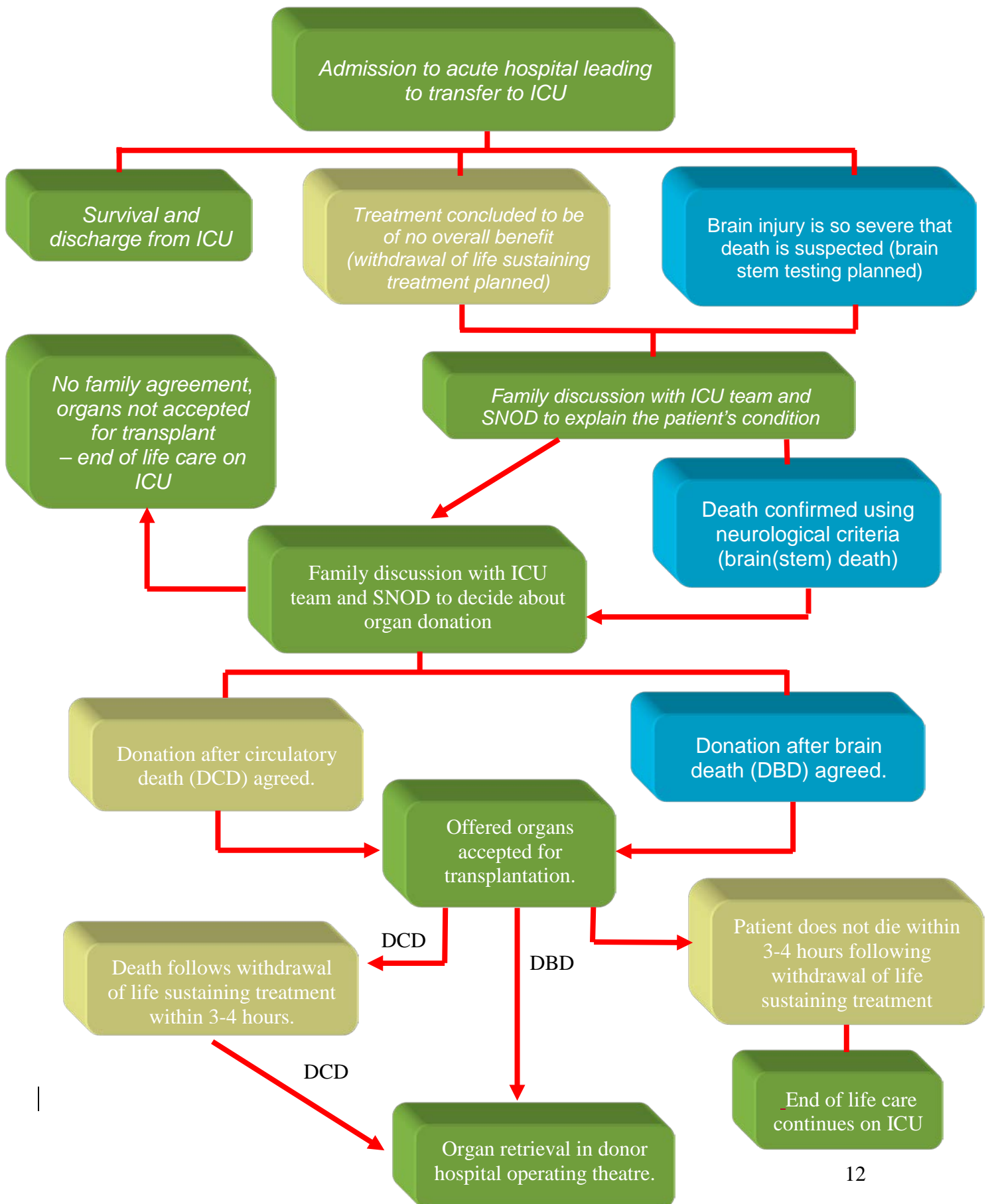
^b The UK is the world leader in DCD heart transplantation.

Donation after circulatory death accounts for 40% of all deceased organ donation in the UK. The UK is considered a world leader in this type of deceased donation. However, as a result of the warm ischaemic organ damage that occurs in DCD, transplantation outcomes can be mixed when compared to DBD organs. DBD outcomes for livers and pancreases tend to be better than DCD but the long-term results for kidneys are equivalent. Lung DCD results are either equivalent or perhaps even superior to DBD lungs. A pioneering initiative by a number of UK heart transplant centres has led to heart transplantation from DCD donors. Results to date are very encouraging and may provide a new chance for life to those 300 patients each year who are placed on the heart transplant waiting list.

Uncontrolled DCD is a version of DCD carried out in France, Spain and historically in a few centres in the UK. It involves rapid organ retrieval following an unexpected death, hence the term 'uncontrolled' compared to a planned, 'controlled' withdrawal of life-sustaining treatment. The usual case involves failed cardiopulmonary resuscitation either in the Emergency Department or in the community. Currently, this version of DCD is not practised in the UK and is not referred to again in this handbook.

The diagram below (**Figure 4**) gives a broad schematic overview of the process of organ donation, although in reality there are other layers of complexity. The local CLOD(s) and SNOD(s) have expertise in recognising and managing these complexities and will be the first point of reference for understanding any issues.

Figure 4. Schematic overview of the process of deceased organ donation.



Tissue Donation

Tissue donation can help thousands of people each year. Donated tissue such as heart valves, bones, tendons and skin can save or dramatically improve the lives of many people. Last year this provided 8,500 tissue products benefiting 2,600 patients. Last year there were an additional 3,000 corneal donors who provided the gift of sight.

Unlike organ donation a potential tissue donor does not have to be mechanically ventilated, therefore, almost anyone who dies in hospital can be considered as a tissue donor and not just those dying in an Intensive Care Unit. However, there are many more contraindications to tissue donation, compared to organ donation, and the donor's medical history and lifestyle will be carefully assessed at the time of referral.

If a referral is made to the National Referral Centre in Liverpool it will be assessed by NHSBT's Specialist Nurse team who then contact the bereaved family. A referral can be made by medical or nursing staff, or even family members. A referral can be made by the Specialist Nurse for Organ Donation (SNOD), if the option of organ donation is also being considered. Most hospitals make referrals by the traditional approach of telephone referral, however, several hospitals throughout the country are Alliance Site hospitals. In these hospitals the referral system has been embedded into normal end of life documentation and referrals are made electronically.

Tissue retrieval takes place in the hospital mortuary and is carried out by NHSBT's retrieval team or in some cases a locally based trained retriever. Tissues can be retrieved much longer after death compared to organ donation (**Table 3**). Throughout the donation, the donor is treated with the utmost respect and dignity. After donation our specialist team will ensure the donor maintains a natural appearance. Tissue donation will not delay funeral arrangements or effect viewing.

Table 3: Retrieval time for tissues.

Tissue	Retrieval time
Eyes	Up to 24 hours after death
Other tissues	Up to 48 hours after death

Once removed, the donated tissues are transferred to a tissue bank where they are examined, tested, treated and stored until they are used in transplant operations.

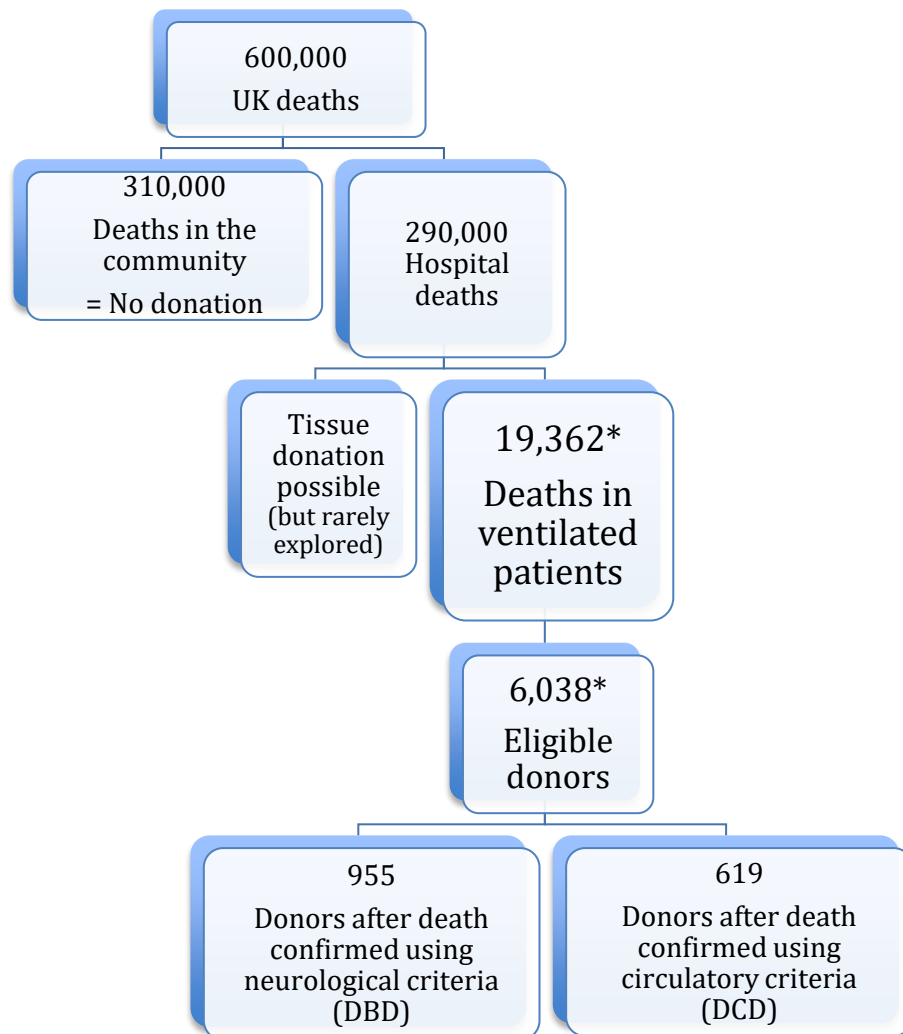
The UK organ donation potential

The public are generally unaware that, of the approximately 600,000 people who die in the UK each year, only around 6,000 (or 1%) could potentially donate organs. This is because organ viability is compromised so quickly after the circulation ceases that unless support is maintained to the moment when organs are retrieved (DBD) or a surgical team is ready to retrieve the organs rapidly after the circulation ceases (DCD), no solid organ donation can occur. Tissue donation does not have to take place as soon after the donor's death.

In practice only patients whose lungs are being mechanically ventilated in an intensive care or emergency department have any realistic opportunity of becoming organ donors, and staff in these hospital departments therefore have an essential role in facilitating donation.

Figure 5 outlines annual deaths in the UK and the potential for organ donation. A key focus for Organ Donation Committees is to investigate the gap between potential donors and actual donors and overcome any barriers to donation that may exist in your hospital/s.

Figure 5. Deaths and organ donation potential in the UK.



*Data from the 2017–18 NHS Blood and Transplant Potential Donor Audit (which looks at all deaths in UK intensive care and emergency departments up to the age of 80). An eligible donor is a patient for whom death was confirmed using neurological criteria or patients who had treatment withdrawn and death was anticipated within four hours, and with no absolute medical contraindications to solid organ donation.

Why is donation after death so difficult?

Although many of the barriers to donation have been addressed, several significant challenges remain to be tackled.

(a) Public support for donation does not equal agreement to donate

Opinion polls repeatedly demonstrate that over 90% of the UK population support organ donation. However, this support is not reflected in consent/authorisation rates that have shown little improvement in recent years. Patients who are potential donors at the time of their death are almost invariably unconscious when donation is being considered, and permission is therefore sought not from the patient themselves but from their grieving family and friends. It is not an ideal time to have a complex conversation and to ask families to agree to donation when they are in grief and shock from hearing that their loved one is going to die.

The burden of decision making for a grieving family is a heavy one, not least because all too often the individual concerned had not left a record of their own decision. It is no wonder that a family, numb and perhaps angry about their sudden and untimely loss, may choose to avoid any further perceived hurt or harm to their very recently deceased loved one, particularly when that person did not leave any clear indication of their wishes in respect of organ donation.

For some families, rituals related to death and the body of a loved one may be of uppermost importance. These views and beliefs should be respected and organ donation should not be perceived as being obstructive to such rituals.

Recognition of deceased organ and tissue donors with an award by the Order of St. John, a chivalrous order of the crown, has been a welcome national development.

(b) Professional unease

Since the principal benefits of organ donation are to a third party, namely the recipient of an organ, some doctors, though fewer than in previous years, regard donation as a breach of their responsibilities to their patient. Such an attitude ignores the benefits of fulfilling a patient's wish to donate after death and the comfort donation usually brings to bereaved families.

While donation itself only occurs after death, it is necessary in DCD for donation to be considered at a time when the patient, although dying, is not yet dead and in DBD consideration of donation may also begin before the death has been confirmed. A clear legal and ethical framework that supports organ donation whilst protecting patients, now exists in the UK.

(c) Clinical uncertainty

Clinicians, philosophers, ethicists, sociologists, faith leaders and others have long debated the meaning of 'death', and more specifically at what point it can be recognised with certainty. Deceased donation places new pressures upon this difficult area, since successful donation is fundamentally dependent upon removing organs that still have vitality from someone who is dead. These difficulties are compounded by the popular image of a person's death occurring at a point in time rather than being a process, and the fear that mistakes might be made if death is diagnosed too quickly.

(d) Organisational pressures

Most district general hospitals will only have a handful of organ donors per year while larger hospitals, particularly those with neurosurgical expertise, may see many more. Donation can be seen as both disruptive to the acute services of a hospital, and at the same time of no apparent benefit to it. Patients who arrive in the Emergency Department with catastrophic brain bleeds or injuries are often labelled with a poor prognosis particularly if turned down for transfer to the Regional Neurosurgical Centre. There may be little incentive to transfer these patients to ICU just for organ donation particularly if resources are scarce. However, clinicians are becoming aware that making an early prognosis of death in this group of patients is risky and now transferring to ICU to allow time to reassess them is becoming the more usual practice.

UK Organ Donation Strategies

In response to growing political, clinical and patient pressure, the Organ Donation Taskforce (ODTF) was assembled in 2006 with a UK-wide remit to identify barriers to deceased organ donation and transplantation and recommend solutions to them. The report was published in January 2008 and had a major influence on organ donation practice in the UK. The 14 recommendations it contained called for a root and branch reform of many aspects of donation after death in the UK. Responsibility for implementation was split between NHS Blood and Transplant (NHSBT) and the four Health Departments of the UK. From this great endeavour, the role of CLOD, SNOD and ODC Chair were created.

The Taskforce recommendations were implemented as part of a five-year plan with a goal of increasing donation by 50% over this period. On 31st March 2013, the five years concluded, and, donation had indeed increased by the targeted 50%.

However, at the end of the five years, the UK remained only a middle order donation country compared to our peers. Another challenge was that the 50% increase in numbers of deceased donors was not mirrored by an equivalent rise in transplanted organs (31%).

A major challenge for transplantation is that donors are becoming older, overweight and with more pre-existing medical problems. For example, in 2017-2018, 62% of deceased donors were aged 50 years or more compared with 50% in 2009-2010. The proportion of clinically obese donors (Body Mass Index (BMI) of 30 or higher) has increased from 24% to 28% in deceased donors over the same time period. In addition, the proportion of deceased donors who have died following trauma has decreased from 11% to 3%. All of these demographic changes add greater challenge and complexity to the utilisation of these, still, lifesaving organs.

The Organ Donation Taskforce Strategy was succeeded by Taking Organ Transplantation to 2020: A UK Strategy (TOT2020)². Whereas the taskforce had one overriding goal – a 50% increase in deceased donation – the TOT2020 Strategy strives toward three aspirations:

1. Consent / authorisation for organ donation – aim for consent / authorisation rate above 80% (currently 67%, countries like Spain achieve 80%)
2. Deceased organ donation – aim for 26 deceased donors per million population (currently 24, see Figure 2 for comparison)
3. Patients transplanted - aim for a deceased donor transplant rate of 74 per million population (currently 62).

² Taking Organ Transplantation to 2020: NHS Blood and Transplant 2013. Available at <http://www.nhsbt.nhs.uk/to2020/> accessed 29th January 2015

At its heart the strategy seeks for the UK to match world class performance in organ donation and transplantation. We know it can be done because other countries are doing it. Many of the barriers to donation identified by the taskforce in 2008 remain and can be summarised as follows:

- The possibility of organ donation after death is relatively uncommon in many hospitals and may be easily overlooked. Educating ICU and Emergency staff as well as developing guidelines and prompts, for example on daily checklists, have helped to increase awareness amongst hospital staff
- Average consent / authorisation* rates for organ donation are 67% - significantly below many other countries and have only slowly improved over many years. A revolution in public attitudes and behaviour towards organ donation is needed and this will require the support and action of hospital Organ Donation Committees. The opportunities which may arise from legislation change are discussed later.
- Donation usually occurs 'out of hours' and places a considerable burden on the emergency services of a donating hospital, particularly for anaesthesia, intensive care and theatres.
- Rarely are the direct benefits of donation visible to the staff involved with the care of a potential donor. Indeed, a potential recipient of a donated organ could live hundreds of miles away from the donating hospital.
- Hospital executives might have some high-level knowledge of the broad clinical benefits of donation and transplantation but usually have limited awareness of the potential for donation in their own hospital. Hospital executives are now biannually updated by reports of Donation Activity in their hospital generated by NHSBT.
- Critical care staff across the country do much to support organ donation already but are nevertheless both sensitive and directly exposed to the tensions that caring for dying patients with the potential to donate brings. A robust ethical and legal framework for donation among which ICU and ED clinicians can work now exists.
- The operational and professional relationships between critical care and transplantation teams have, on occasion, been strained and unsatisfactory.
- In order to overcome barriers to organ donation in local hospitals, further work is required to raise the profile of organ donation in all acute hospitals (and the surrounding community) where deceased donation occurs but where the benefits of transplantation may not be so visible.

* 'Authorisation' is the correct legal term in Scotland and 'consent' the correct term in the rest of the UK.

To assist in this task a Specialist Nurse for Organ Donation (SNOD) is allocated to each acute hospital whose role will be discussed in more detail elsewhere. Working with the SNOD is the Clinical Lead for Organ Donation (CLOD), a local hospital clinician, usually an ICU Consultant, appointed jointly by the hospital and NHSBT.

Organ Donation Committees within acute hospitals should be accountable to hospital boards and a key area of responsibility for the committee is to oversee good donation practice.

Organ Retrieval

Organ retrieval is the process of surgical removal of an organ from a deceased donor in theatre.

A National Organ Retrieval Service (NORS) was introduced in the UK on 1 April 2010. There are always 7 abdominal and 3 cardiothoracic NORS teams available at any given time to retrieve organs from deceased donors in the UK for transplantation. The teams are geographically dispersed across the UK and can be some distance from the donor's hospital. The teams consist of transplant surgeons (Consultants and trainees), scrub nurses, and sometimes operating department practitioners (Perfusionists). The surgical removal of a deceased donor's organs takes place in the local hospital operating theatre.

NORS was established in order to offer the best possible outcomes for all organs offered for transplantation and to allow them to be retrieved in a timely and coordinated fashion. It was intended that the donor hospitals would receive a rapid and efficient retrieval service minimising disruption to their other services. The NORS system means that retrieval operations are performed by experienced surgical teams who work to ensure that the quality of transplantable organs is not compromised. Respect for the donor and donor family are given the highest consideration throughout.

If a team is first on-call for a particular donor hospital, (closest available team to the donor) they are required to attend within an agreed timescale if at least one organ has been accepted for transplantation. If the team is already retrieving when they are called to attend, then a second team is called in to retrieve and so on.

NORS is commissioned by NHS Blood and Transplant, who are also responsible for the audit and quality control of this service. This is done via its standards document National Standards for Organ Retrieval from Deceased Donors.³ NHSBT also facilitates frequent NORS review meetings and welcomes service feedback from transplanting and donating centres.

A new area of development in retrieval surgery is organ recovery. During the dying process, whether that be in DBD or DCD, organ injury occurs. Organ recovery seeks to undo, if possible, this injury leading to better and longer lasting organ transplants, as well as opening up the possibility of using organs that previously would not have been. Organ recovery procedures take place either in the donor after death or on the organ following retrieval from the donor in special machines.

³ More information is available at www.odt.nhs.uk/retrieval/national-organ-retrieval-services

First steps for new organ donation committee chairs

Nearly every acute Trust or Health Board in the UK has established an organ donation committee and so you are likely to be inheriting an existing committee structure. However, the way in which committees operate varies quite considerably between different organisations. Donation committee chairs are drawn from a wide variety of different backgrounds and have varying degrees of experience and understanding of how an NHS organisation operates. The following are some suggested first steps that may be helpful:

Getting to know your Trust / Health Board and understanding your role

- Meet the outgoing chair (if possible) and the local CLOD and SNOD to discuss the sort of work your committee has been doing and the types of issues it faces. Ask for the most recent potential donor audit and ensure that the SNOD or CLOD goes through it with you so that you have an opportunity to ask questions about how to interpret it.
- Ask your CLOD or SNOD to introduce you to relevant departments and personnel e.g. ICU and emergency department consultants and nursing staff, chaplains, theatre staff etc.
- Identify the member of the Executive Board who is responsible for organ donation within your hospital(s) and ask for a meeting to introduce yourself. This can be a good opportunity to air issues of current concern to the donation committee.
- Establish where the donor recognition funding and committee funds are paid and how they are used in your hospital (see the section on Financial Support for more detail).
- Establish what reports are required from your committee both internally within your trust and externally, for example, to your NHSBT region and establish who will be responsible for preparing them.
- Ensure that you are clear about how your committee reports within your Trust / Health Board to the Executive Board. While some donation committees may report directly to the Board, others will report to a Board sub-committee. The important thing is that you report to the appropriate place within your trust to ensure that you are able to be effective and heard. Establish where and how often you are expected to report and whether you, the SNOD or the CLOD will attend when this happens.

Useful resources

- Sign up for Chair Induction, held usually in March each year (occasionally twice a year).
- Arrange a meeting with your Regional Chair who will be able to answer many of your questions, provide help and support and introduce you to other people in your region.
- Read the information contained in this handbook for an overview and introduction to organ donation and transplantation.
- You can find further information and helpful statistics on the Chairs landing page of the NHSBT ODT website www.odt.nhs.uk/deceased-donation/organ-donation-committee
- Ask your Regional Chair or NHSBT team manager to put you in touch with another chair from the region to act as your mentor if you would find this helpful.
- Consider attending a meeting of an organ donation committee in a neighbouring hospital as an observer.

Reviewing your committee

- Review the terms of reference of the committee and consider updating them if necessary. Discuss whether the membership of the committee is sufficient and appropriate. As a new Chair, it might be good to use this as an opportunity to consider whether to refresh the committee's membership.
- All donation committees that have a transplant unit should ensure that a representative from the transplant team is a member of the donation committee.

Structure and Support

The role of acute hospitals

Considerable effort has been invested in developing the UK organ donation strategies, with first the 'Organ Donation Taskforce' document in 2008, and more recently, 'Taking Organ Transplantation to 2020'. This has resulted in numerous high-quality national guidelines and policies to assist frontline staff, as well as the infrastructure to support donation and transplant activity. It is obvious that for the UK to have a successful transplant programme it relies on potential organ donors being reliably identified and managed well in the acute hospital setting.

Whilst great progress has been made since the first strategy was published, with one of the key messages that donation should be a 'usual, not unusual' aspect of clinical practice being largely acknowledged, room for improvement still remains.

The primary role of the Organ Donation Committee is to ensure that national policies, guidelines and best practice are implemented and followed **consistently**. Providing the necessary ongoing training, support and resources to clinical and nursing staff to achieve this is vital. It is often an occasional lapse of otherwise excellent practice that results in a missed organ donor. It is imperative to recognise that these small numbers of missed donors, in individual hospitals, cumulatively make a significant difference across the UK, and consequently to the lives of the people waiting for an organ transplant that we never see. The benefit that every single organ donor makes is immense.

The Chair is responsible, with the assistance of committee members, for identifying the obstacles to donation within their hospital and finding solutions to them. Engagement with the Regional Collaborative is an important means of both sharing your good practice with others, as well as learning from colleagues who have perhaps struggled with similar issues as your own in the past.

Those working outside of the Emergency Department (ED) and Intensive Care Unit (ICU) sometimes misunderstand the practical process of organ donation. It usually takes place on the ICU, although in rare circumstances it has been possible to facilitate donation from the ED, theatre recovery suite and other suitable locations. Building good working relationships and achieving influence in these areas is thus very important for your success.

Clinical Lead for Organ Donation Role

The CLOD in your hospital will be a medical Consultant. They are usually drawn from Critical Care, although some are recruited from a related area, such as Emergency Medicine. The Trust or Health Board is responsible for appointing a suitable applicant in a competitive process. The interview panel should comprise you (as Organ Donation Committee Chair), alongside the Medical Director and the Regional CLOD and/or Regional Manager. NHSBT reimburses the hospital for the role, with most CLODs being remunerated for half to one session (PA) per week, which corresponds to two to four hours per week. The number of sessions allocated to each Trust / Health Board may vary and historically has depended upon the organ donation potential. Large centres may therefore have more than one CLOD, whereas in some areas one CLOD will cover several smaller hospitals. Regardless, the role and expectations are the same. A full job description is available from NHSBT, however the following provides a summary of the role:

- Provide clinical leadership within the hospital, to champion and promote the value of organ donation.
- Maximise donation potential, by minimising missed opportunities in donation and by implementing the recommendations of national guidelines across the whole hospital, focusing on those areas with greatest potential.
- Bring to bear an enthusiasm and energy to ensure that the opportunity exists within their hospital(s) for every individual to become an organ donor should the circumstances arise.
- Be a recognised source of knowledge and expertise on all aspects of deceased donation, including legal and ethical aspects.
- Ensure necessary hospital education and training is provided.
- Establish effective working relationships, with key stakeholders throughout the hospital.

Specialist Nurse - Organ Donation Role

SNODs within the United Kingdom (UK) are employed by NHSBT. There are currently over 200 whole time equivalent SNOD posts across the UK. SNODs are managed within one of twelve regional teams and the distribution of staff is based on the establishment of the small, mid and larger teams.

Almost all SNODs have a substantial background of nursing in critical care or emergency medicine. Each acute hospital with donation potential in the UK has a Specialist Nurse assigned to them, and they have a close and collaborative working relationship with the CLOD and Donation Committee Chair for that hospital or Trust / Health Board. The SNOD has detailed knowledge of donor assessment, legal issues around donation, consent/authorisation, donor stabilisation and interaction with transplant centres, organ offering and organ retrieval teams.

The CLOD and the Committee Chair support the resident SNOD, and the Trust or Health Board should provide practical assistance to make the SNOD's working life in the hospital environment effective – i.e. desk space, IT access, security swipe card and hospital ID badge, car parking facilities (with on-call priorities), library access etc.

The two main duties and responsibilities of the SNOD are the facilitation of donation and hospital development.

Facilitation of donation

SNODs receive donor referrals, facilitate the entire organ/tissue donation process including the taking of consent / authorisation from families and ensure the placement of organs following established national guidelines. SNODs participate in an on call rota to ensure that donor referrals are facilitated 24 hours a day, 365 days per year.

In more detail a SNOD's role for an individual donor will be to:

1. Interview each bereaved donor family and take responsibility for ensuring they are given clear and sensitive information to help them make an informed decision about organ donation; explain the whole donation process ensuring the family's understanding.
2. Provide, support and give reassurance to donor families using skills developed through appropriate training from NHSBT to help them during their decision making process.
3. Obtain consent/authorisation regarding the donation of organs and tissues, in accordance with current legislation, including opt out legislation within Wales (and soon elsewhere). Make sensitive and comprehensive enquiries

ensuring that there are no social/lifestyle and/or medical contraindications to donation.

4. Perform an on-site physical assessment of the donor, examine documentary evidence, and liaise with the Consultant medical staff and the General Practitioner, to ascertain suitability of organ / tissue donation.
5. Offer emotional support to all donor families and staff during and after the process of organ/tissue donation, in accordance with national donor family guidelines.
6. Co-ordinate and facilitate the whole process of donation, liaising and negotiating with numerous disciplines including transplanting centres, co-ordinator colleagues, local and zonal retrieving teams, anaesthetic and theatre staff.
7. Perform the final act of care and fulfil any wishes the family may have.
8. Act as the donor and donor family's advocate during the whole process of organ/tissue retrieval, in accordance with the Nursing & Midwifery Council Code of Practice.

Hospital Development

SNODs have an essential role to educate health professionals and promote donation within the hospital and the wider community the hospital serves. For this reason, every acute hospital has one or more SNODs assigned to the hospital.

In more detail a SNOD's role within a hospital will be to:

1. Work collaboratively with the CLOD, Organ Donation Committee and others to formulate, review and maintain policies and protocols providing information and direction on donor identification and referral.
2. Develop and deliver comprehensive educational strategies to promote organ/tissue donation in their hospital.
3. Motivate and educate senior clinicians to refer all potential donors.
4. Develop and maintain influential relationships with consultant anaesthetists, intensivists, nursing staff, retrieval teams, laboratory and mortuary staff at participating hospitals and with HM Coroner / Procurator Fiscal in the advancement of the organ/tissue donation process.

Establish and maintain effective lines of communication with transplant surgeons, recipient transplant co-ordinators, NHSBT, other Specialist Nurses in Organ Donation and all relevant staff in existing and potential donating centres in relation to organ/tissue donation.

5. Liaise with NHSBT ensuring all relevant documentation including audit requirements are met such as the Potential Donor Audit.
6. Promote and educate health care professionals and the general public about the benefits of organ/tissue donation and transplantation.

Potential Donor Audit (PDA)

A national audit of deaths occurring in Intensive Care Units and the potential for deceased organ donation has been in progress since April 2003. As research showed the potential for donation from Emergency Departments⁴, from April 2011 the PDA was extended to cover this area as well.

The data for the PDA is collected from the critical care units and emergency departments by the SNOD who reviews every death from these areas for the potential for deceased organ donation to have occurred and the data is returned electronically to NHSBT's Directorate of Organ Donation and Transplantation in Bristol, where it is verified and collated.

Although the audit tool is not without limitations, nevertheless data gathered to date has provided a valuable insight into organ donation in the UK. There is an expectation that Organ Donation Committee Chairs, along with the CLOD and SNOD, should regularly review the data that describes the donation potential and activity of their organisation. There is a nationally agreed template for this data, which is sent on a six monthly basis to an organisation's Clinical Lead and the Hospital Chief Executive. Chairs of the Donation Committee will need to review their hospital's activity and progress, and should be regularly reporting these through established governance routes.

It is essential that regular and systematic reviews of this data are carried out by Organ Donation Committees to identify where the potential for donation has not been realised and that such instances are individually investigated. This data can be used to formulate strategies and action plans both at a hospital and local level and also regionally and nationally.

⁴ Aubrey .P, Arber. S, Tyler. M; (2008) [The organ donor crisis: the missed organ donor potential from the accident and emergency departments.](#); Transplant Proceedings 40 (4) 1008-11

Regional Organisation

Donation in NHSBT is organised in 12 Organ Donation Services regions (**Figure 6**), each with a Regional Manager supported by Team Managers and a Regional Clinical Lead for Organ Donation. A new role for regions is to appoint an established Committee Chair as a Regional Chair for Organ Donation Committees. The Regional Chair will ensure that the views and needs of local hospital organ donation committee chairs are represented.

Regional Collaborative events are held twice a year and their purpose is to enable all hospitals and the communities they serve to maximise the gift of organ donation by providing a bridge between national and local initiatives. The meetings also provide the opportunity to compare donation activity data, share best practice, adopt a common approach to difficult areas of practice and liaise with clinicians from branches of transplantation medicine. The collaborative events are attended by all CLODs, SNODs and Donation Committee Chairs from the region. To achieve NHSBT's vision of delivering world class performance in organ donation and transplantation, Regional Collaboratives are expected to be at the forefront of implementing the TOT2020 strategy and any future strategy.

Sometimes, staff from the communications and marketing functions at NHSBT attend the regional collaborative meetings. Take the opportunity to talk to them about what you are doing to promote organ donation in your local area and to pick up hints and tips.

Figure 6. The 12 UK Organ Donation Services Teams (Regions)



Financial support

NHSBT provides direct financial support in three ways.

Donor Recognition Funding

In order to help you plan your committee activities Donor Recognition Funding is paid to your organisation at the start of each financial year.

Each Organ Donation Committee has a base allowance of £1,000 funding. This is supplemented by taking the remainder of a national pool of £2m donor recognition funding, divided by the number of proceeding solid organ donors in the previous fiscal year and distributed to each Trust / Board in accordance with how many proceeding donors they had.

For example:

If there were 1500 proceeding solid organ donors in the UK in 2017/18 and 167 UK Organ Donation Committees, for a hospital with ten donors in 2017/18, their recognition fund for 2018/19 would be £1,000 plus $\frac{£2,000,000 - £1,000}{167} \times 10 = £13,220$.

NHSBT seeks to direct these funds to the Organ Donation Committees, thereby ensuring that Organ Donation funding reaches where it will be of most benefit to the organ donation service. However, once the money is given to your organisation, NHSBT has no direct control on how this money is used or distributed.

NHSBT's intention is that the money should support future donation activity within a hospital and that the Donation Committee should play an active part in advising how these funds are used.

Funding for Clinical Leads

Clinical Leads need time in their job plan to do their work, and NHSBT provides specific financial support for this. Most CLODs are remunerated for half to one session (PA) per week, which corresponds to two to four hours per week. Hospitals will receive this funding on a quarterly basis once a Clinical Lead has been appointed and NHSBT is informed of the appointment through the return of a completed 'Annex A' form. The Annex A form can be provided by the NHSBT Regional Manager.

Clinical Lead and Organ Donation Committee expenses

The Organ Donation Committee also receives an additional amount for any expenses relating to work undertaken as part of the Committee or by the Clinical

Lead for Organ Donation. This may include, for example, travel to a Regional Collaborative or level meeting on organ donation. This payment is £500 per Committee. The payment will be made to your Trust / Health Board on an annual basis at the beginning of the financial year. In Scotland the Regional Team holds and administers these funds.

Donation Committees should liaise with their respective hospital finance teams to understand how these funding streams are allocated within their organisation and ensure that the funds received are being utilised in the correct manner. For hospitals with higher levels of donation activity and which are therefore in receipt of greater amounts of reimbursement, Clinical Lead and expense monies, it may be beneficial for a finance representative to attend the Donation Committee.

In addition to the direct financial support outlined above, NHSBT provides induction events to support new Committee Chairs and Clinical Leads.

Public Engagement and Promotion

The individual interest Chairs have in driving forward public promotion of organ donation varies. This section gives some background, resource links and ideas for you and your Committee to consider.

Surveys repeatedly demonstrate that the vast majority of the population support organ donation in principle. But we shouldn't be complacent as the proportion of people who say they would definitely donate some or all of their own organs is lower, and the levels of support in principle do not translate into equivalent consent rates. Also, there are differences in knowledge and attitudes among different age, socio-economic and ethnic groups.

Local organ donation committees are well placed to engage their local community around organ donation. We recommend this engagement should:

- Help people understand the basics about organ donation, tap into people's motivations to donate (saving lives) and address barriers and misconceptions.
- Tell powerful local stories – whether this is the story of a donor family and the pride they felt helping a loved one to save lives, the story of a patient who has had a transplant or stories of staff members involved in donation.
- Be audience focused and tap into trusted community leaders wherever possible. For example, if you want to engage with a particular ethnic group, which are the key local groups or organisations that can help you to reach them? Working in partnership is likely to be a better approach than trying to reach this group alone, particularly if your committee does not reflect the people you are trying to reach.
- Explain how people's faith and beliefs are respected as part of the organ donation process. SNODs already discuss faith and beliefs with families. Now, when people register a decision to donate on the NHS Organ Donor Register they can answer a question asking whether they want the NHS to speak to their family and anyone else appropriate so organ donation can go ahead in line with their faith and beliefs. If queries or concerns relating to faith or belief issues are raised (e.g. whether burial would be delayed or if any last rites need to be performed), the SNOD will identify the best way to enable donation to go ahead in discussion with the family, while respecting any religious or cultural considerations. For more information visit: <https://www.organdonation.nhs.uk/faq/religion/>
- We cannot forget young people. Committees can encourage local schools to adopt the Teaching Resources for use with 11-16 year olds. There is a

template letter you can use to reach out to local schools.
<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/organ-donation-teaching-resources/>

- Encourage everybody to make a decision about organ donation, record it, and share it with those closest to them. Many people do not understand the importance of sharing their organ donation decision with their loved ones or the role which families play before organ donation goes ahead. Organ donation committees can help to explain this.
- Collaborate with your hospital communications team wherever possible. If you have their buy-in, they may be able to help you to get press releases out, help identify organisational spokespeople etc.
- Use social media channels to promote organ donation. Your hospital will have social channels that already have an audience so don't forget to use those. This is another reason to build a good working relationship with your hospital communications team.

NHS Blood and Transplant has developed a 'Get involved' section on its website that contains lots of hints and tips, statistics and assets you can use in any community outreach.

- **Get involved:** <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/>
- **Access key messages:** <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/key-messages-and-information/>
- **Download digital materials:** <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/>
- **Access local statistics:** <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/share-statistics/>
- **Access teaching resources:** <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/organ-donation-teaching-resources/>

In addition, make sure you follow NHS Blood and Transplant's social media channels (as there is always lots of content you can share) and make the most of existing educational and real people videos:

- Facebook, Twitter and Instagram @NHSOrganDonor
- You Tube: <https://www.youtube.com/user/nhsorgandonation>

Legislation Change

It's becoming even more important that people understand organ donation as the Governments in England, Scotland, the Channel Islands and the Isle of Man are looking to change the basis of consent from 'opt in' to 'opt out.' Wales introduced 'opt out' in 2015. Northern Ireland has no plans to change the legal basis of consent.

Where the system is set to change, it will be vitally important to inform people that the law is changing and what choices are available to people. There is a risk that if people do not know that the system is changing, that once deemed consent/deemed authorisation is implemented, families will not be sure whether their loved one knew the law had changed and had indeed intended to be a donor, if they had not recorded an opt in or opt out decision.

NHS Blood and Transplant will be developing the campaign around the change in the law in England and the Scottish Government will be responsible for the campaign in Scotland. Committees should think about what role they can play in informing people in their local area about the law change. This may include:

- Planning local talks and attending local events with high levels of footfall eg summer fayres, garden festivals etc
- Liaising with the media
- Sharing real people stories on social media
- Reaching out to schools
- Reaching out to local employers

You can follow the promotional guidance on the NHSBT website:

<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/tips-and-guidance/>

But please note that committees based in Wales, Scotland and Northern Ireland should link in with the teams responsible for organ donation promotion in those countries as their campaigns have their own identity and materials.

Media and Publicity

It is important to keep organ donation at the forefront of people's minds within the community you serve. You can use the media and social media to educate and inform your local community about donation as well as encourage them to join the NHS Organ Donor Register and to discuss donation with their families.

Although many press enquiries about organ donation and transplantation are directed centrally towards NHSBT, regional press frequently approach local hospitals with questions too, particularly those with transplant units.

The news section of organdonation.nhs.uk contains the latest press releases from NHS Blood and Transplant relating to organ donation and transplantation:

<https://www.organdonation.nhs.uk/news-and-campaigns/news/>

It is worth considering how you can use annual events, awareness days and weeks for specific conditions, outside of Organ Donation Week, such as religious festivals, to promote organ donation and transplantation through the media and on your hospital's social media channels. You can find lists of awareness days through various websites such as www.awarenessdays.com

Some donation committees have also run longer and successful campaigns through their local media using real life stories, relevant statistics and local well-known ambassadors to encourage greater support for organ donation. You can find local up-to-date statistics for your area here: <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/share-statistics/>

Prior to undertaking any media work, please check your own organisation's Press Office/Communication Department's media policy.

If you receive media interview requests for SNODs based in your hospital, please inform the NHSBT press office, as SNODs are employed by NHSBT who will provide media training and support.

The NHSBT press office phone number is 01923 367 600. Out of hours is 0117 969 2444. Email pressoffice@nhsbt.nhs.uk

If you receive any press queries that could be potentially jeopardise public trust in organ donation or damage the reputation of your hospital around organ donation and transplantation, please ensure you escalate this to your hospital communications team and the NHSBT press office.

Frequently Asked Questions

1. Where can I find support and advice?

In the first instance speak to your local SNOD or CLOD. The Team Manager from your regional collaborative who is responsible for your hospital will also be able to help you. If you would like support from a more experienced chair, then the team manager will be able to put you in touch with someone from your region or your region may have a Regional Chair for Organ Donation Committees. If you have a particular training need consider asking your team if this can be included within the agenda for a collaborative meeting or whether they can organise a training session for you and other chairs in your region.

You can find further information and helpful statistics on the Chairs landing page of the NHSBT ODT website www.odt.nhs.uk/deceased-donation/organ-donation-committee.

2. What is the most important function of the donation committee?

The most important function of the committee is to review the Potential Donor Audit at each meeting and ensure that the reasons for any missed opportunities in donation are understood and that appropriate action is being taken. In particular the committee needs to understand why potential donors were not referred, why appropriate patients were not tested for confirmation of death using neurological criteria, why families were not approached, why consented donors did not proceed and why the number of organs retrieved from a donor was lower than expected.

3. Apart from attending committee meetings, what other meetings and events do I need to attend?

- **Local meetings** – aim to have a meeting with your SNOD & CLOD a few weeks before each committee meeting in order to review activity since the last meeting and agree the agenda for the next. Other ad hoc meetings with your SNOD and CLOD may be needed if specific issues arise.
- **Organ Donation Week** – this is in September each year. Many donation committees arrange promotional events for organ donation to coincide with it and chairs are encouraged to attend and support these events.
- **Regional Collaboratives** – each region holds a Collaborative meeting twice a year. It is important for you to attend these meetings if you can, as they are opportunities to receive updates, share best practice and local initiatives, discuss matters of regional significance and for you to meet and get to know

other chairs, SNODs and CLODs from your area as well as the managers from the region.

- **Level Meetings** – your Trust / Health Board will have been assigned a Level between 1-4, where 1 represents hospitals with the highest number of donors each year and 4, least. All hospitals of every size are important, and last year Level 3 and 4 hospitals accounted for 20% of all UK donors; an essential and valued contribution. Every two years Level meetings are held, where similar sized donating hospitals can gather and share best practice.
- **National Congress** – this is organised by NHSBT and is held periodically but not more than once a year. It is a valuable opportunity to bring together the whole transplant and donation community to discuss issues of current importance and deliver training. The agenda of the Congress is drawn up to include specific events for the committee Chairs and is a great opportunity to meet people involved in donation work across the UK.

4. How can I encourage better attendance at donation committee meetings?

Hospital staff often have to attend many different meetings during their working week and juggle these with clinical commitments. It is important therefore that donation committee meetings are both interesting and relevant to them to encourage them to attend. If you are having difficulty in maintaining attendance, discuss this with your SNOD and CLOD and consider the following:

- Are you sending out reminders and meeting papers to the committee in good time? It is worth reminding particular people in person to attend and you can ask your SNOD or CLOD to do this.
- Are you holding your meetings at the right time/place? Are you clashing with other meetings, ward rounds etc?
- Are the meetings too long or too frequent?
- Do you need all committee members to attend every meeting? If you know that you are unlikely always to need the contribution of some individuals consider suggesting that they attend only particular meetings of relevance to them.
- Is it always the same people who do all the talking at each meeting? If so, consider asking new people to present to the committee on a topic relevant to them to attract them to the meeting
- Review the membership of the committee – have you got the right people on your circulation list? Consider rotating the membership

- Introduce topics of current interest to the agenda to broaden the discussion beyond the trust
- Is the committee effective? If you are not managing to implement change then members will not feel it is worth attending.

5. Who can use the money from NHSBT?

See the section on Financial Support.

The donor recognition funding is primarily intended to support organ donation in your hospital. Many donation committees have used these funds for donation related projects e.g. refurbishing the relatives' room or supporting donation promotion in their area. If you would like to use the funding for a particular purpose, then it will be up to you to negotiate this with your own Trust / Health Board.

The committee funds provided by NHSBT may be used to support costs incurred by your committee or yourself e.g. travel costs for the chair or other committee expenses and they may also be used to fund particular projects the committee agrees such as printing costs for a promotion activity etc. Some committees find that it is hard to access their committee funds through their hospital's finance departments and prefer to ask their Regional Collaborative to hold their committee funds for them.

6. How should I go about running a promotional campaign for organ donation?

There are many different ways in which you could consider promoting organ donation in your local area and while some campaigns can involve a great deal of work and take a considerable time, others can be quite limited in scope, easier to achieve but nonetheless effective. The following points will give you a few starting points which may be helpful:

- Make contact with your hospital's Communications department and ask if they can provide someone to attend your committee meetings or at least be responsible for organ donation
- Ask for support from a prominent and senior member of staff within the trust, e.g. a medical director, who can endorse your efforts
- Make the most of Organ Donation Week and local events– you might want to think about what you can do in the hospital setting itself such as a stand in the hospital promoting organ donation. But also think about how you can take the message outside the hospital into the community. Remember that you want to try to reach people who may not know much about organ donation. Are there

any big events where you could have a presence? NSHBT will be able to provide leaflets, promotional pens, stickers etc .

- Ask the SNODs to approach donor families or transplant recipients who would be happy to be involved. If they are comfortable with publishing their story then this is an excellent way to promote donation and the Trust's Communications department will usually be happy to assist in finding an appropriate way to facilitate this – whether by placing an article in an internal publication or in a local or national newspaper or by using other media.
- Use your committee funds to pay for any expenses incurred e.g. printing or refreshments.
- Measure what you do so you can show the impact of your efforts

Whatever you do, it's really important that you deliver accurate information about organ donation. You can find key messages, stats and guidance on the NHS Blood and Transplant website:

Tips and guidance: <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/tips-and-guidance/>

Key messages and information: <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/key-messages-and-information/>

Appendix 1. A summary of the current published NHS Best Practice, Ethical, Legal and Professional Guidance

1. Human Tissue Acts (2004 and 2006)

The Human Tissue Act 2004 (HT Act) covering England, Wales and Northern Ireland [2] and the Human Tissue (Scotland) Act 2006 [3] set out the legislative requirements for seeking consent and authorisation to donation, both living and deceased.

Primacy of the prior expressed consent or authorisation of the patient is established by the Acts. Registration on the Organ Donor Register equals consent or authorisation for the purposes of donation, with the family having no legal right of veto, though in practice donation is never forced upon a dissenting family in the UK.

www.hta.gov.uk

The Human Transplantation (Wales) Act received Royal Assent on 10th September 2013, with the law coming into full effect on 1st December 2015. The Act introduced to Wales a soft-opt out system of organ donation, or what is termed deemed consent.

The Organ Donation (Deemed Consent) Act 2019 received Royal Assent on 15 March 2019. It will be known as Max and Keira's Law. To learn more about Max and Keira's story watch <https://www.youtube.com/watch?v=wLnTeSXvs>. This law will apply in England from Spring 2020.

Some further information is available from the:

a. Human Tissue Authority: Code of Practice on the Human Transplantation (Wales) Act 2013

This document is intended for healthcare professionals. It provides invaluable, pragmatic guidance on all aspects of the Act.

<https://www.hta.gov.uk/guidance-professionals/codes-practice/code-practice-10-human-transplantation-wales-act>

b. NHSBT professional website (access via the Chair Landing Page)
www.odt.nhs.uk/deceased-donation/organ-donation-committee.

2. Academy of Medical Royal Colleges Code of Practice for the Diagnosis and Confirmation of Death (2008)

The current UK Code of Practice for the Diagnosis and Confirmation of Death was published by the Academy of Medical Royal Colleges in 2008. This was the successor to previous versions and updated the Codes of Practice published in 1976, 1979, 1983 and 1998 for the diagnosis of death using neurological criteria. It was notable for being the first Code of Practice to provide guidance on the diagnosis of death following cardiorespiratory arrest (circulatory criteria), and the first code of practice to remove organ donation considerations from the guidance.

An education video series on the diagnosis of death using neurological criteria is available here:

<https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/donation-after-brainstem-death/diagnosing-death-using-neurological-criteria/>

3. Legal guidance from all four UK jurisdictions on DCD (2009-2011)

Donation after circulatory death (DCD) may be in the person's interests:

- By maximising the chance of fulfilling the donor's wishes about what happens to them after death.
- By enhancing the donor's chances of performing an altruistic act of donation.
- By promoting the prospects of positive memories of the donor after death.

The following steps are permissible to facilitate DCD:

- Delaying withdrawal of life-sustaining treatment.
- Changing the patient's location.
- Maintaining physiological stability.

4. Joint professional statement from the Intensive Care Society and the British Transplantation Society (2010) [7]

This document:

- Stated professional support for DCD.
- Gave professional support for admission to ICU purely for organ donation.

- Defined suitability criteria for donation.
- Provided guidance for treatments before and after death.

**5. GMC Guidance: ‘Treatment and care towards the end of life’ (2010) [8]
Included the following statements:**

“If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility” and “You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator [specialist nurse - organ donation].”

6 Joint professional statement from the College of Emergency Medicine and the British Transplantation Society (2011)

Provided:

- Professional support for the robust identification of potential donors in the Emergency Department.
- Professional support for managing organ donation from the Emergency Department if admission to ICU is not possible.

7. The UK Donation Ethics Committee operated from 2009 – 2016, before its closure.

Their many carefully considered and influential guidances can be accessed at www.aomrc.org.uk/reports-guidance/ukdec-reports-and-guidance/

8. NICE Guidance CG135 ‘Organ Donation for Transplantation’ (2011)

Set out the expected standard of practice applicable in England, Wales and Northern Ireland, and recommended:

- Triggered referral if there is a:
 - Plan to withdraw life-sustaining treatment.
 - Plan to perform brain stem testing.
 - Catastrophic brain injury (early referral), defined as the absence of one or more cranial nerve reflexes, e.g. one fixed pupil, and a Glasgow Coma Scale score of 4 or less that is not explained by sedation.

- While assessing the patient's best interests clinically, stabilise the patient in an appropriate critical care setting while the assessment for donation is performed. For example, an adult intensive care unit or in discussion with a regional paediatric intensive care unit.
- A collaborative approach to the family for organ donation involving:
 - A specialist nurse for organ donation.
 - A local faith representative if appropriate.

9. College of Emergency Medicine Best Practice Guidance for End of Life Care (2012)

This guidance stated that:

- Organ and tissue donation should be considered as a usual part of end of life care in the Emergency Department.
- Emergency Department staff should consider organ donation from all patients that are expected to die, whose trachea is intubated and whose lungs are ventilated.
- Referrals should be made via specialist nurses in organ donation.

More information on organ donation and transplantation can be found on the following websites

www.odt.nhs.uk

www.organdonation.nhs.uk

www.nhsbt.nhs.uk

Appendix 2. Glossary of Abbreviations and Terms

CLOD	Clinical Lead for Organ Donation. A senior hospital doctor (most often from intensive care) who provides clinical leadership to champion and promote the value of organ donation. See page 25.
DBD	Donation after brain(stem) death. Deceased donor whose death has been diagnosed using neurological criteria. The donor is maintained on a ventilator after death has been confirmed and the heart, lungs and other organs remain functioning up to the point that the donor's organs are retrieved. See page 9.
DCD	Donation after Circulatory Death. Deceased donation following the withdrawal of life-sustaining treatment and the diagnosis of death after the heart has stopped beating. Approximately 40% of deceased donations in the UK each year. See page 9.
Deceased Organ Donor	Any deceased donor from whom at least one organ has been retrieved with the intention to transplant. Usual organ donations: heart, lungs, liver, kidney, pancreas. Novel and rare organ donations: limb, face, uterus.
Deceased Tissue Donor	Any deceased donor from whom tissue has been retrieved. Usual tissue donations: eyes for corneas, whole heart for valve and heart tissue, skin, bone, tendons and meniscus.
NORS	National Organ Retrieval Service. NORS is commissioned by NHSBT. Organ retrieval is the process of surgical removal of an organ from a deceased donor in theatre. See page 21.

NHSBT	NHS Blood and Transplant. NHSBT is a special health authority established to support organ transplantation (donation and retrieval) across the UK and blood transfusion in England. NHSBT is funded by and accountable to the four Departments of Health in the UK government. NHSBT does not commission transplantation but does oversee the transplant waiting list and organ offering.
Order of St. John	The Most Venerable Order of the Hospital of St. John of Jerusalem. An order of chivalry of the British Crown. Awards “The Order of St. John Award for Organ Donation” (ceremony and postal) and “The Order of St. John Award for Tissue Donation” (postal only).
PDA	Potential Donor Audit. A national audit of deaths occurring in Intensive Care Units and Emergency Departments. Data collected by SNODs and used to create local hospital, regional and national performance reports. See page 29.
Regional Collaborative	Donation in NHSBT is organised into 12 Regional Collaboratives which match NHSBT’s Organ Donation Services teams (see Figure 6, page 30). Each Regional Collaborative has a Regional Manager supported by Team Managers, a Regional Clinical Lead for Organ Donation and a Regional Chair for Organ Donation Committees. The Regional Chair will ensure that the views and needs of local hospital organ donation committee chairs are represented. Regional Collaborative events are held twice a year. See page 30.
SNOD	Specialist Nurse for Organ Donation. A senior nurse employed by NHSBT who facilitates organ donation and retrieval and works in a designated donor hospital to provide hospital development. See page 26.