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Timely Identification and Referral of Potential Organ Donors

A Strategy for Implementation
of Best Practice

Timely Identification and Referral of Potential Organ Donors

Version	Version 1.0
Target Audience	Hospital Clinical Leads for Organ Donation Hospital Donation Committee chairs and members Specialist Nurses for Organ Donation, NHS Blood and Transplant Organ donation management teams, NHS Blood and Transplant Senior clinical team members in Intensive Care and Emergency Medicine Acute hospital Governance Leads National Donation Committee members
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Author	Donor Identification and Referral Strategy Group, NHS Blood and Transplant
Title	Timely Identification and Referral of Potential Organ Donors A Strategy for Implementation of Best Practice
Description	This document provides practical guidance on how hospital staff and SN-OD teams may develop and implement processes to ensure potential patients are reliably identified in a timely and acceptable way

Preface

Every efficient process for the identification and assessment of potential organ donors has three fundamental requirements. It is clearly important that all patients who might be potential organ donors when they die are recognised and referred to the teams of specialist nurses who coordinate donor assessment and organ retrieval (specialist nurses-organ donation, SN-ODs). It is also important that this referral is made as early as practicable and that the specialist nurses teams respond in a timely manner. Finally, it is crucial that the referral systems that are in place are acceptable to both the clinical staff who care for potential donors and as well as to the families of potential donors.

The Organ Donation Taskforce established minimum criteria for the identification and referral of potential donors across the UK. In more recent guidance, the National Institute of Health and Clinical Excellence (NICE) have published recommendations that apply to practice in England, Wales and Northern Ireland that built on these minima.

This document has been developed at the request of NHS Blood and Transplant (NHSBT) and written by a group of senior hospital clinicians and experienced NHSBT personnel. It provides practical guidance on how hospital staff and SN-OD teams might develop and implement processes to ensure that patients of all ages who fulfil the criteria for referral are reliably identified in a timely and acceptable way. Whilst it is acknowledged that NICE guidance has no regulatory force in Scotland, it is nevertheless hoped that the principles of good practice upon which the guidance is based will be recognised and incorporated into practice throughout the UK. In this way, it will be possible to give more patients the option of donation and maximise the gift, whilst at the same time preserving the spirit of trust and altruism that underpins deceased organ donation in the UK.

Alex Manara, Chair

Paul Murphy

Anthony Clarkson

1. Introduction

Any successful deceased donation programme has a fundamental reliance on the identification and referral of all potential donors. It is perhaps less clear that donation also benefits from referrals of potential donors being made as early as practicable and responded to as efficiently as possible.

Hospital staff have had understandable anxieties about some aspects of early referral of potential donors. These include:

- Making a referral of a potential donor without a family's knowledge (even though this is about planning care and can give real clarity to the options for end of life care that may be available to their loved one).
- The need to continue to support a patient whilst an initial assessment over donation potential is being made.
- The referral of patients on the basis of the degree of neurological impairment (i.e. deep coma and absence of cranial nerve reflexes) who are still being managed actively.

Although these concerns have been addressed in a number of national documents (see Appendix A), the proposals contained within this strategy should give clinical staff even greater confidence that when a patient in their care is identified as a potential donor and referred to the local SN-OD team, they are at all times acting in the best interests of that patient.

2. Current identification and referral criteria

2.1 Organ Donation Taskforce recommendations

In 2008, the Organ Donation Taskforce recommended that as a minimum, patients should be referred either when the intention to confirm death by neurological criteria had been established (for donation after brain-stem death, DBD) or when a clinical decision to withdraw active treatment had been made (for donation after circulatory death, DCD).ⁱ

These criteria (for details, see Appendix B) were limited – perhaps unintentionally – to potential donors with catastrophic brain injury, and thereby excluded the small but nevertheless important proportion of potential DCD donors who might be dying from other causes. The Taskforce also stopped short of recommending the adoption of clinical trigger referral systems such as those used in the United States, although it did encourage individual units to explore their potential.

2.2 NICE Recommendations on Donor Identification and Referral

In December 2011 NICE issued a short clinical guideline on organ donation. The guideline applies to practice in England, Wales and Northern Ireland and recommends that hospital staff initiate discussions with a Specialist Nurse for Organ Donation (SN-OD) when one of the following criteria are met (see Appendix C):

- ‘defined clinical trigger factors in patients who have had a catastrophic brain injury, namely:
 - the absence of one or more cranial nerve reflexes **and**
 - a Glasgow Coma Scale (GCS) score of four or less that is not explained by sedation

unless there is a clear reason why the above clinical triggers are not met (for example because of sedation) and/or a decision has been made to perform brain-stem death tests, whichever is the earlier.

- The intention to withdraw life-sustaining treatment in patients with a life-threatening or life-limiting condition which will, or is expected to, result in circulatory death.’

In effect, the guidance from NICE has served to both meet the aspiration of the Taskforce to introduce clinical triggers for the referral of patients with very severe brain injury and also to expand the potential for DCD to all critically ill patients who are expected to die following a decision to limit or withdraw treatment. In advocating the referral of gravely ill patients who are still receiving full active treatment, the NICE guidance aims to give the SN-OD team early notice of the possibility of a potential donor in a particular clinical area. It is important that SN-OD teams are sensitively proactive in monitoring the progress of these patients.

ⁱ The World Health Organisation definitions of potential organ donors.¹

A potential DBD donor: a person whose clinical condition is suspected to fulfil brain death criteria.

A potential controlled DCD donor: a person in whom the cessation of circulatory and respiratory functions is anticipated to occur within a time frame that will enable organ recovery.

3. Benefits of more timely identification and referral

The need to identify and refer all potential donors is self-evident. However, there are also many advantages to identifying and referring a potential donor as soon as possible, which are largely realised through earlier involvement of the SN-OD team. These include:

- Access to expert clinical advice, for example on the neurological determination of death (brain-stem death testing).
- Prompt application of the donor care bundle to support the physiological optimisation of potential DBD donors.
- Identification and resolution of potential Coronial/Procurator Fiscal issues.
- More rapid assessment of marginal donors, particularly DCD donors.
- Early tissue typing and virology screening (a source of considerable delay, particularly to cardiothoracic organ retrieval).
- Involvement of SN-OD team with donor families and the planning and conduct of the approach for consent/authorisation.

Overall, it is anticipated that an earlier collaboration with the SN-OD team will result in improved family consent/authorisation rates, an increase in the number of organs that are retrieved and a better experience for hospitals and families (regardless of whether donation takes place or not). The key to realising these important benefits is collaboration: donor hospital staff need to be prepared to enter into this collaboration, whilst SN-OD teams must be available to respond and support hospital staff as quickly and effectively as possible.

3.1 Timescales

Organising a safe and effective organ retrieval takes time. It requires detailed assessment of the potential donor, careful evaluation of potential recipients and mobilisation of the relevant retrieval team(s) who might be some distance away. Retrieval of the thoracic organs frequently lengthens the process yet further, principally because suitably matched recipients have to be identified and admitted to the transplanting centre before retrieval begins. Although it is important to be realistic about these timings, particularly with regards to the benefits of the extended physiological optimisation of potential DBD donors, it is crucial that avoidable delays are kept to a minimum. Early identification and referral should assist in this regard.

Duration of the donation process may have a particular impact on the acceptability of DCD donation to families. It is perhaps of note that there has been a considerable lengthening of the DCD pathway over recent years and that this has been associated with a fall of family consent/authorisation rates from 61% in 2006-07 to 52% in 2011-12.

4. Introducing a systematic and timely referral policy

Donation Committees and SN-OD teams are asked to collaborate to develop and implement a policy that ensures that all potential donors are identified and referred in a timely fashion. The objectives of this policy should be that:

1. **All** potential organ donors are identified.
2. All potential donors are identified and referred in a **timely fashion**.
3. SN-ODs are deployed in a way that **best meets the needs of referring hospitals**, thereby minimising any subsequent delays in the donation pathway.

Satisfying these objectives will require a partnership approach between hospitals and the local SN-OD team.

Various systems for identification and referral, each with their own benefits and disadvantages, are presented below. In many instances a single solution may not be the answer; for example one that works well for ICU during the working day may be less well suited to an Emergency Department (ED). However, this is not a prescriptive list and local teams are encouraged to develop bespoke solutions should this be of added value. A small number of principles apply however:

- Every hospital should have a written policy for the identification and timely referral of all potential donors (making donor identification routine business of the unit).
- Whilst it is very unlikely that every hospital within a regional collaborative will adopt the same approach, it is requested that every donating area within a given hospital adopts a consistent approach.
- Where individual clinicians may feel conflicted about referring patients for whom they are caring, consider approaches that 'decouple' early referral from that clinician.

In so doing, and where relevant, organisations will be able to demonstrate their compliance with this element of NICE guidance.

4.1 Role of the SN-OD

Most attention to date has focussed upon how hospital staff might identify and refer potential donors and how the potential perceived conflicts involved in this might be overcome. However, SN-OD teams also have an important role to play, both in terms of how quickly they can respond to a referral and also how they themselves can be proactively involved in donor identification by having a systematic and reliable presence on an ICU.

4.2 Approaches for improving the identification and referral of potential donors

Approach 1: Attendance by a member of the SN-OD team

An early daily attendance by a member of the SN-OD team – preferably the embedded SN-OD for that unit – would mean that any patients meeting the referral criteria would be identified without the need of formal referral.

Advantages	Disadvantages
No need for formal notification	Not currently available out of hours and on weekends
Less concern of a perceived conflict of interest by ICU staff	Absences for annual leave, sick leave, professional leave
Promotes team work	May cause unease in some ICU staff
	Less effective for ED

Hospitals favouring this option are advised to consider how information regarding the donation potential of patients on the unit will be passed onto the specialist nurses. NHSBT is currently planning to offer this level of support to hospitals with the highest donation potential (Level 1 hospitals).ⁱⁱ

Approach 2: Early daily phone call from member of the SN-OD team

This will allow the regional team to be aware of the donor potential across the region on a daily basis.

Advantages	Disadvantages
No need for formal notification	SN-OD may be unfamiliar to ICU staff
Less concern of a perceived conflict of interest by ICU staff	May cause unease in ICU staff
Available to all hospitals all year round	Less effective for ED
	Intrusive for units with low donor potential (1-2 donors per annum)

ⁱⁱ NHSBT categorises hospital sites into one of four levels according to their donation potential as recorded by the Potential Donor Audit. Level 1 hospitals have a minimum of 32 potential deceased donors annually.

Approach 3: Incorporation into daily ICU Team Safety Brief

Following on from the universal implementation of WHO safety checks in theatre, ICU daily safety briefs are increasingly being used in UK ICUs. An example of the safety brief form being used at North Bristol NHS Trust is shown in Appendix D.

Advantages	Disadvantages
Organ donation becomes part of routine ICU daily business	Can only be effective in ED if repeated in every shift
Donation considered by all members of the ICU team	May fail to identify patients whose donation potential emerges later in the day
Less concern about conflict of interest	
Donation potential considered at start of every day	
Initiated by ICU team not individuals	

Approach 4: Incorporation of referral into a Standard Operating Procedure

A Standard Operating Procedure that directs the care of patients in whom brain-stem death is suspected or for whom treatment limitation or withdrawal is considered appropriate can automatically prompt referral at a particular point in the pathway.

Advantages	Disadvantages
Common management and audit tool	Needs initiation by individual of ICU team
Directs clinician through whole donor pathway	Paperwork kept at bedside
	May result in later referrals

Approach 5: Nurse led referrals

This is likely to be particularly suited to the ED where donor potential changes rapidly and cannot be determined routinely using the above methods. However it is also suitable for ICU.

Advantages	Disadvantages
Easily incorporated into local care pathways	Needs initiation by individual member of ED nursing staff
Empowers ICU/ED nursing staff	Needs a rapid response from the SN-OD team
Proven impact in some hospitals	Other members of team may not be aware of referral
	Potential risk of confusing and inappropriate referrals.

5 Monitoring progress

5.1 Implementation

It is hoped that teams and hospitals will have developed and introduced donor identification and referral policies by 31 December 2012. Support will be offered where required.

SN-OD teams will continue to be asked to report on the time that SN-ODs spend in hospitals, with a new aim that a SN-OD will be present at an appropriate time at least five days per week on the ICUs of all level 1 hospitals. Local SN-OD teams may choose to agree standards with hospitals in their area to ensure the team is aware of the current donor potential within each ICU. For example the standard may be *'the local SN-OD team will have a log of the donor potential (even if it is zero) for all their hospitals by x o'clock each day'*.

5.2 Effectiveness

Potential donors who are not identified and/or referred will continue to be captured and reported by the Potential Donor Audit (PDA). The next update of the PDA will also assess the timeliness of the referral. In addition, SN-OD teams will be managed against the time interval between referral and their attendance at an ICU or ED.

5.3 Healthcare regulators

Trusts and Health Boards in England, Wales and Northern Ireland will be required to assess themselves against the NICE guidance on Organ Donation and implement the criteria for referral that are recommended. NICE have developed a baseline assessment tool that Donation Committees might find helpful in assessing their current compliance with these recommendations, available at <http://www.guidance.nice.org.uk/CG135>.

In England, Care Quality Commission inspectors might choose to focus upon the NICE guidance on organ donation during their visits, and Trusts compliant with it might also choose to incorporate this into their self-determined CQUIN (Commissioning for Quality and Innovation) account. In Northern Ireland, adoption and implementation of NICE guidance is supported by the Health and Social Care Board, whilst in Wales it is the responsibility of Healthcare Inspectorate Wales.

APPENDIX A: Relevant extracts from various pieces of national guidance

UK Donation Ethics Committee²

There is no ethical dilemma if the treating clinician wishes to make contact with the SN-OD at an early stage, while the patient is seriously ill and death is likely, but before a formal decision has been made to withdraw life-sustaining treatment. Such early discussions might be valuable for a variety of reasons. These include establishing whether there are contra-indications for organ donation, in which case the issue of donation either does not need to be raised with the family at all, or if the family raise the issue it can be explained why organ donation is not appropriate. Other practical and organisational factors might be relevant – if the SN-OD is based at a distant location then early contact can help to minimise distressing delays for the family.

The family will not be approached about organ donation unless and until the decision to withdraw life-sustaining treatment has been made and independently agreed, and the family has accepted this. The patient's ODR status should be known before the family are approached. If the family raise the issue at an earlier stage any information should be noted and discussions handled sensitively according to the family's needs, but decisions should not be formalised until the decision to withdraw life-sustaining treatment has been made.

The Organ Donation Taskforce recommended that, as a minimum, the SN-OD should be notified when the decision to withdraw treatment had been agreed, and that the Organ Donor Register should be checked at this point if this had not already been done. However, it encouraged units to consider developing earlier referral criteria based on clinical condition alone.

UKDEC is in agreement with the Organ Donation Taskforce recommendations. Flexibility is needed, and in many cases it will be a matter of clinical judgement, supported by local protocols where appropriate, as to when the SN-OD should be made aware of the case.

Early involvement of the SN-OD with the family (sometimes known as the 'long contact model') means the SN-OD joins the clinical team when they begin to talk through with the family that further life-sustaining treatment is no longer in their relative's best interests. It has been the subject of some debate within the transplant community, with some arguing that it leads to higher consent rates for donation as the SN-OD is already part of the team supporting the family before the approach is made. Others argue that there is a risk of coercion, and fragmentation of support to the family as, if the family decide donation is not appropriate, the SN-OD may leave.

General Medical Council³

Organ donation

81 *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.*

82 *You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator. You must take account of the requirements in relevant legislation and in any supporting codes of practice, in any discussions that you have with the patient or those close to them. You should make clear that any decision about whether the patient would be a suitable candidate for donation would be made by the transplant coordinator or team, and not by you and the team providing treatment.*

Legal guidance on non-heart beating organ donation

Current legal guidance from the Department of Health and from the Welsh Assembly Government⁴ (covering practice in England and Wales) advises that, '[m]aintenance of life-sustaining treatment may be considered to be in the best interests of someone who wanted to be a donor if it facilitates donation and does not cause them harm, or place them at significant risk of experiencing harm or distress'.

Current legal guidance from the Scottish Government⁵ advises that, '[t]here are a number of steps that can be taken before a person has died, which can optimise the chances of a successful donation and transplant. These steps fall into the broad categories of actions to check the person's wishes about donation and their suitability to be a donor, maintaining treatment and the timing of its withdrawal to coordinate with organ retrieval and introducing new treatment or activities that improve the chances of a successful organ transplant.'

Current legal guidance from the Northern Ireland Department of Health, Social Services and Public Safety⁶ states, 'There are occasions when haemodynamic or ventilatory instability before the surgical retrieval team is ready jeopardises the prospects of successful donation. Some interventions are designed to temporarily reverse such instability. If it is established that a person wanted to be an organ donor and such interventions facilitate donation, then, these steps may be considered to be in that person's best interests... they must be weighed against any significant risk of harm or prejudice to dignity in maintaining each treatment, and any distress that may be caused to family by certain procedures.'

British Medical Association⁷

The research data analysed by NICE showed that the use of clinical triggers and a requirement to refer according to standard criteria led to an increase in both referrals and donors. It is hoped that implementation of the NICE guideline will result in early and consistent donor referral. This, combined with the clinical lead and specialist nurse providing support and guidance to staff and the donation committee investigating all cases where potential donors are lost, should lead to an increase in referral rates and, subsequently, an increase in donors across the UK. Clinical management of potential donors, before and after referral, is also an important issue. This includes decisions about the timing of withdrawal of treatment (which should take account of the individual's wish to become a donor where that is known), and the initial stabilisation and assessment of potential donors. Work is currently underway to develop and test an 'intensive care bundle' to help intensivists to provide clinical care to potential donors in a way that will maximise donation potential.

APPENDIX B: Minimum Notification Criteria from the Organ Donation Taskforce

Recommendation 5 from the Organ Donation Taskforce was as follows:⁸

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

The Taskforce asked the Donation Advisory Group of UK Transplant to develop these minimum criteria. This was done in consultation with the Intensive Care Society and with the support of the Royal College of Anaesthetists. The minimum notification criteria as published by the Organ Donation Taskforce read as follows:

- *When no further treatment options are available or appropriate, and there is a plan to confirm death by neurological criteria, the SN-OD should be notified as soon as sedation/analgesia is discontinued, or immediately if the patient has never received sedation/analgesia. This notification should take place even if the attending clinical staff believe that donation (after death has been confirmed by neurological criteria) might be contra-indicated or inappropriate.*
- *In the context of a catastrophic neurological injury, when no further treatment options are available or appropriate and there is no intention to confirm death by neurological criteria, the SN-OD should be notified when a decision is made by a consultant to withdraw active treatment and this has been recorded in a dated, timed and signed entry in the case notes. This notification should take place even if the attending clinical staff believe that death cannot be diagnosed by neurological criteria, or that donation after cardiac death might be contra-indicated or inappropriate.*

The Taskforce viewed these criteria as an acceptable but minimum description of what was necessary, and as such recommended that they be implemented in all Trusts and Health Boards.

APPENDIX C: NICE recommendations on the identification and referral of potential organ donors⁹

Identifying patients who are potential donors

1.1.1 *Organ donation should be considered as a usual part of 'end-of-life care' planning.*

1.1.2 *Identify all patients who are potentially suitable donors as early as possible, through a systematic approach. While recognising that clinical situations vary identification should be based on either of the following criteria:*

- *defined clinical trigger factors in patients who have had a catastrophic brain injury, namely:
 - *the absence of one or more cranial nerve reflexes **and***
 - *a Glasgow Coma Scale (GCS) score of four or less that is not explained by sedation unless there is a clear reason why the above clinical triggers are not met (for example because of sedation) and/or a decision has been made to perform brainstem death tests, whichever is the earlier**
- *the intention to withdraw life-sustaining treatment in patients with a life-threatening or life-limiting condition which will, or is expected to, result in circulatory death.*

1.1.3 *The healthcare team caring for the patient should initiate discussions about potential organ donation with the specialist nurse for organ donation at the time the criteria in recommendation 1.1.2 are met.*

APPENDIX D: ICU safety brief proforma (courtesy of North Bristol NHS Trust)

North Bristol NHS Trust	Safety Briefing Safer Patient Initiative	Quality Improvement & Audit
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Date:		
Consultant(s):		
EARLY SHIFT	Yes	No
Medical staff		
Trained nursing staff		
Untrained nursing staff		
LATE SHIFT	Yes	No
Medical staff		
Trained nursing staff		
Untrained nursing staff		
NIGHT SHIFT	Yes	No
Medical staff		
Trained nursing staff		
Untrained nursing staff		

CDs Checked?	Yes	No
Grab Bag Checked?	Yes	No
Is there at least one fully staffed level 3 bed available for immediate use?	Yes	No
If no, is there patient(s) waiting to be discharged to the ward?	Yes	No
Have any of the patients been admitted with or developed a Pressure Sore? If yes... Where was it acquired?	Yes	No
What grade is it?		
AIMS form completed/referral to TVN made?		

TOPICS	EARLY	LATE	NIGHT
Bed status			
North	Pts	Dep	Staff
South			
Total			
Southmead			
Potential Admissions:			
Potential Discharges: If yes, gender breach?			
CSM informed? (Name & Time)			
Number of patients with CVADs			
Total number of CVADs			
Any suspected CVAD BSI's? If yes, patients hospital number			
Any MRSA +ve patients? If yes, protocol being followed?			
Any agitated or confused pts?			
Any other Issues? (Equipment etc)			
Do any patients meet the criteria for notifying a SNOD*			Yes No
SNOD Informed? (In house SNOD or pager 07659591642) (Name & Time)			Yes No

APPENDIX E: Membership of the Donor Identification and Referral Strategy Group

Dr Alex Manara (chair)	Consultant in Anaesthesia and Critical Care, North Bristol NHS Trust; Regional Clinical Lead for Organ Donation (South West)
Emma Billingham	Senior Commissioning Manager, NHSBT
Jackie Brander	Team Manager, Organ Donation (Midlands), NHSBT
Anthony Clarkson	Assistant Director, Organ Donation, NHSBT
Jane Griffiths	Regional Manager for Organ Donation (London and Northern Ireland), NHSBT
Professor Arpan Guha	Consultant, Intensive Care Medicine, Royal Liverpool University Hospital; Regional Clinical Lead for Organ Donation (North West)
Lesley Logan	Regional Manager for Organ Donation (Northern and Scotland), NHSBT
Olive McGowan	Head of Service Development, NHSBT
Karen Morgan	Regional Manager for Organ Donation (South West and Wales), NHSBT
Dr Paul Murphy	Consultant in Anaesthesia and Critical Care, Leeds Teaching Hospitals NHS Trust, National Clinical Lead for Organ Donation, NHSBT
Dr Angus Vincent	Consultant in Anaesthesia and Critical Care Newcastle; Regional Clinical Lead for Organ Donation (Northern)

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