Information for Organ Donation Committee Chairs

Blood and Transplant

Organ Donation and Transplantation
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Introduction

Organ transplantation is one of the greatest success stories of modern medicine; it saves and transforms 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 recommendations, the UK has seen a welcome increase in organ donation and transplantation with a resulting decrease in patients waiting for a transplant. (Figure 1) However despite the 60% 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.

Despite the significant progress made since 2008 improvements are still possible along the organ donation pathway. The UK has set the ambitious goal to match world class performance in terms of organ donation and transplantation by 2020. 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.

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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.

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Table 1: Median waiting times to kidney only transplant for all adult patients registered for transplant between 1 April 2007 – 31 March 2011, by ethnicity.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of patients registered</th>
<th>Median</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>6685</td>
<td>1047</td>
<td>1021 - 1073</td>
</tr>
<tr>
<td>Asian</td>
<td>1296</td>
<td>1330</td>
<td>1263 - 1397</td>
</tr>
<tr>
<td>Black</td>
<td>701</td>
<td>1363</td>
<td>1278 - 1448</td>
</tr>
<tr>
<td>Other</td>
<td>245</td>
<td>1147</td>
<td>1005 - 1289</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>8927</strong></td>
<td><strong>1114</strong></td>
<td><strong>1091 - 1137</strong></td>
</tr>
</tbody>
</table>

Figure 2: International deceased organ donation rates in 2014, expressed as donors per million of population.
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 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. See Figure 3.

Figure 3: Organ Donation Committee Chairs professional background. From the 2014 ODC Chair Survey.

While some chairs are employed by the hospital in another capacity (for example as chaplains or non-executive directors), many 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, hence this handbook.

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. In particular it is important as chair that you should:

- 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 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
- Take a leading part in the promotion of organ donation both in your hospital and within your local community
- Represent, with the CLOD and SNOD, your trust/health board at Regional Collaborative meetings.
An Introduction to Organ Donation and Transplantation

Types of organ and tissue donation

There are four types of donation that are possible from a human body (see Table 2). 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 by neurological criteria became accepted in the 1960’s and 70’s, donation after brain (stem) death (DBD) became possible.

In DBD, deceased donors are maintained on a ventilator after death has been declared while the heart, lungs and other organs are supported, optimised and remain functioning up until to the point of organ retrieval. By contrast in DCD, damage (warm ischaemia) will occur to the donor’s organs in the final stages of the donor’s life as the circulation fails. Warm ischaemic damage affects the organs’ viability for transplantation and the prospect of a successful outcome rapidly falls (as quickly as within 20 minutes for the liver).

DCD donation was effectively abandoned in the UK for 25 years due to the challenges of this type of donation and the introduction of DBD. However because of 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.
Table 2: The four types of donation that are possible from a human body.

<table>
<thead>
<tr>
<th>Type</th>
<th>Requires</th>
<th>Donated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living</td>
<td>Consenting living donor; donating a non-vital part of the human body.</td>
<td>Kidneys (1114 transplants)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Liver lobe (32 transplants)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lung lobe (0) - internationally performed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bone marrow</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Blood (Approximately 2 million donations)</td>
</tr>
<tr>
<td>Tissue donation</td>
<td>Deceased in mortuary ideally within 4hrs after death; donation usually within 24hrs.</td>
<td>Cornea donors (3146)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heart valves</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bone and ligaments</td>
</tr>
<tr>
<td>Donation after brainstem death (DBD)</td>
<td>Organ recovery in theatre with circulation maintained in a</td>
<td>780 donors resulted in transplants:</td>
</tr>
<tr>
<td></td>
<td>mechanically ventilated patient where death has been confirmed using</td>
<td>Kidney (1321)</td>
</tr>
<tr>
<td></td>
<td>neurological criteria.</td>
<td>Liver (727)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pancreas (203)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intestine (26)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lung (182)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heart (193)</td>
</tr>
<tr>
<td>Controlled donation after circulatory</td>
<td>Organ recovery commencing in theatre ideally within a maximum of 15 min after death diagnosed using circulation criteria following the withdrawal of life-sustaining treatment.</td>
<td>540 donors resulted in transplants:</td>
</tr>
<tr>
<td>death (DCD)*</td>
<td></td>
<td>Kidney (821)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Liver (153)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pancreas (43)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lung (35)</td>
</tr>
</tbody>
</table>

* See text for a description of uncontrolled DCD.

DCD in the UK usually involves a mechanically ventilated patient predominantly 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 recommends 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/authorisation to withdrawal is usually a minimum of 12 hours, and this timeframe can occasionally lead some families to revoke their consent/authorisation.

Donation after circulatory death accounts for 40% of all deceased organ donation in the UK, making the UK a world leader in this form of donation. As a result of the warm ischaemic organ damage that occurs in DCD, transplantation outcomes are 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. Heart DCD has only recently commenced in some centres in the UK and outcome results are awaited.

Uncontrolled DCD is a version of DCD carried out in France, Spain and historically in a few centres in the UK. Currently, there is a pilot in process in Edinburgh. 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.

**The UK organ donation potential**

The public are generally unaware that, despite approximately 550,000 deaths in the UK each year, the number of people who could potentially donate organs is only around 5,000. This is because organ viability is compromised so quickly after the circulation ceases that unless support is maintained up until organ recovery (DBD) or a surgical team is ready to recover the organs rapidly after the circulation ceases (DCD), no solid organ donation can occur. Tissue donation may still be possible however.

In effect, this means that only patients whose lungs are being mechanically ventilated in an intensive care or emergency department have any realistic possibility of becoming organ donors, and highlights the essential role staff in these areas of the hospital have in facilitating donation.

Figure 4 outlines annual deaths in the UK and the potential for organ donation. In 2013-14 there were 5,926 potential organ donors, and consent/authorisation for solid organ donation was given by the family in 1,928 patients, resulting in 1,320 donors. 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 4: Deaths in the UK and the organ donation potential.

- **550,000**
  - UK deaths

- **200,000**
  - Deaths in the community = No donation

- **350,000**
  - Hospital deaths

- **15,000**
  - Deaths in ventilated patients

- **5,926***
  - Potential donors

- **780**
  - Donations after brainstem death

- **540**
  - Donations after circulatory death

* Donation data from the 2013–14 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). A potential donor for the purposes of this figure is a patient who may be deceased using neurological criteria but is yet to be tested (1,787 patients), or had treatment withdrawn in the intensive care unit or Emergency Department in 2013–14, where death was anticipated within 4 hours, and had no absolute medical contraindications to solid organ donation (4,139 patients).
The UK Organ Donation Strategy

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 has 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.

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 in the UK had increased by the targeted 50%. For three years, more deceased donations and transplants were carried out than ever before and, for the first time, the transplant waiting list has decreased (Figure 1).

However, the increase in donation was mostly accounted for by a 153.5% increase in DCD compared to only a 15.8% increase in DBD (Figure 5 and 6). Kidney recipients have been the biggest beneficiaries of the 50% increase whereas those waiting for other organs, particularly hearts (which currently only come from DBD donors), have benefited much less. At the end of the five years, the UK remains only a middle order donation country (Figure 2).

Figure 5: Number of DBD donors and transplants in the UK, 1 April 2004 to 31 March 2014

![Number of DBD donors and transplants in the UK, 1 April 2004 to 31 March 2014](chart_image)
The Organ Donation Taskforce Strategy, with the support of all four UK health departments, has been 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 has four:

1. **Consent/authorisation for organ donation** – aim for consent/authorisation rate above 80% (currently 60%)
2. **Deceased organ donation** – aim for 26 deceased donors per million population (currently 20, Spain regularly achieves over 30)
3. **Organ utilisation** – aim to transplant 5% more of the organs offered from consented, actual donors
4. **Patients transplanted** - aim for a deceased donor transplant rate of 74 per million population (currently 55).

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 has helped to increase awareness amongst hospital staff.

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Information for Organ Donation Committee Chairs

• Average consent/authorisation rates for organ donation are 60% - significantly below many other countries and have not improved over the last seven years. This is a major focus of the TOT2020 strategy document. A revolution in public attitudes and behaviour towards organ donation is called for and this will require the support and action of hospital Organ Donation Committees.

• 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 have limited awareness of the potential for donation in their own hospital. Hospital executives are now regularly updated by reports of Donation Activity in their hospital generated by NHSBT.

• Intensive care staff across the country do much to support organ donation already, but are nevertheless both sensitive and directly exposed to the tensions that exist between their primary and absolute duty of care to their critically ill patients and the potential of those patients to donate organs should they die. A robust ethical and legal framework for donation among which ICU and ED clinicians can work now exists.

• The operational and professional relationships between intensive 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.

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.

* ‘Authorisation’ is the correct legal term in Scotland and ‘consent’ the correct term in the rest of the UK.
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 engagement

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. Asking families to agree to donation in the midst of the grief and shock of hearing their loved one is going to die is not an ideal time to have such a complex conversation.

Family consent/authorisation rates are at around 60% - significantly lower than the opinion polls, which demonstrate general support for donation, might lead one to expect – and family refusal is becoming the biggest single obstacle to improving rates of donation. Consent/authorisation rates for non-white families are much lower (Table 3).

Table 3: Consent/Authorisation rates for organ donation by ethnicity, 1 April 2013 – 31 March 2014

<table>
<thead>
<tr>
<th>Eligible donor</th>
<th>White</th>
<th>Ethnic Minority Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBD</td>
<td>74%</td>
<td>38%</td>
</tr>
<tr>
<td>DCD</td>
<td>57%</td>
<td>33%</td>
</tr>
</tbody>
</table>

The burden of decision making for a grieving family is a heavy one, not least because all too often the individual concerned had not registered any indication of their wishes. 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 feelings should be respected and organ donation should not be perceived as being obstructive to such rituals.

Recognition of deceased organ 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
A doctor's primary duty of care is to his or her patient. Although 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.

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.

A clear legal and ethical framework that supports organ donation whilst protecting patients, now exists in the UK. The establishment of the independent UK Donation Ethics Committee has been important in providing guidance on some of the more complex issues faced by clinicians.

(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 that transferring to ICU provides time to reassess them and is becoming the more usual practice.
Organ Retrieval

A National Organ Retrieval Service (NORS) was introduced in the UK on 1 April 2010. The service comprises seven abdominal organ retrieval teams and six cardiothoracic organ retrieval teams. They 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 high consideration throughout.

Retrieval teams are on call 24 hours per day, seven days per week. If a team is first on-call for a particular hospital where there is a donor, they are required to attend within an agreed timescale if at least one organ has been accepted for transplant. Each team has a designated first on call geographical area, based on the premise that travel time to any hospital should be less than three hours. There are some exceptions to this principle for remote hospitals. If the local team is already retrieving when they are called to attend another donor, a second team will be called in to retrieve, and so on. A small number of donors may be attended by local kidney transplant teams and this will typically occur for DCD donors when only kidneys have been accepted for transplant. There is no expectation that local kidney teams retrieve organs, but they are appropriately reimbursed if they are willing and able to do so.

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. NHSBT also facilitates frequent NORS review meetings and welcomes service feedback from transplanting and donating centres.

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First steps for new committee chairs

Nearly every acute trust or hospital board in the UK has established an organ donation committee and so you are likely to be inheriting an existing 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 with how an NHS trust operates. The following are some suggested first steps that may be helpful:

• 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.

• If it would be helpful to you, ask the NHSBT team manager to put you in touch with another chair from the region to act as your mentor. Alternatively you can ask to attend a meeting of an organ donation committee in a neighbouring trust as an observer.

• Make sure that you are clear about where your committee fits in to the structure of your trust or health board, where it reports to and how often, and whether you, the CLOD or the SNOD is expected to attend when the committee reports.

• 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.

• Read the NHSBT TOT2020 Strategy and consider what your own trust will need to do in order to contribute to the Strategy's objectives.

• Identify the member of the Executive Board who is responsible for organ donation within your trust and ask for a meeting to introduce yourself. This can be a good opportunity to air issues of current concern to the donation committee.

• Ensure that you are clear about how your committee reports within your trust to the Executive Board. This will vary enormously from trust to trust – some donation committees report directly to the Board whereas 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 how often you are expected to report and whether you, the SNOD or the CLOD will attend when this happens.

• Find out what reports are required from your committee both internally within your trust and externally to your regional collaborative and establish who will be responsible for preparing them.

• Establish where the reimbursement and committee funds are paid and how they are used in your trust.

• All donation committees in hospitals that have a transplant unit should ensure that a representative from the transplant team is a member of the donation committee.
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, 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 on going 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 depending on the hospital configuration 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.
The diagram below (Figure 7) 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 7 – A broad schematic overview of the process of organ donation**
Clinical Lead for Organ Donation Role

The CLOD in your hospital will be a medical Consultant. They are usually drawn from Intensive Care, although some are recruited from a related area, such as Emergency Medicine. The Trust or Healthboard is responsible for appointing a suitable applicant in a competitive process. The interview panel should comprise you, 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 one session (PA) per week, which corresponds to four hours per week. The number of sessions allocated to each Trust/Healthboard 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 to ensure national policy, strategy and best practice is implemented locally
- 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 education and training is provided
- Promote and champion organ donation.
Specialist Nurse - Organ Donation Role

SNODs within the United Kingdom (UK) are employed by NHS Blood and Transplant. There are currently 212 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 (Appendix 2).

Almost all SNODs have a substantial background of nursing in intensive 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/healthboard. 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 two main duties and responsibilities of the SNOD are the facilitation of donation and hospital development.

Facilitation of donation

SNODs receive all donor referrals from within the hospital, 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. 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 intensive care and emergency department health professionals 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.

5. 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.

6. Liaise with NHSBT ensuring all relevant documentation including audit requirements are met such as the Potential Donor Audit.

7. Promote and educate health care professionals and the general public about the benefits of organ/tissue donation and transplantation.
Information for Organ Donation Committee Chairs

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 there was potential for donation from Emergency Departments\(^4\), from April 2011 the PDA was extended to cover this area as well.

The data for the PDA is collected from the intensive 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.

Financial support

Recommendation 8 of the ODTF Report was that “Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.”

NHSBT provides direct financial support for a hospital’s support of donation in three ways (see below).

Donation Committees should liaise with their respective 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 below, NHSBT has established a central Education Fund in order to support Committee Chairs and Clinical Leads. This fund will be utilised to provide both induction for new Chairs and CLODs and support and ongoing development for existing Chairs and CLODs.

Reimbursement

NHSBT currently provides reimbursement of £2,086 per consented/authorised DBD or DCD Donor to cover the possible costs of caring for an organ donor within the donor hospital. The payment is not intended to be an incentive to organ donation, but a recognition of costs involved of the individual organisations in caring for these patients. The payment is made regardless of whether donation proceeds or not. The reimbursement is made by NHSBT on a quarterly basis. Although NHSBT has no direct control over how organisations use the funds, there is a clear expectation that it will be used to reimburse past or support future donation activity within a hospital and the Donation Committee should play an active part in administering these funds. A summary of donors eligible for reimbursement can be provided by the Specialist Nurse for Organ Donation within each hospital.

Funding for Clinical Leads

Clinical leads need time in their job plan to do their work, and NHSBT provides specific financial support for this, more for larger centres where the role is often split, and to individuals who take on regional and national activities. One PA corresponds to four hours per week and the hospital is therefore reimbursed for the consultant clinician’s time. 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 workshop on organ donation. From 1st April 2015 this payment will be £500 per Committee. The payment will be made at Trust/Board level on an annual basis at the beginning of the financial year.
Regional Organisation

Donation in NHSBT is organised in 12 regions, each with a Regional Manager supported by Team Managers and a Regional Clinical Lead. Regional Collaborative events are held a minimum of 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.

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.

It is worth considering how you can use annual events, such as awareness days and weeks for specific conditions, to promote organ donation and transplantation through the media and on your hospital’s social media channels. 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.

Prior to undertaking any media work, please check your own organisation’s Press Office/Communication Department’s media policy, as well as liaising with the NHSBT press office should you need any advice or statistics. 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
Marketing and Partnerships.

Taking Organ Donation and Transplantation to 2020 details four anticipated outcomes, the first of which concerns the attitudes of society and individuals, and that "Attitudes to organ donation will change and people will be proud to donate, when and if they can".

To meet this end the Marketing team at NHSBT are leading the Communications element of the Behaviour Change Strategy to deliver three objectives:

1. To increase the number of registrants on the ODR by at least 50% by 2020 (from a baseline of 20m in 2014), rebalancing it towards people who are from BAME groups, older (50+) groups and from hard-pressed/financially stretched groups.

2. To stimulate conversations and debate about organ donation, particularly through leveraging the ODR as a marketing tool.

3. To present donation as a benefit to families in the end of life and grieving process.

In 2014/15 a number of test and trial activities will be undertaken in order to establish the most effective ways of reaching these audiences and testing the messages that have the most impact. This phase one activity will continue throughout 2015/16* in order to provide a solid basis by which to campaign from 2016 to 2020. *subject to ERG funding

One of the most significant pieces of activity involved in phase one will be trialling ‘hot-house’ pilots in England, where significant activity is undertaken at a local level and is supported by the national Marketing team. This activity will be based on existing marketing models used within the health sector, and measured against isolated activity in other areas. The impact on Committees will be to engage and work with local Communications teams to plan, deliver and measure this activity.

In addition to the hothousing activity, discussion panels and workshops around their most successful local interventions within regions, will assist in shaping our local/national model to provide campaigning packs, materials, templates and toolkits to anyone in their areas that wishes to promote organ donation.

This model which is more long-term has been used very successfully for campaigns such as Change for Life and Stoptober, building a movement of local partners to help us all achieve outcome one of the strategy.

This work is fundamental to the success of the behaviour change strategy and meeting our ambitious objectives. Communications and the relationship with the national Marketing team will be increased and improved in order to support delivery of these two proven methods of behaviour change success.
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 trust will also be able to help you and 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. 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.

There are several useful websites which you might also find helpful. These are listed in the Appendix 1 of this book.

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 ‘drop-offs’ in performance 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/authorised 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 & CLOD may be needed if specific issues arise.

- **Transplant Week** – this will be moving to September each year from 2015. 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 approximately 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.

- **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. Accommodation and the Congress are usually free of charge.
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 & 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 local hospital.
- 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 page 24 above about finance.

The reimbursement money is primarily intended to compensate trusts/hospital boards for the additional costs associated with supporting and caring for consented potential donors. However many donation committees have agreed locally to use 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 reimbursement moneys for a particular purpose then it will be up to you to negotiate this with your own trust/board.

The committee funds provided by NHSBT may be used to support costs incurred by your committee 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
- Transplant Week – start small with a stand in the hospital promoting organ donation. NHSBT 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
Appendix 1 –

A summary of the current published Best Practice, Ethical, Legal and Professional Guidance


Primacy of the prior expressed consent/authorisation of the patient is established by the Acts. Registration on the Organ Donor Register equals consent/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/authorisation.

Further information is available from the following sources:

National Assembly for Wales
Details a complete record of the passage of the Bill through the Welsh National Assembly, along with the responses to the consultation processes.


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.


NHSBT microsite
www.odt.nhs.uk
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.

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:
- Changing the patient’s location.
- Maintaining physiological stability.


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)

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.”

“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].”


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. Independent UK Donation Ethics Committee (2011) – An Ethical Framework for controlled donation after circulatory death

Provided guidance on roles, responsibilities, and conflicts of interest:

- Early referral to the SNOD is acceptable.
- Two senior clinicians should make the decision that life-sustaining treatment should be withdrawn.
- Care should be in an appropriate environment and provided by staff with the appropriate skills and experience to deliver the end of life care plan.
- After death, it is acceptable for the treating clinician to take actions necessary to facilitate donation, e.g. tracheal re-intubation.

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 intensive 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.


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 –
SNOD Team/Regional Collaborative Map
NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England and North Wales. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs.

We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells. Their generosity means each year we’re able to supply around 1.9 million units of blood to hospitals in England and North Wales and around 4,200 organ and 5,800 tissue donations, which save or improve thousands of lives.

For more information
Visit  nhsbt.nhs.uk
Email  enquiries@nhsbt.nhs.uk
Call  0300 123 23 23

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