Organ donation: improving donor identification and consent rates for deceased organ donation
NICE guideline

Guideline Appendices

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Appendix A Scope

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

SCOPE

1 Guideline title

Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation

1.1 Short title

Organ donation for transplantation

2 The remit

The Department of Health has asked NICE: ‘To produce a clinical guideline on improving donor identification and consent rates for cadaveric organ donation’.

<table>
<thead>
<tr>
<th>Terms used in this scope</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain-stem death</td>
</tr>
<tr>
<td>Cardiac death</td>
</tr>
<tr>
<td>Potential donors</td>
</tr>
</tbody>
</table>

3 Clinical need for the guideline

3.1 Epidemiology

a) Organ transplantation has a major role in the management of patients with failure of a single organ system of either the kidneys, small bowel, liver, pancreas, heart, lung, or thymus, and of combined organ failure of the heart and lung, the kidney and pancreas, the liver and kidney, or liver and small bowel. Transplants may be needed because of primary organ disease, such as chronic inflammatory disease of the kidneys or cardiomyopathy, or because of secondary effects such as kidney, islet cell and pancreas transplants in people with diabetes, and lung transplants in people with cystic fibrosis.

b) The distribution of the population on the transplant waiting list is 75% white, 25% non-white; 59% male, 41% female; 7% aged 0–17 years, 18% aged 18–34 years, 39% aged 35–49 years, 20% aged 50–59 years, 15% aged 60+ years.

c) There is a shortage of organs for transplant resulting in long waits for transplantation and a significant number of deaths while waiting transplantation.

d) Approximately 8,000 people in the UK are waiting for an organ transplant. This figure is rising by about 5% per year because of a number of factors, such as: increasing prevalence of renal and liver disease; ethnic diversity of the UK population; lower thresholds for transplantation and better clinical management of serious illnesses. The true need is likely to be greater and is rising rapidly with changing demographics of the UK. Of particular note are an ageing population and an anticipated increase in the incidence of type 2 diabetes, a condition that can cause kidney failure and lead to the need for a kidney transplant.
e) At any one time, a significant number of patients may be suspended from the active list. This is because their condition has temporarily deteriorated to the extent that a transplant is too risky. In 2008–09, 2552 transplants used organs from deceased donors; however, another 1178 patients were listed for transplant, of whom 448 died before receiving one and 730 were removed from the list.

f) Data from NHS Blood and Transplant, on transplant activity in the UK 2008–09, showed that only 86% of potential donors after brain-stem death, and 42% of potential donors after cardiac death, were referred to donor coordinators. Of those families approached, permission was refused for donation to proceed for 38% of possible DBD (donation after brain-stem death) donors, and 42% of possible DCD (donation after cardiac death) donors.

3.2 Current practice

a) Europe has an average of 17.8 donors per million people. The UK has one of the lower rates at 15.5 donors per million people.

b) Clinical practice, and whether families are asked to consider organ donation, varies significantly across the UK. The conversion rates for potential donors becoming actual donors in 2008/09 varied between 23.7% and 43%. In 2008–09, the mean conversion rate in UK intensive care units for potential donors becoming actual donors was about 51% for DBD to 15% for DCD.

c) Kidney transplantation is more cost-effective than haemodialysis for treating stage 5 chronic kidney disease, but it is less commonly used than it should be due to shortage of transplantable kidneys. An increase in transplant rates will have a beneficial impact on resources and will increase quality of life for patients that are suitable for transplantation and are currently on dialysis.

d) NHS Blood and Transplant data show that only 5% of deceased donors are of Asian or African–Caribbean descent, even though
these groups form 25% of the kidney transplant waiting list. People of Asian or African–Caribbean descent are three to four times more likely than white people to develop end-stage renal failure and to need a kidney transplant. People from these populations are also much less likely to give consent for organ donation when asked.

e) A UK transplant\(^1\) survey in 2003 showed that the public is very supportive of organ donation in principle, with 90% in favour. Nearly 17 million people are already on the NHS Organ Donor Register. However, the actual donation rate in the UK remains poor. This may be partly because of bereaved relatives not consenting to organ donation. Many reviews of organ donation have been done in the past, but all failed to resolve the problems that result from the lack of a structured and systematic approach to organ donation.

f) The guideline will focus on identifying potential donors and obtaining consent for solid organ donation under current legislation. It will help to address the burden of disease by increasing the availability of organs for transplant. It will address current inequalities by helping to make organ donation a usual part of NHS practice, meaning that families of all potential organ donors are approached and supported, irrespective of factors such as ethnicity and religion.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, ‘Further information’).

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections.

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\(^1\) In 2003, UK transplant subsequently changed to NHS Blood and Transplant.
4.1 Population

4.1.1 Groups that will be covered

a) Families, relatives and legal guardians of potential DBD donors (adults and children).

b) Families, relatives and legal guardians of potential DCD donors (adults and children).

c) Within this population, the following groups have been identified as needing special consideration:

- people from black and minority ethnic groups.
- people with differing religious beliefs.

4.1.2 Groups that will not be covered

a) Groups involved in giving consent on organ donation other than those described in sections 4.1.1a and 4.1.1b.

4.2 Healthcare setting

a) NHS hospitals.

4.3 Clinical management

4.3.1 Key clinical issues that will be covered

- Structures and processes for identifying potential DBD and DCD donors
  - timing of referral
  - criteria for consideration

- Structures and processes for obtaining consent for deceased organ donation for transplantation, including the optimum timing for approaching families about consent.

- Coordination of the care pathway from identification of potential donors to consent.
Competencies of healthcare professionals involved in the activities described in sections 4.3.1 a, b and c.

### 4.3.2 Clinical issues that will not be covered

a) Systems for declaring a willingness to donate before death.

b) Tissue donation.

c) The processes of organ retrieval.

d) Living organ donation.

e) Assessment of organs for transplantation.

f) Organ donation for training and medical research.

g) Prioritisation of organ allocation, including the structures and processes of organ transfers within or outside the UK.

### 4.4 Main outcomes

a) Rates of identification of potential donors.

b) Rates of consent for donation.

c) Rates of organ donation for transplantation.

d) Rates of successful transplants.

e) Rates of viable organs retrieved.

f) Rates of family, relatives and legal guardians refusal.

g) Families, relatives and legal guardians’ experience of the structures and processes for organ donation.

### 4.5 Economic aspects

It is unlikely that standard HE modelling techniques will apply to this guideline. In the absence of these a cost impact analysis will be undertaken that looks...
at how identification and consent impacts on current resources. The cost impact analysis will be included in the main text of the guideline.

4.6 Status

4.6.1 Scope
This is the final scope.

4.6.2 Timing
The development of the guideline recommendations will begin in September 2010.

5 Related NICE guidance
There is no related NICE guidance for this topic.

6 Further information
Information on the guideline development process is provided in:

- ‘How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS’
- ‘The guidelines manual’.

These are available from the NICE website (www.nice.org.uk/GuidelinesManual). Information on the progress of the guideline will also be available from the NICE website (www.nice.org.uk).
Appendix B Guideline development methods

This guideline was developed in accordance with the process for short clinical guidelines set out in ‘The guidelines manual’ (2009) (see www.nice.org.uk/GuidelinesManual). There is more information about how NICE clinical guidelines are developed on the NICE website (www.nice.org.uk/HowWeWork). A booklet, ‘How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS’ (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

Search strategies
Medline search strategies for the Organ Donation guideline

Scoping searches
Scoping searches were undertaken in March 2010 using the following websites and databases (listed in alphabetical order); browsing or simple search strategies were employed. The search results were used to provide information for scope development and project planning.

<table>
<thead>
<tr>
<th>Guidance/guidelines</th>
<th>Systematic reviews/economic evaluations</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Medical Association</td>
<td>Clinical Evidence</td>
</tr>
<tr>
<td>Canadian Medical Association Infobase</td>
<td>Cochrane Database of Systematic Reviews (CDSR)</td>
</tr>
<tr>
<td>Clinical Knowledge Summaries</td>
<td>Database of Abstracts of Reviews of Effects (DARE)</td>
</tr>
<tr>
<td>Department of Health</td>
<td>Health Economic Evaluations Database (HEED)</td>
</tr>
<tr>
<td>Donor Family Network</td>
<td>Health Technology Assessment (HTA) Database</td>
</tr>
<tr>
<td>European Transplant Co-ordinators Organisation</td>
<td>NHS Economic Evaluation Database (NHS EED)</td>
</tr>
<tr>
<td>General Medical Council</td>
<td>NHS R&amp;D Service Delivery and Organisation (NHS SDO) Programme</td>
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<tr>
<td>Guidelines International Network (GIN)</td>
<td>National Institute for Health Research (NIHR) Health Technology Assessment Programme</td>
</tr>
<tr>
<td>Human Tissue Authority</td>
<td>TRIP Database</td>
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<tr>
<td>National Guideline Clearing House (US)</td>
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<tr>
<td>National Health and Medical Research Council (Australia)</td>
<td></td>
</tr>
<tr>
<td>National Institute for Health and Clinical Excellence (NICE) – guidance published &amp; in development</td>
<td></td>
</tr>
<tr>
<td>National Institute for Health and Clinical Excellence (NICE) – topic selection</td>
<td></td>
</tr>
</tbody>
</table>
Main searches
The following sources were searched for the topics presented in the sections below.

- Cochrane Database of Systematic Reviews – CDSR (Wiley)
- Cochrane Central Register of Controlled Trials – CENTRAL (Wiley)
- Database of Abstracts of Reviews of Effects – DARE (CRD)
- Health Technology Assessment Database – HTA (CRD)
- CiNAHL (NHS Evidence)
- EMBASE (Ovid)
- MEDLINE (Ovid)
- MEDLINE In-Process (Ovid)

The MEDLINE search strategies are presented below. They were translated for use in all of the other databases.

Search for identification of potential organ donors

1  exp Death, Sudden/

2  Brain death/

3  ("brain stem" or brainstem or brain-stem or brain or neuro* or medulla*)
   adj3 (death* or dead or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*)).ti,ab.

4  (cardiac or heart or cardio*)
   adj3 (death* or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*)).ti,ab.

5  (post mortem* or cadaver* or dead or death* or deceased).ti,ab.

6  or/1-5
exp "Tissue and organ procurement"/ or Tissue donors/

((don* or procur*) adj3 (tissue* or organ*)).ti,ab.

7 or 8

Decision Making/

(identif* or select* or confirm* or establish* or ascertain* or verif* or
distinguish* or classif* or recogniz* or recognis* or determin* or deci* or qualif*
or refer* or recruit* or initiat* or criteri* or accept* or potential* or attitud* or
characteris* or find* or discover* or verif* or diagnos*).ti.

10 or 11

6 and 9 and 12

animals/ not humans/

13 not 14

limit 15 to english language

Search for clinical triggers for referral to organ donation team

exp "Tissue and organ procurement"/ or Tissue donors/

((don* or procur*) adj3 (tissue* or organ*)).ti,ab.

1 or 2

trigger*.tw.

"Referral and Consultation"/

Models, Organizational/

("task force" or "taskforce" or "task-force").ti,ab.

or/4-7

3 and 8

animals/ not humans/

9 not 10

limit 11 to english language

Search for papers about obtaining consent for organ donation
1  exp Death, Sudden/

2  Brain death/

3  (("brain stem" or brainstem or brain-stem or brain or neuro* or medulla*)
adj3 (death* or dead or injur* or sever* or irreversib* or damage* or traum* or
fail* or arrest*)).ti,ab.

4  ((cardiac or heart or cardio*) adj3 (death* or injur* or sever* or irreversib*
or damage* or traum* or fail* or arrest*)).ti,ab.

5  (postmortem or post-mortem or post mortem* or cadaver* or dead or
death* or deceased).ti,ab.

6  or/1-5

7  exp "Tissue and organ procurement"/ or Tissue donors/

8  ((don* or procur*) adj3 (tissue* or organ*)).ti,ab.

9  7 or 8

10 exp Informed Consent/ or exp Third-Party Consent/ or exp Consent
Forms/ or exp Presumed Consent/ or exp Parental Consent/

11  (consent* or agree* or accept* or allow* or permi* or sanction* or
aprov* or cooperat* or co-operat* or compl* or obtain* or assent* or authoris* or
authoriz* or concur* or accede* or endors*).ti.

12  10 or 11

13  6 and 9 and 12

14  animals/ not humans/

15  13 not 14

16  limit 15 to english language
Search for timing of approach

1  exp Death, Sudden/

2  Brain death/

3  ("brain stem" or brainstem or brain-stem or brain or neuro* or medulla*) adj3 (death* or dead or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*).ti,ab.

4  ((cardiac or heart or cardio*) adj3 (death* or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*).ti,ab.

5  (postmortem or post-mortem or post mortem* or cadaver* or dead or death* or deceased).ti,ab.

6  or/1-5

7  exp "Tissue and organ procurement"/ or Tissue donors/

8  ((don* or procur*) adj3 (tissue* or organ*).ti,ab.

9  7 or 8

10  Time/ or Time Factors/ or Time Management/

11  (time* or timing*).tw.

12  10 or 11

13  exp Informed Consent/ or exp Third-Party Consent/ or exp Consent Forms/ or exp Presumed Consent/ or exp Parental Consent/

14  (consent* or agree* or accept* or allow* or permi* or sanction* or approv* or cooperat* or co-operat* or compl* or obtain* or assent* or authoris* or authoriz* or concur* or accede* or endors*).ti.

15  13 or 14

16  6 and 9 and 12 and 15
Animals/ not Humans/
16 not 17
limit 18 to english language

Search for care pathways in organ donation
1 exp Death, Sudden/
2 Brain death/
3 ("brain stem" or brainstem or brain-stem or brain or neuro* or medulla*) adj3 (death* or dead or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*).ti,ab.
4 ((cardiac or heart or cardio*) adj3 (death* or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*)).ti,ab.
5 (postmortem or post-mortem or post mortem* or cadaver* or dead or death* or deceased).ti,ab.
6 or/1-5
7 exp "Tissue and organ procurement"/ or Tissue donors/
8 ((don* or procur*) adj3 (tissue* or organ*)).ti,ab.
9 7 or 8
10 Critical pathways/
11 "Delivery of Health Care, Integrated"/
12 Patient care planning/
13 ((care or clinical or integrated or multidisciplinary or critical) adj3 (pathway* or path* or plan* or protocol* or procedure* or program* or
programme* or manag* or process* or outline* or algorithm* or map* or schedul*)).ti,ab.

14  or/10-13

15  6 and 9 and 14

16  animals/ not humans/

17  15 not 16

Search for competencies of staff in organ donation

1  exp “Tissue and organ procurement”/ or Tissue donors/

2  ((don* or procur*) adj3 (tissue* or organ*)).ti,ab.

3  1 or 2

4  Inservice Training/

5  exp Professional Competence/

6  (competenc* or skill* or train* or abilit* or expert* or role* or capab* or capacit* or technique* or know*).ti,ab.

7  or/4-6

8  (coordinator* or co-ordinator* or "co ordinator").ti,ab.

9  exp Nurses/

10  nurse.ti,ab.

11  exp Medical Staff/

12  (doctor* or consultant* or physician* or surgeon* or attending or clinician*).ti,ab.

13  ((critical or intensive or medical) adj3 (staff or personnel or care)).ti,ab.

14  or/8-13
15 3 and 7 and 14
16 animals/ not humans/
17 15 not 16
18 limit 17 to english language

**Search for economic studies**

1 exp Death, Sudden/

2 Brain death/

3 ("brain stem" or brainstem or brain-stem or brain or neuro* or medulla*) adj3 (death* or dead or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*).ti,ab.

4 (cardiac or heart or cardio*) adj3 (death* or injur* or sever* or irreversib* or damage* or traum* or fail* or arrest*).ti,ab.

5 (postmortem or post-mortem or post mortem* or cadaver* or dead or death* or deceased).ti,ab.

6 or/1-5

7 exp "Tissue and organ procurement"/ or Tissue donors/

8 ((don* or procur*) adj3 (tissue* or organ*)).ti,ab.

9 7 or 8

10 Economics/ use mesz

11 exp "Costs and Cost Analysis"/

12 Economics, Dental/

13 exp Economics, Hospital/

14 exp Economics, Medical/
15 Economics, Nursing/
16 Economics, Pharmaceutical/
17 Budgets/
18 exp Models, Economic/
19 Markov Chains/
20 Monte Carlo Method/
21 Decision Trees/
22 econom$.tw.
23 cba.tw.
24 cea.tw.
25 cua.tw.
26 markov$.tw.
27 (monte adj carlo).tw.
28 (decision adj2 (tree$ or analys$)).tw.
29 (cost or costs or costing$ or costly or costed).tw.
30 (price$ or pricing$).tw.
31 budget$.tw.
32 expenditure$.tw.
33 (value adj2 (money or monetary)).tw.
34 (pharmacoeconomic$ or (pharmac$ adj economic$)).tw.
35 or/10-34
36 "Quality of Life"/ use mesz
37 quality of life.tw.
38 "Value of Life"/ use mesz
39 Quality-Adjusted Life Years/ use mesz
40 quality adjusted life.tw.
41 (qaly$ or qald$ or qale$ or qtime$).tw.
42 disability adjusted life.tw.
43 daly$.tw.
44 Health Status Indicators/ use mesz
45 (sf36 or sf 36 or short form 36 or shortform 36 or sf thirtysix or sf thirty six or shortform thirtysix or shortform thirty six or short form thirtysix or short form thirty six).tw.
46 (sf6 or sf 6 or short form 6 or shortform 6 or sf six or sfsix or shortform six or short form six).tw.
47 (sf12 or sf 12 or short form 12 or shortform 12 or sf twelve or sftwelve or shortform twelve or short form twelve).tw.
48 (sf16 or sf 16 or short form 16 or shortform 16 or sf sixteen or sfsixteen or shortform sixteen or short form sixteen).tw.
49 (sf20 or sf 20 or short form 20 or shortform 20 or sf twenty or sftwenty or shortform twenty or short form twenty).tw.
50 (euroqol or euro qol or eq5d or eq 5d).tw.
51 (qol or hql or hqol or hrqol).tw.
52 (hye or hyes).tw.
53 health$ year$ equivalent$.tw.
54  utilit$.tw.
55  (hui or hui1 or hui2 or hui3).tw.
56  disutili$.tw.
57  rosser.tw.
58  quality of wellbeing.tw.
59  quality of well-being.tw.
60  qwb.tw.
61  willingness to pay.tw.
62  standard gamble$.tw.
63  time trade off.tw.
64  time tradeoff.tw.
65  tto.tw.
66  or/36-65
67  35 or 66
68  6 and 9 and 67
69  animals/ not humans/
70  68 not 69
71  limit 70 to english language
**Review protocols and clinical questions**

Key Clinical Issues and Review Questions

<table>
<thead>
<tr>
<th>Key Clinical Issues</th>
<th>Review Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structures and processes including timing for referral and criteria for consideration for identifying potential DBD and DCD donors</td>
<td><strong>Review question 1:</strong> What structures and processes including timing for referral and criteria for consideration are appropriate and effective for identifying potential DBD and DCD donors?</td>
</tr>
<tr>
<td>Structures and processes for obtaining consent for cadaveric organ donation for transplantation, including the optimum timing for approaching the families about consent.</td>
<td><strong>Review question 2:</strong> What structures and processes are appropriate and effective for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors?</td>
</tr>
<tr>
<td>Coordination of the care pathway for conversion of potential donors to actual donors.</td>
<td><strong>Review question 3:</strong> When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?</td>
</tr>
<tr>
<td>Competencies of healthcare professionals involved in the activities described above.</td>
<td><strong>Review question 4:</strong> How the care pathway of deceased organ donation should be coordinated to improve potential donors giving consent?</td>
</tr>
<tr>
<td></td>
<td><strong>Review question 5:</strong> What key skills and competencies are important for healthcare professionals to improve the structures and processes for identifying potential DBD and DCD; to improve structures and processes for obtaining consent; and to effectively coordinate the care pathway from identification to obtaining consent?</td>
</tr>
<tr>
<td>Review Protocols</td>
<td>Details</td>
</tr>
<tr>
<td>------------------</td>
<td>---------</td>
</tr>
<tr>
<td><strong>1. Review question 1</strong></td>
<td>What structures and processes including timing for referral and criteria for consideration are appropriate and effective for identifying potential DBD and DCD?</td>
</tr>
<tr>
<td><strong>2. Objectives</strong></td>
<td>To identify all relevant literature on structures and processes including timing for referral and criteria for consideration for identifying potential DBD and DCD donors.</td>
</tr>
<tr>
<td><strong>3. Language</strong></td>
<td>English only</td>
</tr>
<tr>
<td><strong>4. Study design</strong></td>
<td>No restrictions.</td>
</tr>
<tr>
<td><strong>5. Status</strong></td>
<td>Published papers (full papers only)</td>
</tr>
</tbody>
</table>
| **6. Population & Healthcare setting** | Inclusion:  
- Families, relatives and legal guardians of potential DBD and DCD donors (adults and children).  
  - Subgroups considerations: (i) people from Black and minority ethnic groups; (ii) people with differing religious beliefs.  
- Healthcare professionals  
  Setting:  
- Hospitals. | |
| **7. Intervention** | Appropriate and effective structures and processes including timing for referral and criteria for consideration for identifying potential DBD and DCD donors. | |
| **8. Comparisons** | N/A | |
| **9. Outcomes** |  
- Rates of identification of potential donors.  
- Rates of consent for donation.  
- Rates of organ donation for transplantation (donors per million population per year).  
- Rates of conversion for potential donors with consent to actual donors.  
- Rates of successful transplants.  
- Rates of viable organs retrieved.  
- Rates of family, relatives and legal guardians refusal.  
- Families, relatives and legal guardians’ experience of the structures and processes for organ donation. | |
| **10. Other criteria for inclusion/ exclusion of studies** | Exclusion:  
- The structures and process for identifying potential DBD and DCD donors for single organs.  
- Systems for declaring a willingness to donate ante-mortem.  
- Tissue donation  
- The processes of organ retrieval.  
- The structures and process of living organ donation.  
- Assessment of organs for transplantation.  
- Organ donation for training and medical research.  
- Prioritisation of organ allocation, including the structures and processes of organ transfers within or outside the UK. | |
| **11. Search strategies** | Please see Appendix B. | |
| **12. Review strategies** | Appropriate NICE Methodology Checklists, depending on study designs, will be used as a guide to appraise the quality of individual studies. | |
- Data on all included studies will be extracted into evidence tables. 
- Where statistically possible, a meta-analytic approach will be used to give an overall summary effect. 
- All key outcomes from evidence will be presented in GRADE profiles, or modified evidence profiles depending on the study design, and further summarised in evidence statements.

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<tr>
<th>Details</th>
<th>Notes &amp; Status</th>
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<tbody>
<tr>
<td>1. Review question 2</td>
<td>What structures and processes are appropriate and effective for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors?</td>
</tr>
<tr>
<td>2. Objectives</td>
<td>To identify all relevant literature on structures and processes for obtaining consent for deceased organ donation for transplantation.</td>
</tr>
<tr>
<td>3. Language</td>
<td>English only.</td>
</tr>
<tr>
<td>4. Study design</td>
<td>No restrictions.</td>
</tr>
<tr>
<td>5. Status</td>
<td>Published papers (full papers only)</td>
</tr>
</tbody>
</table>
| 6. Population & Healthcare setting | Inclusion: 
- Families, relatives and legal guardians of potential DBD and DCD donors (adults and children). 
- Subgroups considerations: (i) people from Black and minority ethnic groups; (ii) people with different religious beliefs. 
Setting: 
- Hospitals. |
| 7. Intervention | Structures and processes for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors. |
| 8. Comparisons | N/A |
- Rates of consent for donation. 
- Rates of organ donation for transplantation (donors per million population per year). 
- Rates of conversion for potential donors with consent to actual donors. 
- Rates of successful transplants. 
- Rates of viable organs retrieved. 
- Rates of family, relatives and legal guardians refusal. 
- Families, relatives and legal guardians’ experience of the structures and processes for organ donation. |
| 10. Other criteria for inclusion/ exclusion of studies | Exclusion: 
- The structures and process for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors for single organs. 
- Groups involved in giving consent on organ donation other than population specified above. 
- Systems for declaring a willingness to donate ante-mortem. 
- Tissue donation 
- The processes of organ retrieval. 
- The structures and process of living organ donation. 
- Assessment of organs for transplantation. 
- Organ donation for training and medical research. 
- Prioritisation of organ allocation, including the |
structures and processes of organ transfers within or outside the UK.

11. Search strategies
Please see Appendix B.

12. Review strategies
- Data on all included studies will be extracted into evidence tables.
- Where statistically possible, a meta-analytic approach will be used to give an overall summary effect.
- All key outcomes from evidence will be presented in GRADE profiles, or modified evidence profiles depending on the study design, and further summarised in evidence statements.

<table>
<thead>
<tr>
<th>Details</th>
<th>Notes &amp; Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Review question 3</td>
<td>When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?</td>
</tr>
<tr>
<td>2. Objectives</td>
<td>To identify all relevant literature on optimum timing for approaching the families about consent.</td>
</tr>
<tr>
<td>3. Language</td>
<td>English only</td>
</tr>
<tr>
<td>4. Study design</td>
<td>No restrictions.</td>
</tr>
<tr>
<td>5. Status</td>
<td>Published papers (full papers only)</td>
</tr>
</tbody>
</table>
| 6. Population & Healthcare setting | Inclusion:  
- Families, relatives and legal guardians of potential DBD and DCD donors (adults and children).  
- Subgroups considerations: (i) people from Black and minority ethnic groups; (ii) people with different religious beliefs.  
Setting:  
- Hospitals. |
| 7. Intervention | Optimum timing for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent. |
| 8. Comparisons | N/A |
- Rates of consent for donation.  
- Rates of organ donation for transplantation (donors per million population per year).  
- Rates of conversion for potential donors with consent to actual donors.  
- Rates of successful transplants.  
- Rates of viable organs retrieved.  
- Rates of family, relatives and legal guardians refusal.  
- Families, relatives and legal guardians’ experience of the structures and processes for organ donation. |
| 10. Other criteria for inclusion/exclusion of studies | Exclusion:  
- The optimal timing for approaching families, relatives and legal guardians of potential DBD and DCD donors for single organs to obtain consent.  
- Groups involved in giving consent on organ donation other than population specified above.  
- Systems for declaring a willingness to donate ante-mortem.  
- Tissue donation  
- The processes of organ retrieval.  
- The structures and process of living organ donation.  
- Assessment of organs for transplantation. |
- **Organ donation for training and medical research.**
- **Prioritisation of organ allocation, including the structures and processes of organ transfers within or outside the UK.**

11. **Search strategies**

Please see Appendix B.

12. **Review strategies**

- Data on all included studies will be extracted into evidence tables.
- Where statistically possible, a meta-analytic approach will be used to give an overall summary effect.
- All key outcomes from evidence will be presented in GRADE profiles, or modified evidence profiles depending on the study design, and further summarised in evidence statements.

<table>
<thead>
<tr>
<th>Details</th>
<th>Notes &amp; Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Review question 4</strong></td>
<td>How the care pathway of deceased organ donation should be coordinated to improve potential donors giving consent?</td>
</tr>
<tr>
<td>2. <strong>Objectives</strong></td>
<td>To identify all the relevant literature on structures and processes for the coordination of the care pathway from identification to consent.</td>
</tr>
<tr>
<td>3. <strong>Language</strong></td>
<td>English only</td>
</tr>
<tr>
<td>4. <strong>Study design</strong></td>
<td>No restrictions.</td>
</tr>
<tr>
<td>5. <strong>Status</strong></td>
<td>Published papers (full papers only)</td>
</tr>
</tbody>
</table>
| 6. **Population & Healthcare setting** | Inclusion: NA  
Setting: Hospitals |
| 7. **Intervention** | Structures and processes for the coordination of the care pathway from identification to consent. |
| 8. **Comparisons** | N/A |
Rates of consent for donation.  
Rates of organ donation for transplantation (donors per million population per year).  
Rates of conversion for potential donors with consent to actual donors.  
Rates of successful transplants.  
Rates of viable organs retrieved.  
Rates of family, relatives and legal guardians refusal.  
Families, relatives and legal guardians' experience of the structures and processes for organ donation. |
| 10. **Other criteria for inclusion/ exclusion of studies** | Exclusion:  
The co-ordination of the care pathway for single organs to improve potential donors giving consent.  
Groups involved in giving consent on organ donation other than population specified above.  
Systems for declaring a willingness to donate ante-mortem.  
Tissue donation  
The processes of organ retrieval.  
The structures and processes of living organ donation.  
Assessment of organs for transplantation. |
Organ Donation - Appendices

### 11. Search strategies

Please see Appendix B.

### 12. Review strategies

- Data on all included studies will be extracted into evidence tables.
- Where statistically possible, a meta-analytic approach will be used to give an overall summary effect.
- All key outcomes from evidence will be presented in GRADE profiles, or modified evidence profiles depending on the study design, and further summarised in evidence statements.

### Details

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Review question 5</strong></td>
<td>What key skills and competencies are important for healthcare professionals to improve the structures and processes for identifying potential DBD and DCD donors; to improve structures and processes for obtaining consent; and to effectively coordinate the care pathway from identification to obtaining consent?</td>
</tr>
<tr>
<td><strong>2. Objectives</strong></td>
<td>To identify all the relevant literature on the competencies of healthcare professionals involved in the activities described above.</td>
</tr>
<tr>
<td><strong>3. Language</strong></td>
<td>English only</td>
</tr>
<tr>
<td><strong>4. Study design</strong></td>
<td>No restrictions.</td>
</tr>
<tr>
<td><strong>5. Status</strong></td>
<td>Published papers (full papers only)</td>
</tr>
</tbody>
</table>
| **6. Population & Healthcare setting** | Inclusion:
- Families, relatives and legal guardians of potential DBD and DCD donors (adults and children).
  - Subgroups considerations: (i) people from Black and minority ethnic groups; (ii) people with different religious beliefs.
- Hospitals |
| **7. Intervention** | Key skills and competencies of healthcare professionals involved in the structures and processes for identifying potential DBD and DCD; the structures and processes for obtaining consent; and the coordination of the care pathway from identification to consent. |
| **8. Comparisons** | N/A |
| **10. Other criteria for inclusion/Exclusion** | Key skills and competencies for single organ donation. |
### Exclusion of Studies

- Groups involved in giving consent on organ donation other than population specified above.
- Systems for declaring a willingness to donate ante-mortem.
- Tissue donation.
- The processes of organ retrieval.
- The structures and processes of living organ donation.
- Assessment of organs for transplantation.
- Organ donation for training and medical research.
- Prioritisation of organ allocation, including the structures and processes of organ transfers within or outside the UK.

### 11. Search Strategies

Please see Appendix B.

### 12. Review Strategies

- Data on all included studies will be extracted into evidence tables.
- Where statistically possible, a meta-analytic approach will be used to give an overall summary effect.
- All key outcomes from evidence will be presented in GRADE profiles, or modified evidence profiles depending on the study design, and further summarised in evidence statements.
**Appendix C References of all included studies**

**Review question 1**

<table>
<thead>
<tr>
<th>Selection based on title and abstract = 90 (full papers ordered)</th>
<th>Excluded = 1433</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection based on full papers = 14</td>
<td>Excluded = 76</td>
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</tbody>
</table>

Total number of studies included = 14
- 13 studies part of evidence
- 1 study as supporting evidence

**Review question 2**

<table>
<thead>
<tr>
<th>Selection based on title and abstract = 133 (full papers ordered)</th>
<th>Excluded = 1165</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection based on full papers = 38</td>
<td>Excluded = 95</td>
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</tbody>
</table>

Total number of studies included = 38
- 5 studies duplicate

**Review question 3**

<table>
<thead>
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<th>Excluded = 206</th>
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</thead>
<tbody>
<tr>
<td>Selection based on full papers = 10</td>
<td>Excluded = 38</td>
</tr>
</tbody>
</table>

Total number of studies included = 10
Review question 4

<table>
<thead>
<tr>
<th>Total number of studies retrieved from searches = 390</th>
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</thead>
<tbody>
<tr>
<td>Selection based on title and abstract = 40 (full papers ordered)</td>
</tr>
<tr>
<td>Selection based on full papers = 4</td>
</tr>
<tr>
<td>Total number of studies included = 4</td>
</tr>
</tbody>
</table>

Review question 5

Although searches were undertaken for this question, the technical team and the GDG considered that evidence already reviewed and included for other questions would adequately inform evidence based recommendations on the skills and competencies needed by healthcare professionals. For example, where a lack of knowledge or skills were identified for healthcare professionals as part of review question 2, a recommendation was made that healthcare professionals should have those skills and knowledge in order to deliver the other recommendations made in the guideline.

Included studies

Review question 1

Ref ID: 154

Ref ID: 96

Ref ID: 252

Dickerson, J, Valadka, AB, Levert, T, Davis, K, Kurian, M, Robertson, CS Organ donation rates in a neurosurgical intensive care unit. Journal of
Ref ID: 865

Ref ID: 1719

Ref ID: 789

Ref ID: 24

Ref ID: 188

Ref ID: 182

Ref ID: 355

Ref ID: 95

Ref ID: 746

Murphy, F, Cochran, D, Thornton, S Impact of a Bereavement and Donation Service incorporating mandatory 'required referral' on organ donation rates: a model for the implementation of the Organ Donation Taskforce's
Ref ID: 28

Ref ID: 446

Ref ID: 819

Ref ID: 56

Ref ID: 486

Ref ID: 517

Ref ID: 239

Ref ID: 226

Ref ID: 143

Ref ID: 61
Ref ID: 818

Ref ID: 114

Ref ID: 1387

**Review question 2**

ACRE, TC Effect of "collaborative requesting" on consent rate for organ donation: randomised controlled trial (ACRE trial). *BMJ* 2009; **339**: b3911.
Ref ID: 37

Bellali, T, Papazoglou, I, Papadatou, D Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive & Critical Care Nursing* 2007; **23**: 216-25.
Ref ID: 138

Bellali, T, Papadatou, D Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? *Death Studies* 2006; **30**: 883-917.
Ref ID: 174

Ref ID: 959

Brown, CV, Foulkrod, KH, Dworaczyk, S, Thompson, K, Elliot, E, Cooper, H, Coopwood, B Barriers to obtaining family consent for potential organ donors. *Journal of Trauma-Injury Infection & Critical Care* 2010; **68**: 447-51.
Ref ID: 16

Brown, CVR, Foulkrod, KH, Dworaczyk, S, Thompson, K, Elliot, E, Cooper, H, Coopwood, B Barriers to obtaining family consent for potential organ donors. *Journal of Trauma - Injury, Infection and Critical Care* 2010; **68**: 447-51.
Ref ID: 1727 (Duplicate)

Burroughs, TE, Hong, BA, Kappel, DF, Freedman, BK The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosomatic Medicine* 1998; **60**: 156-62.
Ref ID: 477
Ref ID: 425

Ref ID: 345

Ref ID: 1725

Douglass, GE, Daly, M Donor families' experience of organ donation. *Anaesthesia and Intensive Care* 1995; **23**: 96-98.
Ref ID: 1281

Frauman, AC, Miles, MS Parental willingness to donate the organs of a child. *Anna Journal* 1987; **14**: 401-4.
Ref ID: 776

Ref ID: 1398

Ref ID: 290

Jacoby, LH, Breitkopf, CR, Pease, EA A qualitative examination of the needs of families faced with the option of organ donation. *DCCN - Dimensions of Critical Care Nursing* 2005; **24**: 183-89.
Ref ID: 234

Ref ID: 1305

Ref ID: 1558 (Duplicate)
Ref ID: 1730

Ref ID: 526

Ref ID: 554

Ref ID: 1527

Ref ID: 288

Ref ID: 686

Ref ID: 72

Ref ID: 1733

Ref ID: 548

Ref ID: 360
Ref ID: 387

Ref ID: 1203 (Duplicate)

Ref ID: 1734

Ref ID: 397

Ref ID: 1452 (Duplicate)

Ref ID: 20

Ref ID: 115

Ref ID: 386

Ref ID: 506

Ref ID: 403

Young, D, Danbury, C, Barber, V, Collett, D, Jenkins, B, Morgan, K, Morgan, L, Poppitt, E, Richards, S, Edwards, S, Patel, S Effect of “collaborative requesting” on consent rate for organ donation: Randomised controlled trial
Review question 3
Bellali, T, Papadatou, D Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? *Death Studies* 2006; **30**: 883-917.
Ref ID: 174

Ref ID: 959

Bellali, T, Papazoglou, I, Papadatou, D Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive & Critical Care Nursing* 2007; **23**: 216-25.
Ref ID: 138

Ref ID: 634

Ref ID: 290

Jacoby, LH, Breitkopf, CR, Pease, EA A qualitative examination of the needs of families faced with the option of organ donation. *DCCN - Dimensions of Critical Care Nursing* 2005; **24**: 183-89.
Ref ID: 234

Niles, PA, Mattice, BJ The timing factor in the consent process. *Journal of Transplant Coordination* 1996; **6**: 84-87.
Ref ID: 130

Sanner, MA Two perspectives on organ donation: experiences of potential donor families and intensive care physicians of the same event. *Journal of Critical Care* 2007; **22**: 296-304.
Ref ID: 1733

Siminoff, LA, Lawrence, RH, Zhang, A Decoupling: what is it and does it really help increase consent to organ donation? *Progress in Transplantation* 2002; **12**: 52-60.
Ref ID: 97

Vane, DW, Sartorelli, KH, Reese, J Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma
Review question 4

Ref ID: 53

Ref ID: 62

Ref ID: 284

Ref ID: 443
Appendix D Full GRADE evidence profiles

KEY:
NS = not serious
S = serious
NA = not assessable or applicable

Review question 1:
What structures and processes including timing for referral and criteria for consideration are appropriate and effective for identifying potential DBD and DCD donors?
The characteristic of imprecision was not assessed for this question as the type of evidence included often did not allow any assessment of the preciseness of any summary estimate.

GRADE profile 1: Structures and processes for identifying potential DBD and DCD donors

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of studies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 studies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 x Audit retrospective studies-[A], [P], [Ma] 1 x Audit report-[G&amp;E]</td>
<td>Studies showed that one of the factors for low identification rates were that healthcare professionals missed identifying potential donors.</td>
<td>Very low</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------</td>
<td></td>
</tr>
<tr>
<td><strong>No. of studies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 x Medical records retrospective review-[G]</td>
<td>Analysis</td>
<td></td>
</tr>
<tr>
<td>3 x Survey questionnaires- [O], [W], [M]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 x Audit prospective study- [T]</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Limitation</strong></td>
<td><strong>Consistency</strong></td>
<td></td>
</tr>
<tr>
<td>S (a) NA S (b) S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A study showed that there was an improvement in identification of potential donors in hospitals with a donor action programme implemented.</td>
<td>Very low</td>
<td></td>
</tr>
<tr>
<td><strong>Indirectness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S (a) S (b) S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Studies showed a lack of organ donation protocol or knowledge of the referral process in emergency departments may be a cause for non identification of potential donors.</td>
<td>Very low</td>
<td></td>
</tr>
<tr>
<td><strong>Other considerations</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S (a) S (b) S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Studies showed that health care professionals did not approach family members to make a decision about donation.</td>
<td>Very low</td>
<td></td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very low</td>
<td></td>
</tr>
</tbody>
</table>

Organ Donation - Appendices
<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
<td>Inconsistency</td>
</tr>
<tr>
<td>study-[A]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 1 x Audit retrospective study-[A] | S (a) | NA | S (b) | S (c) | - Hospital consultants- A&E, anaesthetists and neuro-surgeons  
  - Emergency trauma team  
  - A&E nursing and medical staff                                                                                                       | Very low |
| 1 study               |             |              |              |                    | A study showed that HM coroner’s involvement was seen as too complex, acting as a barrier cited by health care staff as to why patients may not be recognized as potential donors in the A&E department.                                                                                                         |         |
| 1 x Audit retrospective study-[A] | S (a) | NA | S (b) | S (c) | Studies showed that lack of confidence and experience of A&E staff in offering the option of donation to acutely bereaved families acted as a barrier cited by health care staff as to why patients may not be recognized as potential donors in the A&E department.                                                                      |         |
| 1 study               |             |              |              |                    | A study showed that health care professionals perceived that a lack of resources and shortage of intensive care beds in the hospital may have contributed to non identification and referral.                                                                                                                            |         |
| 1 x Audit retrospective study-[A]  
  1 x Survey questionnaire-[Pe] | S (a) | NA | S (b) | S (c) | Studies showed that people from African-American origin and people with perceived cultural differences were less likely to donate and also health care professionals were less likely to approach them.                                                                 |         |
| 1 study               |             |              |              |                    | A study showed the following factors which influenced the decision to discuss with families regarding organ donation:                                                                                   |         |
| 1 x Structured questionnaire-[Pl] | S (a) | NA | S (b) | S (c) | - Number of potential organs in a particular donor  
  - Knowledge of contraindications by physician  
  - Cause of death with natural causes of death  
  - Sex of the physician, female physicians are more likely to ask than male colleagues.                                                                                                       |         |
<p>| 2 studies             |             |              |              |                    | Studies showed that health care professionals perceived that a lack of resources and shortage of intensive care beds in the hospital may have contributed to non identification and referral.                                                                                                                            |         |
| 1 x Medical records   |             |              |              |                    | Studies showed that people from African-American origin and people with perceived cultural differences were less likely to donate and also health care professionals were less likely to approach them.                                                                 |         |</p>
<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No. of studies</strong></td>
<td><strong>Analysis</strong></td>
</tr>
<tr>
<td>retrospective review- [G]</td>
<td>1 x Survey questionnaire- [Pe]</td>
</tr>
<tr>
<td>1 study</td>
<td>1 x Medical records retrospective review- [G]</td>
</tr>
<tr>
<td>1 study</td>
<td>1 x Survey questionnaire- [Pe]</td>
</tr>
<tr>
<td>1 study</td>
<td>1 x Survey using a questionnaire- [Mo]</td>
</tr>
<tr>
<td>1 study</td>
<td>1 x Survey using a questionnaire- [Mo]</td>
</tr>
</tbody>
</table>
| 1 study | 1 x Structured questionnaire- [PI] | S (a) | NA | S (b) | S (c) | A study showed that healthcare professionals identified the following factors that acted as barriers for non identification of potential donors:  
  - Lack of time  
  - Did not think  
  - Difficult situation | Very low |

GRADE profile 2: Use of clinical triggers

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Analysis</td>
</tr>
<tr>
<td>No. of studies</td>
<td></td>
</tr>
<tr>
<td>Limitation</td>
<td></td>
</tr>
<tr>
<td>Inconsistency</td>
<td></td>
</tr>
<tr>
<td>Indirectness</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Outcome</td>
<td></td>
</tr>
<tr>
<td>Conversion rate</td>
<td></td>
</tr>
<tr>
<td>Analysis</td>
<td></td>
</tr>
<tr>
<td>Quality</td>
<td></td>
</tr>
</tbody>
</table>

### Conversion rate

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td></td>
</tr>
<tr>
<td>1 x observational</td>
<td></td>
</tr>
<tr>
<td>study-[B]</td>
<td></td>
</tr>
<tr>
<td>S (a) NA S (b) S (c)</td>
<td></td>
</tr>
<tr>
<td>Outcome</td>
<td>2004 2005 p value</td>
</tr>
<tr>
<td>Conversion rate</td>
<td>50% 80% 0.025</td>
</tr>
</tbody>
</table>

A study showed that the conversion rate statistically significantly increased when clinical triggers were used to screen all ICU patients.

### Number of organ donors

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td></td>
</tr>
<tr>
<td>1 x observational</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A study showed that the number of organ donors in Collaborative hospitals increased 14.1% in the first year, a 70% greater increase than the 8.3% increase experienced by non-Collaborative hospitals. Moreover, the increased organ recovery continued into the post-Collaborative periods.</td>
</tr>
</tbody>
</table>

Very low
<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of potential and effective donors</strong></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
<tr>
<td>2 studies</td>
<td>S (a)</td>
</tr>
<tr>
<td>2 x observational studies- [Sh] and [V]</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total number of referrals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
</tr>
<tr>
<td>1 x observational study- [Sh]</td>
<td></td>
</tr>
</tbody>
</table>

IHC-in-house coordinators
LITC- Level I trauma centers
(a) = No RCTs, only audit reports, surveys and medical records review.
(b) = Not transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in UK and legislative rules vary in different countries
(c) = Limited analyses performed
# GRADE profile 3: Use of required referral

## Study characteristics

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other consideration</th>
<th>Analysis</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral rate and number of potential donors</td>
<td>S (a)</td>
<td>NA</td>
<td>No serious</td>
<td>S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>1 x observational study- [M]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral rate and number of potential donors</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 studies</td>
<td>4 x observational studies- [H], [Hi], [R], and [S]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 x retrospective study- [B]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of donors</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 studies</td>
<td>3 x observational studies- [S], [R], and [Sh]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 x retrospective studies- [B], [D], and [G]</td>
<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

## Summary of findings

### Analysis

<table>
<thead>
<tr>
<th>Number</th>
<th>2006-7</th>
<th>2007-8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart beating donors</td>
<td>Non-heart beating donors</td>
<td>Heart beating donors</td>
</tr>
<tr>
<td>Referred</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Accepted</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

There was an increase in referral rate.
There was an increase in the number of potential donors referred to the OPO representative.

Studies showed that there was an increase in the number of donors of between 24% and 275% from potential donors.
### Study characteristics

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of organs retrieved per donor</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>Very low</td>
</tr>
<tr>
<td>1 study</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 x observational study: [S]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of organs retrieved per donor</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>Very low</td>
</tr>
<tr>
<td>1 study</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 x retrospective study: [G]</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

[H] = Higashiwaga et al (2001)

(a) = No RCTs, only audit reports, surveys and medical records review.
(b) = Not Transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in UK and legislative rules vary in different countries
(c) = Limited analyses performed
Review question 2:
What structures and processes are appropriate and effective for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors?

Where possible, imprecision was assessed. Where imprecision was not assessed this was because the type of evidence included often did not allow any assessment of the preciseness of any summary estimate or because the evidence was qualitative.

GRADE profile 4: Effect of ‘collaborative requesting’ on consent rate for organ donation

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No of patients</td>
</tr>
<tr>
<td>Consent to organ donation (ITT)</td>
<td></td>
</tr>
<tr>
<td>1 [Y] RCT</td>
<td>S (a)</td>
</tr>
<tr>
<td>Consent to organ donation (Adjusted for ethnicity, gender, and age)</td>
<td></td>
</tr>
<tr>
<td>1 [Y] RCT</td>
<td>S (a)</td>
</tr>
<tr>
<td>Any solid organ retrieved from all patients (ITT)</td>
<td></td>
</tr>
<tr>
<td>1 [Y] RCT</td>
<td>S (a)</td>
</tr>
<tr>
<td>Any solid organ retrieved from patients who consented (ITT)</td>
<td></td>
</tr>
<tr>
<td>1 [Y] RCT</td>
<td>S (a)</td>
</tr>
</tbody>
</table>

[Y] = Young et. al (2009). Collaborative request (Relatives approached by clinical team and a donor transplant coordinator) vs. routine request (Relatives approached by the clinical team alone)

(a) = Blinding not performed.

(b) = Total no. of events <300.
### GRADE profile 5: Views of families of potential adult donors

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Influence of staff involved in organ donation</strong></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that family members felt that presence of and interaction with nursing staff were strongly valued by both donor and non-donor family members; satisfaction with nurses' behaviors and care was expressed by all, and nurses were seen as a source of emotional support.</td>
</tr>
<tr>
<td>1 x Qualitative Study: [J]</td>
<td></td>
</tr>
<tr>
<td>S (a)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Continuity of care</strong></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that family members felt that treating physicians are not readily available to families, don’t provide continuity of care and information, don’t use simple language, do not verify whether the families have understood everything being explained to them by the physicians.</td>
</tr>
<tr>
<td>1 x Qualitative retrospective study: [H]</td>
<td></td>
</tr>
<tr>
<td>S (a)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Quality of approach</strong></td>
<td></td>
</tr>
<tr>
<td>2 studies</td>
<td>Studies showed that both families of donors and non-donors wanted compassionate care of their loved ones and their being treated with dignity and respect.</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td><strong>No. of studies</strong></td>
<td></td>
</tr>
<tr>
<td>1 x Qualitative retro</td>
<td></td>
</tr>
<tr>
<td>prospective study -</td>
<td></td>
</tr>
<tr>
<td>[H]</td>
<td></td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td></td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td></td>
</tr>
<tr>
<td><strong>Limitation</strong></td>
<td></td>
</tr>
<tr>
<td>S (a)</td>
<td>NA</td>
</tr>
<tr>
<td>S (b)</td>
<td>S (c)</td>
</tr>
<tr>
<td><strong>Indirectness</strong></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td></td>
</tr>
<tr>
<td><strong>Other consideration</strong></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td></td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td></td>
</tr>
<tr>
<td>A study showed that families wanted to be listened to by the staff and the staff to be there for them when needed.</td>
<td></td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td></td>
</tr>
<tr>
<td>Very low</td>
<td></td>
</tr>
</tbody>
</table>

**Provision of information**

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Indirectness</th>
<th>Other consideration</th>
<th>Analysis</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 studies</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>Studies showed that both families of donors and non-donors wanted understandable, prompt, accurate, in-depth and consistent information.</td>
</tr>
<tr>
<td>2 x Qualitative Studies - [J] and [S]</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>2 studies</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>Studies showed that the different kinds of information required by families included the meaning of brain-stem death, the confirmation of death, the reasons for brain-stem testing, other medical information related to the condition of the potential donor, and the whole process of organ donation. Also, it should be made sure that families have understood clearly what they were told and what they asked for.</td>
</tr>
<tr>
<td>1 x Qualitative retrospective study - [H]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that both families of donors and non-donors considered the tone and pace of information giving to be critical. Families considered that they were rushed and pressured, and information was conveyed insensitively. They wanted the information to be conveyed with empathy, concern, and consideration.</td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that both families of donors and non-donors considered privacy for the discussion to gain consent for organ donation as being critically important.</td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sources of support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that families viewed nurses as a source of support during the discussion to gain consent for organ donation.</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
<td>Inconsistency</td>
<td>Indirectness</td>
<td>Other consideration</td>
<td>Analysis</td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that families of donors believed that faith and spiritual support was important to them during the discussion to gain consent for organ donation but non-donor families believed this support to be of less importance.</td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>S (d)</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that some donor families found follow-up care to be useful which helps them to ask further questions and to make the donation feel more personal and sincere following discussion to gain consent for organ donation. But, not all donor families thought this to be useful.</td>
</tr>
<tr>
<td>Views of physicians involved in organ donation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that physicians involved in the organ donation process considered important the need to be certain of decisions and of the process and also found the entire process very stressful.</td>
</tr>
<tr>
<td>Factors associated with decision stability or satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that one factor associated with consent in potential adult donors was an understanding of the term brain death.</td>
</tr>
<tr>
<td>Factors associated with decision instability or dissatisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that the factors associated with denial of consent in potential adult donors were:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- a lack of discussion of donation with the deceased</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- poor timing of donation discussion</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- not being told of the death before the first mention of donation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- not being given enough time to discuss the donation decision with others</td>
</tr>
<tr>
<td>Factors associated with the decision to grant consent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 studies</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>Studies showed that the following factors were associated with families of potential donors granting consent to organ donation:</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
<td>Inconsistency</td>
<td>Indirectness</td>
<td>Other considerations</td>
<td>Analysis</td>
</tr>
<tr>
<td>7 x Retrospective studies- [B], [Br], [M], [F], [D], [N], [Si &amp; L]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● understanding that transplantation was a proven procedure had a high success rate, and knowledge of the benefits or organ donation</td>
</tr>
<tr>
<td>1 x Retrospective study (chart review and interviews)- [Si-b]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● an understanding of the term brain death</td>
</tr>
<tr>
<td>2 x Retrospective studies (survey)- [Si], [P]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● acceptance of death, and confidence in the 'diagnosis of death'</td>
</tr>
<tr>
<td>1 x Cross sectional survey- [C]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● consideration and knowledge of the deceased’s wishes (through carrying a donor card or discussion)</td>
</tr>
<tr>
<td>1 x Retrospective cross sectional qualitative study- [Sq]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● earlier timing of request</td>
</tr>
<tr>
<td>Factors associated with the decision to refuse consent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● involving more family members with the decision</td>
</tr>
<tr>
<td>18 studies</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>● the level of comfort with which the healthcare professional requested consent</td>
</tr>
<tr>
<td>11 x Retrospective studies- [B], [Br], [M], [D], [Si &amp; L], [La S], [No], [So], [Do], [Sh] and [Ch]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● good relationships between the family and the healthcare professionals</td>
</tr>
<tr>
<td>1 x Cross sectional survey- [C]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● satisfaction with treatment (either of the family or the deceased)</td>
</tr>
<tr>
<td>Studies showed that the following factors were associated with families of potential donors refusing consent to organ donation:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● congruence between the views of healthcare professionals and the families at initial approach</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● request for donation being initiated by a healthcare professional (not a physician) with further discussion with an organ donation professional</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● request by different healthcare professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● more time spent with an organ donation professional</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● knowledge of the impact of donation on other processes, such as funeral arrangements</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● knowledge of the costs of donation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● choice of organs for donation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● families being able to discuss both specific and wider issues and getting answers to questions</td>
</tr>
<tr>
<td>Very low</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Study characteristics

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other consideration</th>
<th>Analysis</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 x Retrospective cross-sectional qualitative study- [Sq]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>concern that donation may cause more distress to family members</td>
<td></td>
</tr>
<tr>
<td>1 x Retrospective study (chart review and interviews)- [Si-b]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>uncertainty about the deceased’s wishes</td>
<td></td>
</tr>
<tr>
<td>2 x Retrospective studies (survey)- [Si], [P]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>reluctance to accept the death</td>
<td></td>
</tr>
<tr>
<td>1 x Prospective study- [Si-a]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>social resentment</td>
<td></td>
</tr>
<tr>
<td>1 x Retrospective cross-sectional qualitative study- [Sq]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lack of understanding and confidence in the concept of brain-stem death</td>
<td></td>
</tr>
<tr>
<td>1 x Retrospective study (chart review and interviews)- [Si-b]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lack of family consensus and the family being ‘upset’</td>
<td></td>
</tr>
<tr>
<td>2 x Retrospective studies (survey)- [Si], [P]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>family reticence</td>
<td></td>
</tr>
<tr>
<td>1 x Prospective study- [Si-a]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>making the decision before information was provided by a healthcare or organ donation professional</td>
<td></td>
</tr>
<tr>
<td>12 studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>an absence of key decision makers</td>
<td></td>
</tr>
<tr>
<td>7 x Retrospective studies- [B], [Br], [M], [Si &amp; L], [La S], [F] and [No]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>the length of the process</td>
<td></td>
</tr>
<tr>
<td>1 x Retrospective study (chart review and interviews)- [Si-b]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>not liking the hospital or healthcare professionals</td>
<td></td>
</tr>
<tr>
<td>2 x Retrospective studies (survey)- [Si], [P]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>feeling that the medical care was not optimal</td>
<td></td>
</tr>
<tr>
<td>1 x Prospective study- [Si-a]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>initial approach by a healthcare professional</td>
<td></td>
</tr>
<tr>
<td>12 studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>perception that the healthcare professional did not care or was not concerned, or the healthcare professional showing a lack of respect</td>
<td></td>
</tr>
<tr>
<td>7 x Retrospective studies- [B], [Br], [M], [Si &amp; L], [La S], [F] and [No]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>healthcare professionals stating that the request was required</td>
<td></td>
</tr>
<tr>
<td>1 x Retrospective study (chart review and interviews)- [Si-b]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lack of knowledge of the impact of donation on other processes, such as funeral arrangements</td>
<td></td>
</tr>
<tr>
<td>2 x Retrospective studies (survey)- [Si], [P]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lack of detailed information on the process of organ donation, including the timing of retrieval and information on recipients</td>
<td></td>
</tr>
<tr>
<td>1 x Prospective study- [Si-a]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>initial perception of healthcare professionals that the family were likely to refuse</td>
<td></td>
</tr>
</tbody>
</table>

### Other factors influencing consent for organ donation

<table>
<thead>
<tr>
<th>Studies showed that other factors that influenced the families of potential donors in obtaining consent were:</th>
<th>Very low</th>
</tr>
</thead>
<tbody>
<tr>
<td>donor ethnicity</td>
<td></td>
</tr>
<tr>
<td>donor age</td>
<td></td>
</tr>
<tr>
<td>donor sex</td>
<td></td>
</tr>
<tr>
<td>type of death (trauma or not)</td>
<td></td>
</tr>
<tr>
<td>familial (or consentor)</td>
<td></td>
</tr>
<tr>
<td>level of education</td>
<td></td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
<tr>
<td>(survey)- [Si], [P] 1 x Prospective study (survey)- [Yo] 1 x Retrospective study (audit)- [Pi]</td>
<td></td>
</tr>
</tbody>
</table>

[S] = Sanner et. al (2007)  
[Si-b] = Siminoff et al (2001b)  
[Si] = Siminoff et. al (2002)  
[Sq] = Sque et. al (2007)  
[N] = Niles et. al (1996)  
[Si & L] = Siminoff and Lawrence (2002)  
[La S] = La Spina et. al (1993)  
[So] = Sotillo et. al (2009)  
[Pi] = Pike et. al (1990)  
[Si-a] = Siminoff et al (2001a)
[Sh] = Shaheen et. al (1996)
(a) = No RCTs, only audit reports, surveys and medical records review.
(b) = Not Transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in UK and legislative rules vary in different countries
(c) = Limited analyses performed
(d) = inconsistent themes and results from study
GRADE profile 6: Views of families of potential paediatric donors

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Influence of staff involved in organ donation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that parents of potential paediatric donors were more likely to give consent if they had a good relationship with the ICU personnel and then were more likely accept the irreversibility of their child’s death. Conversely, where this relationship was poor or when staff did not allow parents to be at the child’s bedside, parents of potential paediatric donors were less likely to give consent.</td>
<td>Very low</td>
</tr>
<tr>
<td><strong>Influence of family members</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that parents of potential paediatric donors tended to make the final decision about consent with their spouse but extended family members played a significant role in the decision making process to gain consent. In cases where parents of potential paediatric donors lacked spousal or mate support, consent for donation was less likely.</td>
<td>Very low</td>
</tr>
<tr>
<td><strong>Factors related to consent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that parents of potential paediatric donors gave consent when they were able to accept their child’s death, attribute meaning to the donation (for example, the benefits to the recipient) and when also believed that consent was consistent with their child’s wishes.</td>
<td>Very low</td>
</tr>
<tr>
<td>1 study</td>
<td>A study showed that parents of potential paediatric donors were more likely to decline consent when they had no prior knowledge about organ donation, wanted to know the recipient, considered that their child had been inappropriately cared for, or were unaware of their church’s position on organ donation.</td>
<td>Very low</td>
</tr>
</tbody>
</table>
| 1 study               | A study showed that other factors related to obtaining consent from parents of potential paediatric donors included:  
  • fear of mutilation or disfigurement  
  • subjecting the child to further ‘ordeal’  
  • a reluctance to assume responsibility for another’s organs  
  A study showed that parents of potential paediatric donors who gave consent reported feeling that their grief was eased, through helping others to live or feeling that their child was living on through others.                                                                 | Very low|
## Study characteristics

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that parents of potential paediatric donors were more likely to give consent when family members or friends were approached by health care professionals, and they then approached the parents (indirect approach).</td>
</tr>
</tbody>
</table>

## Method of approach

<table>
<thead>
<tr>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that parents of potential paediatric donors were more likely to decline consent when they the parents were informed in an inappropriate manner and pressured to make a decision.</td>
</tr>
</tbody>
</table>

## Quality of approach

<table>
<thead>
<tr>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
</tr>
</tbody>
</table>

## Provision of information

<table>
<thead>
<tr>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that parents of potential paediatric donors requested the following information before giving consent for organ donation;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the process of organ retrieval</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the outcomes of transplantation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the identity of the recipient</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the possibility of making contact with him or her</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that parents of potential paediatric donors experienced more distress and were less likely to give consent if they were not given information on;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the child’s condition</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the chance of survival of the child</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- the concept of brain death</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other considerations</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 study</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S (c)</td>
<td>A study showed that parents of potential paediatric donors who had given consent for organ donation wanted more information on what happened next, including the process of burial. Some parents of potential paediatric donors expressed resentment and anger at healthcare professionals who never expressed concern about their well-being during the period following the child’s death. They also felt that their act was not socially recognized, that they were quickly forgotten, and few even believed that they had been exploited.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
</tr>
</tbody>
</table>

Organ Donation - Appendices 54 of 205
<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Analysis</td>
</tr>
<tr>
<td></td>
<td>Quality</td>
</tr>
</tbody>
</table>

### Factors associated with the decision to grant consent

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 studies</td>
<td>Studies showed that the following factors were associated with families of potential paediatric donors granting consent to organ donation:</td>
</tr>
<tr>
<td></td>
<td>- belief in the process of donation, and feeling that it was ‘the right thing to do’</td>
</tr>
<tr>
<td></td>
<td>- perception that the child would go on living in others</td>
</tr>
<tr>
<td></td>
<td>- good interaction with healthcare professionals involved in organ donation</td>
</tr>
<tr>
<td></td>
<td>- type of healthcare professional who asked for consent</td>
</tr>
</tbody>
</table>

### Factors associated with the decision to refuse consent

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 studies</td>
<td>Studies showed that the following factors were associated with families of potential paediatric donors refusing consent to organ donation:</td>
</tr>
<tr>
<td></td>
<td>- a perception that the doctors who determined death were not part of the organ donation process</td>
</tr>
<tr>
<td></td>
<td>- lack of information</td>
</tr>
<tr>
<td></td>
<td>- fear or lack of belief in organ donation</td>
</tr>
<tr>
<td></td>
<td>- perception that timing of approach was not optimal</td>
</tr>
<tr>
<td></td>
<td>- feeling that the child had been through enough and fear of further trauma</td>
</tr>
<tr>
<td></td>
<td>- concern that donation would impact on survival</td>
</tr>
<tr>
<td></td>
<td>- consideration of donation was too upsetting</td>
</tr>
<tr>
<td></td>
<td>- poor interaction with healthcare professionals involved in organ donation, including a perception of insensitivity</td>
</tr>
</tbody>
</table>

### Other factors influencing consent for organ donation

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 studies</td>
<td>Studies showed that other factors that influenced the families of potential paediatric donors in obtaining consent were:</td>
</tr>
<tr>
<td></td>
<td>- donor ethnicity</td>
</tr>
<tr>
<td></td>
<td>- familial (or consentor) ethnicity</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
<tr>
<td>study - [P]</td>
<td></td>
</tr>
</tbody>
</table>

[Be-b] = Bellali et. al (2007-b)
[V] = Vane et. al (2001)
(a) = No RCTs, only audit reports, surveys and medical records review.
(b) = Not Transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in UK and legislative rules vary in different countries
(c) = Limited analyses performed
(d) = inconsistent themes and results from study
Review question 3:
When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?

GRADE profile 7: The optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors to gain consent.

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
<tr>
<td>Approach before death</td>
<td>S (a)</td>
</tr>
<tr>
<td>Approach after death</td>
<td>S (a)</td>
</tr>
<tr>
<td>Time difference between approaches</td>
<td>S (a)</td>
</tr>
<tr>
<td>Factors associated with optimal time to approach families of adult potential donors</td>
<td>S (a)</td>
</tr>
</tbody>
</table>
## Study characteristics

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Limitation</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Other consideration</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 studies</td>
<td>S</td>
<td>NA</td>
<td>S</td>
<td>S (a)</td>
</tr>
<tr>
<td>2 x Qualitative Studies - [J] and [S]</td>
<td>NA</td>
<td>NA</td>
<td>S</td>
<td>S (b)</td>
</tr>
<tr>
<td>1 x Qualitative retrospective study - [H]</td>
<td>S (c)</td>
<td>S (b)</td>
<td>S</td>
<td>S</td>
</tr>
<tr>
<td>1 study</td>
<td>S</td>
<td>NA</td>
<td>S</td>
<td>S (a)</td>
</tr>
<tr>
<td>1 x Qualitative Study - [J]</td>
<td>NA</td>
<td>NA</td>
<td>S</td>
<td>S (b)</td>
</tr>
</tbody>
</table>

### Summary of findings

**Analysis**

Studies showed that families of potential adult donors thought that time was needed to allow families to recover from shock, to consider the benefits of donation, allow them sufficient time to discuss the decision with other family members, and to understand the concept of brain-stem death.

**Factors associated with optimal time to approach families of paediatric potential donors**

<table>
<thead>
<tr>
<th>1 study</th>
<th>S</th>
<th>NA</th>
<th>S</th>
<th>S (a)</th>
<th>S (b)</th>
<th>S (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 x qualitative study - [B]</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S</td>
<td>S (c)</td>
<td></td>
</tr>
</tbody>
</table>

A study showed that families of potential adult donors who gave consent thought that the timing of the approach was ‘as good as could have been’ and had time to spend with the family member and to say goodbye.

<table>
<thead>
<tr>
<th>1 study</th>
<th>S</th>
<th>NA</th>
<th>S</th>
<th>S (a)</th>
<th>S (b)</th>
<th>S (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 x qualitative study - [Be-a], [Be-b]</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S</td>
<td>S (c)</td>
<td></td>
</tr>
</tbody>
</table>

A study showed that parents of potential paediatric donors felt that the indirect approach for consent gave them time to consider the request for donation before the discussion with the physician.

<table>
<thead>
<tr>
<th>1 study</th>
<th>S</th>
<th>NA</th>
<th>S</th>
<th>S (a)</th>
<th>S (b)</th>
<th>S (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 x qualitative study - [Be-a], [Be-b]</td>
<td>S (a)</td>
<td>NA</td>
<td>S (b)</td>
<td>S</td>
<td>S (c)</td>
<td></td>
</tr>
</tbody>
</table>

A study showed that parents of potential paediatric donors felt distressed and tended to refuse consent if they were not given the chance to see their child and say their goodbye.

**Quality**

- Very low

[N] = Niles et. al (1996)
[V] = Vane et. al (2001)
[S] = Sanner et. al (2007)
[Be-a] = Bellali et. al (2007-a)
[Be-b] = Bellali et. al (2007-b)
(a) = No RCTs, only audit reports, surveys and medical records review.
(b) = Not transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in the UK and legislative rules vary in different countries.
(c) = Limited analyses performed.
**Review question 4:**
How the care pathway of deceased organ donation should be coordinated to improve potential donors giving consent?

**GRADE profile 8: Co-ordination of the pathway for organ donation and consent from families**

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Donor referrals</strong></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>2 studies</td>
</tr>
<tr>
<td>Limitation</td>
<td>S (a)</td>
</tr>
<tr>
<td>Inconsistency</td>
<td>NA</td>
</tr>
<tr>
<td>Indirectness</td>
<td>S (b)</td>
</tr>
<tr>
<td>Other consideration</td>
<td>S (c)</td>
</tr>
<tr>
<td>Analysis</td>
<td>Studies showed that there was an increase in the donor referrals of between 46% to 450% when hospitals had in-house coordinators coordinating the process in hospitals</td>
</tr>
<tr>
<td>Quality</td>
<td>Very low</td>
</tr>
<tr>
<td><strong>Consent rates</strong></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>1 study</td>
</tr>
<tr>
<td>Limitation</td>
<td>S (a)</td>
</tr>
<tr>
<td>Inconsistency</td>
<td>NA</td>
</tr>
<tr>
<td>Indirectness</td>
<td>S (b)</td>
</tr>
<tr>
<td>Other consideration</td>
<td>S (c)</td>
</tr>
<tr>
<td>Analysis</td>
<td>A study showed that despite demographic differences, the 8 centers with in-house coordinators had higher consent rates (60% vs. 53%) than hospitals without in-house coordinators</td>
</tr>
<tr>
<td>Quality</td>
<td>Very low</td>
</tr>
<tr>
<td><strong>Conversion rates and number of donors</strong></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>4 studies</td>
</tr>
<tr>
<td>Limitation</td>
<td>S (a)</td>
</tr>
<tr>
<td>Inconsistency</td>
<td>NA</td>
</tr>
<tr>
<td>Indirectness</td>
<td>S (b)</td>
</tr>
<tr>
<td>Other consideration</td>
<td>S (c)</td>
</tr>
<tr>
<td>Analysis</td>
<td>Studies showed that there was an increase in the conversion rates of potential donors of between 32% and 67% when hospitals had in-house coordinators coordinating the process in hospitals compared to hospitals without in-house coordinators. Also there was an increase of about 275% in the number of donors when hospitals had in-house coordinators coordinating the process in hospitals compared to hospitals without in-house coordinators.</td>
</tr>
<tr>
<td>Quality</td>
<td>Very low</td>
</tr>
<tr>
<td><strong>Number of organs recovered</strong></td>
<td></td>
</tr>
<tr>
<td>No. of studies</td>
<td>1 study</td>
</tr>
<tr>
<td>Limitation</td>
<td>S (a)</td>
</tr>
<tr>
<td>Inconsistency</td>
<td>NA</td>
</tr>
<tr>
<td>Indirectness</td>
<td>S (b)</td>
</tr>
<tr>
<td>Other consideration</td>
<td>S (c)</td>
</tr>
<tr>
<td>Analysis</td>
<td>Studies showed that there was an increase of between 70% to 312% in the number of organs recovered from donors when hospitals had in-house coordinators coordinating the process in hospitals compared to hospitals without in-house coordinators.</td>
</tr>
<tr>
<td>Quality</td>
<td>Very low</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>Summary of findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>No. of studies</td>
<td>Limitation</td>
</tr>
</tbody>
</table>
| 1 x Retrospective study-  
[R]  
(a) = No RCTs, only audit reports, surveys and medical records review.  
(b) = Not Transferable to other population addressed because studies carried out when specialist nurses for organ donation were not in place and certain interventions were not in place, and some studies not carried out in UK and legislative rules vary in different countries  
(c) = Limited analyses performed |

**Review question 5:**

What key skills and competencies are important for healthcare professionals to improve the structures and processes for identifying potential DBD and DCD; to improve structures and processes for obtaining consent; and to effectively coordinate the care pathway from identification to obtaining consent?

As noted above, evidence from other questions was used to inform recommendations on skills and competencies needed. There are therefore no GRADE profiles for this question.
## Appendix E Evidence tables

**Review Question 1:** What structures and processes including timing for referral and criteria for consideration are appropriate and effective for identifying potential DBD and DCD donors?

**Title:** The organ donation crisis: The Missed organ donation potential from the accident and emergency departments.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
</table>
| ID: 154 | Study group: 770 deaths audited out of 1204 deaths | N/A | Inclusion/Exclusion (study group): Not mentioned | The criteria used to identify potential donors were based on UK transplant criteria for potential heart-beating or controlled non-heart beating organ donors. | N/A | Main barriers cited by health care staff as to WHY patients may not be recognized as potential donors in the A&E department:  
- Non recognition of potential donors  
- Lack of confidence and experience of A&E staff in offering the option of donation to acutely bereaved families  
- No contact details for donor transplant coordinator (DTC)  
- Shortage of intensive care beds  
- HM coroner involvement seen as too complex  
- Limited resources-physical space and manpower.  

The main causative factor for non donation from within A&E departments in the UK is due to an inadequate organ donor program.  

It is imperative that key health care professionals and the bereaved relatives are identified.  

The key professionals are based hospital wide and not just in the A&E. |
Identified key personnel are:

- Hospital consultants - A&E, anesthetists and neuro-surgeons
- Emergency trauma team
- A&E nursing and medical staff
- HM coroners and HM coroners officers

Additional comments:

## Title: Number of potential cadaveric donors: reasons for nonprocurement and suggestions for improvement.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 865</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
<td>N/A</td>
<td>A diagnosis of total cerebral infarction was made prior to cardiac arrest in 18% of patients who died while on ventilator support. Of these, treatment was discontinued in 80% and only 47% became donors. 17% had valid medical or age-related contraindication to organ donation and in others consent was not given. Organ donation was not discussed with relatives in 7% No relative could be located in 2% The survey estimates there were at most 30 donors per million with no medical or age-related contraindication to organ donation were missed.</td>
</tr>
</tbody>
</table>

**Additional comments:**

Title: Detection of potential organ donors: a 2-year analysis of deaths at a German university hospital.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
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</tr>
<tr>
<td>Author:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Petersen et. al (2009)</td>
<td></td>
</tr>
<tr>
<td>Study type:</td>
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<tr>
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<tr>
<td>Study group:</td>
<td>1312 deaths</td>
<td></td>
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<td></td>
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<td>Control group:</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting:</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study period:</td>
<td>2006-2007</td>
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<tr>
<td>Characteristics of cases:</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Baseline Measurements:</td>
<td>Not applicable.</td>
<td></td>
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</tr>
</tbody>
</table>

- Analyzed the factors that might lead to under detection or loss of potential organ donors at the hospital.
- The hospital’s electronic database for deaths related to cerebral complication was examined, as well as additional diseases, neurological findings, donation requests, and donations realized.

- Among 1312 deaths, organ donation should have been considered in 114 cases, but was actually considered in 76.
- In 38/114 cases, organ donation was missed of which 19 were admitted to ICU and 17 admitted to peripheral wards.
- Death due to cerebral complications occurred within 48 hours but medical records were not plausible in terms of exclusion criteria for organ donation.

**Title: Knowledge and attitudes of physicians regarding organ donation.**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/Incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td>ID: 746</td>
<td>Study group: 2,400 questionnaires sent</td>
<td>N/A</td>
<td>Inclusion /Exclusion (study group): Not mentioned</td>
<td>To describe Canadian physicians’ knowledge, commitment, and professional involvement relating to organ donation, and to identify factors related to personal commitment and professional involvement.</td>
<td>N/A</td>
<td>The greatest barrier to organ donation was lack of knowledge about referral processes; 44.6% of physicians reported they did not know how to refer a potential organ donor to the organ-procurement agency.</td>
</tr>
<tr>
<td></td>
<td>831 physicians responded</td>
<td></td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
<td></td>
<td>95.4% of physicians strongly approved of organ donation</td>
</tr>
<tr>
<td></td>
<td>Control group: N/A</td>
<td></td>
<td>Baseline Measurements: Not applicable.</td>
<td></td>
<td></td>
<td>68.3% felt comfortable identifying organ donors</td>
</tr>
<tr>
<td></td>
<td>Study period: Not mentioned</td>
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<td></td>
<td></td>
<td></td>
<td>47.2% believed that brain death is difficult to explain to families.</td>
</tr>
<tr>
<td></td>
<td>Setting: Canada</td>
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<td>57% agreed that they do not like to become involved in organ donation.</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>16% were concerned about potential liability</td>
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<td></td>
<td></td>
<td>74.6% reported that organ donation was emotionally demanding</td>
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<td></td>
<td></td>
<td>75% reported other health professionals were reluctant to approach families about organ donation.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Strategies to improve organ donation</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>65.8% supported the idea that hospitals should be required to participate in organ donation</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>85.3% agreed that hospital protocols should be developed for assessing ventilated patients as potential organ donors.</td>
</tr>
</tbody>
</table>

**Additional comments:**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 486</td>
<td>5000 deceased patients</td>
<td>4877 filled D-forms</td>
<td>717 physicians</td>
<td>N/A</td>
<td>To chart the donor potential for organs in The Netherlands and identify factors influencing whether donation is discussed with the relatives and whether donation request is granted or refused.</td>
<td>N/A</td>
</tr>
<tr>
<td>Author: Ploeg et al (2003)</td>
<td>Study group: N/A</td>
<td>Study period: Not mentioned</td>
<td>Setting: 11 hospitals in The Netherlands</td>
<td>Inclusion</td>
<td>The donation form (D-form) was constructed to obtain information at the time of death of patients.</td>
<td>Maximum potential: 922 out of 4,877 deceased patients</td>
</tr>
<tr>
<td>Study type: Prospective study</td>
<td>Characteristic of cases: Not mentioned</td>
<td>Baseline Measurements: Not applicable.</td>
<td>To chart the donor potential for organs in The Netherlands and identify factors influencing whether donation is discussed with the relatives and whether donation request is granted or refused.</td>
<td></td>
<td>Optimistic potential: 205</td>
<td></td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Realistic potential: 61 out of 205</td>
<td></td>
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<td></td>
<td>Out of 61, only in 42 (69%) was the topic of donation raised.</td>
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<tr>
<td></td>
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<td></td>
<td>Of 717 physicians in the study, 301 (42%) asked the organ donation question one or more times. The reasons given for not discussing donation were:</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Medical contraindication-50%</td>
<td></td>
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<td></td>
<td>No time- 10%</td>
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<td>Did not think of it-5%</td>
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<td>Difficult situation- 4%</td>
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<td></td>
<td></td>
<td>Other reasons-18%</td>
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<td></td>
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<td></td>
<td>In the multilevel analysis, the chance that a physician raises the donation request varies between 2% and 77%</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>Factors that had a strong and significant influence on whether or not the donation request was done were:</td>
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<tr>
<td></td>
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<td></td>
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<td></td>
<td>Number of potential organs in a particular donor (p=0.000)</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td>Knowledge of contraindications by physician (p=0.000)</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Cause of death (p=0.026) with</td>
<td></td>
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<tr>
<td>Factor</td>
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<td>---------------------------------------------</td>
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<tr>
<td>Sex of the physician (p=0.035) female physicians are more likely to ask than male colleagues.</td>
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<tr>
<td><strong>Factors that did not influence were:</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Sex of the patient</td>
<td></td>
<td></td>
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<tr>
<td>Time of death</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of a codicil</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age of the physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position of the physician</td>
<td></td>
<td></td>
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<tr>
<td>Frequency with which the physician confirmed death.</td>
<td></td>
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</tbody>
</table>

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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<td>N/A</td>
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<td></td>
</tr>
<tr>
<td>Author:</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retrospective study (medical records review)</td>
<td>69 hospitals in a non random sample 956 medically suitable potential donors 40 records missing 916 complete data available</td>
<td>Inclusion/Exclusion (study group): Patients were checked to see if they met the criteria for brain death. The study was limited to potential donors who were ≤70 years of age at time of death. Patients were excluded if they had been diagnosed with one or more of 13 categories of ICD-9-CM contraindications for organ donation.</td>
<td>To estimate the potential for solid organ donation and identify modifiable reasons for non-donation.</td>
<td>N/A</td>
<td>Organ donation occurred among 299 of the 916 potential donors [33% (95% CI: 30-36)]</td>
<td></td>
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<tr>
<td></td>
<td>N/A</td>
<td></td>
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<tr>
<td>Study group:</td>
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<tr>
<td>Control group:</td>
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<td></td>
<td></td>
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<tr>
<td>Study period:</td>
<td>Jan 1990 to Dec. 1990</td>
<td>60 records missing 916 complete data available</td>
<td>Characteristics of cases: Not mentioned Baseline Measurements: Not applicable.</td>
<td>N/A</td>
<td>Rates of organ donation decreased substantially with the potential donor’s age: 41% among ages 0 to 18 years to 12% among ages 60-70 years (p&lt;0.0001) Donation was also lower among African American (22%) and Hispanic subjects (17%) compared with non-Hispanic white subjects (41%, p&lt;0.0001). Rates of donation were higher when the cause of death was a motor vehicle accident (45%), a gunshot wound or stabbing (43%), or other head trauma (42%) compared with cerebrovascular (26%), asphyxiation (21%), or cardiovascular (3.2%) (p&lt;0.001). No relationship between size of the 69 hospitals (number of beds) and the donation rate in that hospital which suggests there is no volume or experience effect. Also, whether or not the hospital was a transplant center did not affect the rate of donation.</td>
<td></td>
</tr>
<tr>
<td>Setting: USA</td>
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**Table 1: Predictors of organ donation**

<table>
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<tr>
<th>Predictor variables</th>
<th>Multivariate Odds</th>
<th>95% CI</th>
<th>p value</th>
</tr>
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<tr>
<td>Age (years)</td>
<td></td>
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</tr>
<tr>
<td>0-18</td>
<td>5.75</td>
<td>2.75-12.04</td>
<td>0.0001</td>
</tr>
<tr>
<td>19-29</td>
<td>3.51</td>
<td>1.77-6.98</td>
<td>0.0003</td>
</tr>
<tr>
<td>30-39</td>
<td>5.00</td>
<td>2.50-10.01</td>
<td>0.0001</td>
</tr>
<tr>
<td>40-49</td>
<td>5.10</td>
<td>2.60-10.004</td>
<td>0.0001</td>
</tr>
<tr>
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<td>---</td>
</tr>
<tr>
<td>10.00</td>
<td>5.00</td>
<td>2.00</td>
<td>1.00</td>
</tr>
<tr>
<td>50-59</td>
<td>2.16</td>
<td>1.04-4.50</td>
<td>0.04</td>
</tr>
<tr>
<td>≥60</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ace/ thnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Africa American</td>
<td>0.38</td>
<td>0.23</td>
<td>0.63</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.26</td>
<td>0.13-0.49</td>
<td>0.0001</td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All other</td>
<td>0.25</td>
<td>0.11-0.57</td>
<td>0.0009</td>
</tr>
<tr>
<td>Cause of Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gunshot wound/stabbing</td>
<td>2.70</td>
<td>1.58-4.62</td>
<td>0.0003</td>
</tr>
<tr>
<td>Motor vehicle</td>
<td>2.22</td>
<td>1.40-3.51</td>
<td>0.007</td>
</tr>
<tr>
<td>Other head trauma</td>
<td>1.00</td>
<td></td>
<td></td>
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<tr>
<td>Cerebrovascular</td>
<td>1.33</td>
<td>0.84-2.10</td>
<td>0.22</td>
</tr>
<tr>
<td>All other</td>
<td>1.23</td>
<td>0.66-2.30</td>
<td>0.52</td>
</tr>
</tbody>
</table>

Estimated OR from logistic regression predicting donation (vs. no donation) among potential donors controlling for variables shown, hospital unit, and number of beds.

The odds of donation for patients aged 0 to 49 years were approximately 5 times the odds of potential donors aged ≥60 years.

By contrast, the odds of donation were substantially lower for African Americans (OR=0.38, 95%CI=.23-0.63, p<0.0001) compared with non-Hispanic whites.

**Reasons for Non-donation**

3 major reasons found were:

- The main reason was denial of consent (36%)
- In addition (17%), brain death was evident but family members were not asked to make a decision about donation.
- 10% were not identified as brain dead in the records, despite clinical findings consistent with brain death.
Also, the rate of not asking was also independently associated with race/ethnicity. Compared with non-Hispanic white family members, family members of African American members were less likely to be asked to donate (OR=0.34, 95% CI=0.20-0.62, p=0.0003).

Additional comments:

Title: A survey of personal and professional attitudes of intensivists to organ donation and transplantation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 819</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td>80 out of 242 from 49 hospitals said they had a unit policy according to which families should be approached for organ donation.</td>
</tr>
<tr>
<td>Author:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Unit policy was ‘all families without exception’ in 26, ‘all with agreed exceptions’ at 14 and ‘all with ad hoc exclusions’ in 40. If the latter was assumed to be equivalent to no policy at all, that implied that only 40 had a policy in practice.</td>
</tr>
<tr>
<td>Study type:</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Retrospective study</td>
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</tr>
<tr>
<td>Level of evidence:</td>
<td>(-)</td>
<td></td>
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</tr>
</tbody>
</table>

Methods: A questionnaire survey was carried out to examine the attitudes and practices of Australian and New Zealand intensivists with regard to brain death and organ donation. Each questionnaire consisted of a personal details section, personal attitudes, and unit/hospital practice and policy.

Table 1: The most common reasons for not asking about organ donation

<table>
<thead>
<tr>
<th>Reasons for not asking</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural differences</td>
<td>106</td>
</tr>
<tr>
<td>Family too distressed</td>
<td>104</td>
</tr>
<tr>
<td>Language difficulties</td>
<td>49</td>
</tr>
<tr>
<td>Too tragic</td>
<td>48</td>
</tr>
<tr>
<td>Threats to staff</td>
<td>35</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
</tr>
<tr>
<td>Insufficient beds</td>
<td>12</td>
</tr>
<tr>
<td>Insufficient nurses</td>
<td>9</td>
</tr>
<tr>
<td>You are too stressed</td>
<td>9</td>
</tr>
<tr>
<td>Nurses too stressed</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 517</td>
<td>Study group: 14 ICUs</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>To analyze the problem of identification of potential donors by means of a chart revision of patients who died in 14 ICUs. The Donor Action Programme (DA) provides tools and guidelines to assist hospitals and critical care units in assessing and improving their donation potential. The study period was subdivided into 5 semesters, and every 6 months the following parameters were evaluated: 1. The number of patients with severe brain damage/total number of deaths in ICU 2. The number of brain death diagnosis/patients with GCS=3. All patients with severe brain insult as defined by a GCS value of 3/15, who were admitted to, and died in, ICUs, were assessed by the local transplant coordinators. The co-coordinators entered the medical chart data into a local network that connected all ICUs to the transplant reference centre in real time. The accuracy of the data and the maintenance of homogenous criteria among all the hospitals taking part in the study were guaranteed by continuous controls through the professionals at the transplant reference centre, who verified the compilation of the schedules from each ICU through weekly contacts with the transplant coordinators and the ICU staff.</td>
<td>N/A</td>
<td>The number of evaluated deaths was 649, 654, 573, 593 and 587 in each period. The number of brain dead diagnosis was performed in 87 in 1st semester, 91-2nd, 88-3rd, 118-4th, and 125-5th. This is a significant increase in brain death diagnosis from the beginning to the end of the study from 31% to 53% (p=0.003, ( \chi^2 = 16.072 )). A consensual enhancement of potential donor referrals was also observed. Organ donor referrals to the transplant reference centre has increases from 84 to 112 (p=0.008, ( \chi^2 = 13.779 )) since the implementation of the DA project.</td>
</tr>
<tr>
<td>ID: 1244</td>
<td>Study group: 12 Victorian hospitals 5551 deaths</td>
<td>Inclusion/Exclusion (study group): Excluded those patients &lt;1 year or &gt;75 years of age or with an admission diagnosis of cancer. Also excluded were patients medically not suitable for donation (e.g. multi-organ dysfunction) or those who did not or could not progress to brain death.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author: Opdam et al (2004)</td>
<td>Control group: N/A</td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Prospective study (medical record audit)</td>
<td>Study period: Not mentioned</td>
<td>Baseline Measurements: Not mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td>Setting: Victorian Hospitals, Australia.</td>
<td>To identify all potential donors (not just those in ICUs). The panel members discussed each case and classified according to the following categories:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. Confirmed brain death 2. Likely to progress to brain death with 24h 3. Likely to progress to brain death with &gt;24h but &lt;72h 4. Not likely to progress to brain death within 72h or medically unsuitable for donation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Categories 1-3 were considered to be unrealized potential organ donors and category 4 was considered not to be potential organ donors.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Panel identified 90 patients as possible potential donors 46-category 1-3 which were unrealized 42-category 4 2 medically unsuitable. Families not approached for donation Physiological support not provided Diagnosis of brain death missed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 355</td>
<td>Study group: 15 ICUs 1655 deaths</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned</td>
<td>To estimate the organ donor potential in Denmark, review causes of death in potential organ donors, estimate the donation refusal rate and ascertain reasons for non-donation.</td>
<td>N/A</td>
<td>Medically suitable organ donors-169 (10.2% of all deaths) Cause of death was cerebral lesion in 96% of cases Organ donation realized in 43 cases The rate of non detection by the hospital staff of medical suitable donors was estimated to be 2%</td>
</tr>
</tbody>
</table>

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study group: Phase 1: 6080 deaths Phase 2: 1326 deaths</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>To identify why organ donation did not occur. The study was undertaken in 2 phases: Phase 1 Prospective audit was undertaken of all patients who died in 9 metropolitan hospitals in NSW over 12 months. Phase 2 A prospective 12 month audit undertaken of all patients who died in 4 hospitals in country NSW.</td>
<td>N/A</td>
<td>Phase 1: Metropolitan hospitals 863 patients in coma 515- acute irreversible brain damage Out of 515, 97 classified as unrealistic potential donors Another 87 became unrealistic 106 deemed medically unsuitable 225 realistic medically suitable potential donors</td>
<td>863 patients in coma 515- acute irreversible brain damage Out of 515, 97 classified as unrealistic potential donors Another 87 became unrealistic 106 deemed medically unsuitable 225 realistic medically suitable potential donors</td>
</tr>
<tr>
<td>Control group: N/A</td>
<td>N/A</td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting: NSW, Australia</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type</td>
<td>No. of people</td>
<td>Prevalence/incidence</td>
<td>Patient characteristics</td>
<td>Methods</td>
<td>Reference standard</td>
<td>Results</td>
</tr>
<tr>
<td>------------</td>
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</tr>
</tbody>
</table>


**Title:** Poisoned patients as potential organ donors; postal survey of transplant centers and intensive care units.
| ID: 1387 | **Study group:** 67 doctors total 35 surgeons 32 physicians 30 directors | **Inclusion/Exclusion (study group):** Not mentioned | **Baseline Measurements:** Not mentioned | **Postal questionnaires were sent to transplant surgeons and/or physicians at all UK centers currently undertaking heart, lung, kidney, liver or pancreas transplantation. They were also sent to an equal number of directors of intensive care units at hospitals not undertaking transplantations.** | N/A | Most directors would offer poisoned patients as potential donors and leave the decision concerning organ harvesting to local transplantation team(s).

For the doctors, more than 70% of those involved in transplantation would consider to accept patients who had been poisoned with methanol, cyanide or carbon monoxide as organ donors. |

**Title: National survey of potential heart beating solid organ donors in Sweden.**

<table>
<thead>
<tr>
<th>ID: 95</th>
<th>Study type: Retrospective study</th>
<th>Author: Moller et al. (2009)</th>
<th>Setting: Sweden</th>
<th>Study period: Last quarter of 2007</th>
<th>Control group: N/A</th>
<th>Study group: 875 deaths</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The questionnaire consisted of 10 major questions concerning brain injury, mechanical ventilation, death diagnosis, and why donation did not take place among potential donors.</td>
<td>N/A</td>
</tr>
</tbody>
</table>

### Title: Improved organ procurement through implementation of evidence-based practice

<table>
<thead>
<tr>
<th>ID: 96</th>
<th>Level of Evidence: ()</th>
<th>Study type: Observational</th>
<th>Authors: Bair et al (2006)</th>
</tr>
</thead>
</table>

Describes the effect of the introduction of the US Organ Donation Breakthrough Collaborative. As part of this,
- all ICU patients screened daily for organ donation clinical triggers for referral

Results showed

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2005</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversion rate</td>
<td>50%</td>
<td>80%</td>
<td>0.025</td>
</tr>
<tr>
<td>Referral rate</td>
<td>98%</td>
<td>99%</td>
<td>n.s.</td>
</tr>
<tr>
<td>Timely notification</td>
<td>90%</td>
<td>94%</td>
<td>n.s.</td>
</tr>
<tr>
<td>Appropriate requester</td>
<td>89%</td>
<td>87%</td>
<td>n.s.</td>
</tr>
</tbody>
</table>

However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.

**Additional comments:** Not able to isolate the effect of clinical triggers. Limited number of data points.

**Title: US organ donation breakthrough collaborative increases organ donation**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/ Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 61</td>
<td>describes the effect of a whole programme to improve the organ donation system (US Organ Donation Breakthrough Collaborative). Part of the ‘formal’ concerted effort was teaching hospital staff clinical triggers for referral (GCS of 5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Results showed that**

"The number of organ donors in Collaborative hospitals increased 14.1% in the first year, a 70% greater increase than the 8.3% increase experienced by non-Collaborative hospitals. Moreover, the increased organ recovery continued into the post-Collaborative periods. Between October 2003 and September 2006, the number of total US organ donors increased 22.5%, an increase 4-fold greater than the 5.5% increase measured over the same number of years in the immediate pre-Collaborative period. The study did not involve a randomized design, but time-series analysis using statistical process control charts shows a highly significant discontinuity in the rate of increase in participating hospitals concurrent with the Collaborative program, and strongly suggests that the activities of the Collaborative were a major contributor to this increase."

However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone. The authors did note that rapid testing adaptation and replication of successful practices were key to the success and the example cited was that of the use of clinical triggers.

"OPOs had long known that an early, timely notification before brain death was associated with higher rates of donation. Physicians and nurses would often resist or fail to see the importance of the timing of referrals. Learning from other teams the clinical status of the patient that was used to prompt or ‘trigger’ a referral led to early collaboration between OPO staff and hospital staff in any number of process measures measured in donation."

**Additional comments:** Not able to isolate the effect of clinical triggers. Although not RCT, high quality time series study, with good number of data points.

**Reference:**

Title: Implementation of an intervention plan designed to optimize donor referral in a donor hospital network.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 114</td>
<td>Study group: Not mentioned</td>
<td>Inclusion</td>
<td>The purpose of this study was to measure the impact of an intervention plan designed to optimize the donor detection process and donor referral patterns.</td>
<td>The number of potential donors increased by 27.46% (324 in period 1 vs. 413 in period 2, p&lt;0.02).</td>
</tr>
<tr>
<td>Author: Van Gelder et al. (2006)</td>
<td>Control group: N/A</td>
<td>/Exclusion(study group): Not mentioned</td>
<td>A multiple point plan was designed on the basis of 3 essential equal pillars;</td>
<td>The number of effective donors increased by 30.86% (230 vs. 301, p&lt;0.05) from period 1 to period 2.</td>
</tr>
<tr>
<td>Study type: Observational study</td>
<td>Study period: Jan 1996 to Dec 2003</td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
<td>The number of donor hospitals per year increased by 37% (16 in period 1 vs. 22 in period 2, p&lt;0.02).</td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td>Setting: Belgium</td>
<td>Baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Measurements: NA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Information on donation criteria

Clinical pathways brain death
Clinical pathways donor management
Clinical pathways organizational aspects of the procedure
Donor manual (protocol) electronically available
Yearly donor symposia concentrating on donor related issues
Newsletter every 6 months with donor related subjects.

Period 1 was from Jan 1996 to Dec 1999 where the above protocol did not exist.
Period 2 was from Jan 2000 to Dec 2003, after implementation of the new protocol.

Additional comments: However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.

Title: Increasing organ recovery from level I trauma centers: the in-house coordinator intervention.

<table>
<thead>
<tr>
<th>ID: 143</th>
<th>Study type: Observational study</th>
<th>Author: Shafer et al (2004)</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study group: Not mentioned</td>
<td>Study group: Not mentioned</td>
<td>Control group: N/A</td>
<td>Study period: 1999 to 2002</td>
<td>Setting: 8 LITCs in New York, Los Angeles, Houston, and Seattle.</td>
<td>Inclusion /Exclusion (study group): Not mentioned</td>
<td>Characteristics of cases: Age of donors-1 month to 18 years 27 boys 6 girls</td>
</tr>
</tbody>
</table>

Additional comments: However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.

**Title:** Organ procurement 1999-2000: how is Hawaii doing?  
**Organ donation in Hawaii: impact of the final rule**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
</table>
| ID: 188 and 182   | Total no. of deaths: 4,679 (in 1999) and 4,730 (in 2000) | Definition of potential donors:  
- brain dead  
- 70 years or younger  
- no evidence of HIV, cancer, life-threatening transmissible disease at time of death | Final Rule specified that all hospitals notify OPOs of all deaths and imminent deaths to maintain eligibility for reimbursement  
Date: 2000 | Pre-introduction of Final Rule  
Date: 1999 | 12 months | Results were |
|                   | Setting: 17 major acute care hospitals in Hawaii | | | | | |
| Level of evidence: () | Study type: Observational | | | | | |
| Authors: Higashiwaga et al (2001) | | | | | | |
| Authors: Higashiwaga et al (2002) | | | | | | |

<table>
<thead>
<tr>
<th>Process variable</th>
<th>Number</th>
<th>1999</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potential donors identified</td>
<td>60</td>
<td>66</td>
<td></td>
</tr>
<tr>
<td>Total potential donors</td>
<td>75</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>Identification rate</td>
<td>80%</td>
<td>83%</td>
<td></td>
</tr>
<tr>
<td>Referral</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potential donors referred</td>
<td>40</td>
<td>56</td>
<td></td>
</tr>
<tr>
<td>Total potential donors</td>
<td>75</td>
<td>79</td>
<td></td>
</tr>
<tr>
<td>Referral rate</td>
<td>53%</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>Consent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potential donor family approached</td>
<td>48</td>
<td>64</td>
<td></td>
</tr>
<tr>
<td>Consent for donation given</td>
<td>28</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Consent rate</td>
<td>58%</td>
<td>52%</td>
<td></td>
</tr>
</tbody>
</table>

**Additional comments:** Retrospective chart review.


[Identification: required referral]
<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/ Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 28</td>
<td>Setting: Single NHS Trust in UK</td>
<td>Potential organ donors</td>
<td>Required referral Implemented through an addendum to the Liverpool Care of the Dying pathway documentation Date: 2007-8</td>
<td>Standard practice before introduction of required referral Date: 2006-7</td>
<td>12 months</td>
<td>Results were</td>
</tr>
<tr>
<td>Level of evidence: ()</td>
<td>Study type: Observational</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authors: Murphy et al (2009)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Results were**

<table>
<thead>
<tr>
<th></th>
<th>2006-7</th>
<th>2007-8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Accepted</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Heart beating donors</td>
<td>7</td>
<td>31</td>
</tr>
<tr>
<td>Non-heart beating donors</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

**Additional comments:** Prospective study. Although attributes the increases to required referral, was part of a wider intervention. Most changes occurred before required referral, but not clear when a controlled non-heart beating donation programme was introduced and how this may have impacted on the results.

**Title:** Concentrated professional education to implement routine referral legislation increases organ donation

| ID: 239 | Setting: 136 hospitals in a transplant programme in the US | Intervention: Routine referral, required due to legislation, and implemented through professional educational initiatives, provision of sample hospital policies, reallocation of resources | Comparison: Pre-introduction of routine referral | Follow-up: 24 months | Outcome and Results: Results were

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Referrals</th>
<th>1994</th>
<th>1996</th>
<th>Increase (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential organ donors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>528</td>
<td>824</td>
<td>56</td>
<td></td>
</tr>
<tr>
<td>Medically suitable referrals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>342</td>
<td>427</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Donors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>175</td>
<td>217</td>
<td>24</td>
<td></td>
</tr>
</tbody>
</table>

Additional comments: Limited number of data points. Not clear if attributable to routine referral alone as part of complex educational initiative.

### Title: Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
</table>
| ID: 226 | Setting: 20 non-donor hospitals in US | Non-donor hospitals:  
- >100 beds,  
- regional or community centres,  
- had ICUs, operating rooms, staff neurologists and an anaesthesiologist  
- community based providing services to local residents | Placement of in-house co-ordinators  
Establishment of routine notification  
Free telephone service  
In-service training  
Date: 1991-7 | Pre-introduction practice  
Date: 1991-3 | 24 months | Results were |

<table>
<thead>
<tr>
<th></th>
<th>1991-3</th>
<th>1995-7</th>
<th>Increase (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organ referrals</td>
<td>22</td>
<td>121</td>
<td>450</td>
</tr>
<tr>
<td>Hospitals making organ referrals</td>
<td>13</td>
<td>19</td>
<td>46</td>
</tr>
<tr>
<td>Organ donors</td>
<td>2.67</td>
<td>10</td>
<td>275</td>
</tr>
<tr>
<td>Hospitals with at least 1 donor</td>
<td>3</td>
<td>5</td>
<td>67</td>
</tr>
<tr>
<td>Organs recovered</td>
<td>8.01</td>
<td>33</td>
<td>312</td>
</tr>
</tbody>
</table>

**Additional comments:** Limited number of data points. Complex intervention, so not able to attribute changes to single factor. Introduction into non-donor hospitals, so not able to estimate impact in hospitals with existing donor programmes.

Title: US organ donation breakthrough collaborative increases organ donation

<table>
<thead>
<tr>
<th>Level of Evidence</th>
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<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 61</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Level of evidence: ()**

**Study type:** Observational

**Authors:** Shafer et al (2008)

Describes the effect of a whole programme to improve the organ donation system (US Organ Donation Breakthrough Collaborative). Part of the ‘formal’ concerted effort was

- establishment of a system wide commitment to ‘unconditionally identify all opportunities for donation.’

Results showed that

‘The number of organ donors in Collaborative hospitals increased 14.1% in the first year, a 70% greater increase than the 8.3% increase experienced by non-Collaborative hospitals. Moreover, the increased organ recovery continued into the post-Collaborative periods. Between October 2003 and September 2006, the number of total US organ donors increased 22.5%, an increase 4-fold greater than the 5.5% increase measured over the same number of years in the immediate pre-Collaborative period. The study did not involve a randomized design, but time-series analysis using statistical process control charts shows a highly significant discontinuity in the rate of increase in participating hospitals concurrent with the Collaborative program, and strongly suggests that the activities of the Collaborative were a major contributor to this increase.’

However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.

**Additional comments:** Not able to isolate the effect of required referral. Although not RCT, high quality time series study, with good number of data points.

**Title: Organ donation rates in a neurosurgical intensive care unit.**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 172</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author: Dickerson et. al (2002)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
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<tr>
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<tr>
<td>Study group: Not mentioned</td>
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<tr>
<td>Control group: N/A</td>
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<tr>
<td>Study period: 1996 to 1999</td>
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<tr>
<td>Setting: BGTH, Houston</td>
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<tr>
<td>Inclusion/Exclusion/study group: Not mentioned</td>
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<tr>
<td>Characteristics of cases: Not mentioned</td>
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<tr>
<td>Baseline Measurements: Not mentioned</td>
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<tr>
<td>The objective of the study was to analyze donation rates in a busy NICU in which doctors and nurses work closely with the local OPO. Once declaration of death is confirmed, the OPO is given early notification of all potential organ donors at BGTH. An OPO coordinator is available in house 24 hours a day, and this person determines the medical suitability of potential donors. The OPO coordinators also receive specialized training in request techniques.</td>
<td>Of the 98 eligible donors identified by the OPO, consent was obtained and organs were recovered in 72 cases, yielding a successful organ procurement rate of 73.5%. The in-house OPO coordinator was called before the confirmatory cerebral radionuclide study was performed. Also the early notification gave the OPO coordinator sufficient time to locate next of kin and to begin investigating the medical suitability of the potential donor.</td>
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**Additional comments:**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 24</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author:</td>
<td>Graham et. al (2009)</td>
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<td>Study type:</td>
<td>Retrospective study</td>
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<tr>
<td>Level of evidence: (-)</td>
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<tr>
<td>Study group:</td>
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<tr>
<td>Control group:</td>
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<tr>
<td>Study period:</td>
<td>Not mentioned</td>
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<tr>
<td>Setting:</td>
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<tr>
<td>Inclusion/Exclusion(study group):</td>
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<tr>
<td>Characteristics of cases:</td>
<td>Not mentioned</td>
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<tr>
<td>Baseline Measurements:</td>
<td>Not mentioned</td>
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<tr>
<td>The objective of the study was to take cues from the National Organ Donation Breakthrough Collaborative overarching principles and best practices and spread these principles and practices through existing pathways within NYPHS (New York-Presbyterian Healthcare system). One of the key principles was to have in-house OPOs.</td>
<td>Improvements were moderate. The overall system conversion rate improved by 42% during the first 6 months. The system wide consent rate increased by 30% over the baseline year. The overall number of organs per donor was essentially unchanged from the baseline year.</td>
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</table>

### Title: A continuous quality improvement process to increase organ and tissue donation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 252</td>
<td>Study group:</td>
<td>Inclusion (Exclusion)</td>
<td>The objective of the study was to outline the CQI (continuous quality improvement) process and compare the number of organ donor referrals with that of LifeShare of the Carolinas at the time of implementation and 10 months after the implementation of the CQI process. An important part of this process was to have in-house OPO coordinators and have routine referrals.</td>
<td>With implementation of the CQI process, referrals for organ and tissue donors during the 10 month study increased from 49/90 (54%) in March 1994 to 105/107 (98%) in December 1994. Organ donors increased from 15 to 27 (80%).</td>
</tr>
<tr>
<td>Author: Burris et. al (1996)</td>
<td>Study group: Not mentioned</td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
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<tr>
<td>Study type: Retrospective study</td>
<td>Control group: N/A</td>
<td>Baseline Measurements: Not mentioned</td>
<td></td>
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<tr>
<td>Level of evidence: (-)</td>
<td>Study period: Mar 1994 to Dec 1994</td>
<td>Setting: USA</td>
<td></td>
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</tbody>
</table>

## Supporting evidence

### Title: Religious attitudes regarding organ donation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 1719</td>
<td>Study group: 183 responses</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>A preliminary survey designed to ascertain beliefs held by religious leaders was designed.</td>
<td>N/A</td>
<td>98% of chaplains and clergy responded they were very comfortable with discussing organ donation. They also said they would feel comfortable counseling a family about organ donation. 80% of chaplains and 54% of clergy answered that their congregants sought their professional opinion about organ donation. All respondents believed that organ donation was not a sin and respondents also agreed that religious beliefs supported their feelings about organ donation.</td>
</tr>
</tbody>
</table>

### Additional comments:

**Review Question 2:** What structures and processes are appropriate and effective for obtaining consent from families, relatives and legal guardians of potential DBD and DCD donors?

**Title:** Effect of ‘collaborative requesting’ on consent rate for organ donation: randomized controlled trial (ACRE trial)

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/ Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 896</td>
<td>Total no. of patients: Baseline = 317 Excluded= 116 Collaborative request group: 101 Routine request group: 100</td>
<td>Inclusion: Participants were the relatives of patients declared dead by criteria for brain stem death or awaiting BSD testing who were to be approached regarding organ donation. Exclusion: Excluded units with in house donor transplant coordinators and a collaborative requesting rate over 50% when the study started.</td>
<td>Relatives approached by clinical team and a donor transplant coordinator (collaborative request) when a request for organ donation was made. They were allowed to decide whether to request organ donation during the interview when the results of the BSD tests were discussed or whether to request organ donation in a subsequent interview (‘decoupling’ the request).</td>
<td>Relatives approached by the clinical team alone (routine request) when a request for organ donation was made.</td>
<td>NA</td>
<td>Table 1: Consent rates for organ donation</td>
</tr>
<tr>
<td>Level of evidence: ()</td>
<td>Study type: RCT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Authors: Young et. al (2009)</td>
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</tr>
</tbody>
</table>

**Table 1: Consent rates for organ donation**

<table>
<thead>
<tr>
<th>Consent to organ donation (%)</th>
<th>All (n=201)</th>
<th>Routine request (n=101)</th>
<th>Collaborative request (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent to organ donation (%)</td>
<td>119(59)</td>
<td>62</td>
<td>57</td>
</tr>
<tr>
<td>Any solid organ retrieved (% of all patients)</td>
<td>102(51.7)</td>
<td>57(56)</td>
<td>45(45)</td>
</tr>
<tr>
<td>Per protocol</td>
<td>140</td>
<td>73</td>
<td>67</td>
</tr>
<tr>
<td>Consent to organ donation (% per protocol patients)</td>
<td>89(64)</td>
<td>44(60)</td>
<td>45(67)</td>
</tr>
<tr>
<td>Any solid organ retrieved (% per protocol patients)</td>
<td>76(54)</td>
<td>39(53)</td>
<td>37(55)</td>
</tr>
</tbody>
</table>

**ITT analysis**

OR: 57/62= 0.83 (95% CI: 0.47 to 1.46)

**Adjusted OR**

There was no difference in the rates between groups with the
risk adjusted ratio of the odds of consent in the collaborative requesting group relative to routine group was 0.80 (95% CI-0.43 to 1.53, p-0.49)

Per protocol analysis (not mentioned in initial methodology)

The risk adjusted ration of the odds of consent was 1.47 (95% CI-0.67 to 3.20, p-0.33)

Any solid organ retrieved from all patients (ITT)

OR- 0.63 (95% CI- 0.36 to 1.10)

Any solid organ retrieved from patients who consented (ITT)

OR- 0.81 (95% CI- 0.44 to 1.50)

Consent was more likely if the patient was white (8.43 for white vs. non white, p<0.001), female (0.60 for male vs. female, p-0.12), and in the 25-34 range (0.85 for 25-34 vs. >60 years, p-0.12).

There was a slightly lower conversion rate (number of donors from whom solid organs were actually retrieved as a proportion of donors in whom consent for donation had been obtained) in the collaborative requesting group compared with the routine requesting group (OR- 79/92= 0.86, 95% CI-0.74 to 1, p-0.043)

Additional comments:
Randomisation was performed (telephone based). Blinding not performed. Power calculation used. Allocation concealment not mentioned. Confounding mentioned (adjusted for age group of patients, ethnicity and sex). Patients lost to follow up and excluded after randomisation was mentioned. All parameters were analysed as intention to treat.

Title: A qualitative examination of the needs of families faced with the option of organ donation.

<table>
<thead>
<tr>
<th>ID: 234</th>
<th>Author: Jacoby et al (2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study type: Qualitative study (interviews)</td>
<td>Level of evidence: (-)</td>
</tr>
</tbody>
</table>

### Study group:
- 98 potential participants
- 50 donor family
- 48 non-donor family
- 33/50 refused in donor group
- 42/48 refused in non-donor group
- 11 finally participated from donor group
- 5 from non-donor group

### Control group:
- N/A

### Study period:

### Setting:
- 3 sites in New York

### Inclusion/Exclusion (study group):
- Eligible legal next of kin who consented or refused donation of their loved one’s organs.

### Characteristics of cases:
- Age range: 31-65 years (mean: 43 yrs)

### Baseline Measurements:
- Not mentioned

### Methods:
- The objective was to examine donor and non-donor family members’ perceived needs for support while in the hospital intensive care setting and to gain an in-depth understanding of specific support considerations on the basis of a theoretical framework.

- The research questions were:
  1. How do donor and non-donor families describe and interpret the communication and behaviors of people they interacted with during the donation process and how do these descriptions differ?
  2. What can we learn from families’ accounts of their perceived need for support in relation to their donation decision and how do the 2 groups differ in this respect?
  3. What are the implications for care and interventions that would effectively address families’ perceived needs for support?

### Contextual Staff and others present
- The presence of and interaction with nursing staff were strongly valued by both donor and non-donor family members; satisfaction with nurses’ behaviors and care was expressed by all.

- They also agreed that treating physicians tended not to be sufficiently available to them and provided inadequate continuity in care.

- Comments in both groups about medical staff varied from ‘cold,’ ‘distant,’ and ‘unavailable,’ to ‘caring,’ and ‘very competent.’

### Timing of approach
- Families in the non-donor group felt they had not been adequately prepared for the request for organ donation.

- They also felt they had not been clearly informed that their loved one was brain dead before being approached about organ donation.

- In contrast, donor families depicted the timing of the approach ‘as good as could have been’ and no one described problems with the manner of the approach by staff members.

- Being given the time and opportunity to spend time with their loved one and to ‘say goodbye’...
was a recurring theme among donor families.

**Behavioral Quality of care**

A common need in both groups was compassionate care of their loved one, and for their loved one to be treated with dignity and respect.

Participants expressed a desire to be listened to and to be understood and to have staff members just ‘be there’ for them.

Also, both groups with respect to care was the need to receive information that was understandable as well as prompt, accurate, in-depth, and consistent about their loved one’s condition.

Continuity of medical staff was another common desire expressed among both groups.

**The donation approach and decision making process**

Family members considered the tone and pace of the information about organ donation to be critical.

Non-donor families tended to report that the information was conveyed in a rushed manner and felt their decision had to be made too quickly.

Donor families expressed similar concerns and felt that it was important not to feel pressure in arriving at a decision about donation.
Tone, as expressed by both groups, referred to information being conveyed with empathy, concern, and consideration for their feeling. Examples: ‘you want to hear the truth, but there is a way to deliver the truth too,’ sitting outside the room like a hawk.’

**Informational Understanding of information received**

Brain death was a difficult concept to understand for both groups.

**Primary sources of information**

Families preferred to interact with a single physician and as a cognitive need to the degree that they felt information about the status of their loved one ought to have been consistent from physician to physician.

**Informational support needs**

Both groups commonly recounted the perception that physicians did not explain information adequately or sufficiently.

Family members said it would have been valuable to have physicians check their understanding of the information they were given.

Participants in both groups commented on the insensitive manner in which information often was conveyed to them.
Many would have liked information about organ donation process in its entirety.

**Emotional support needs**

Participants indicated that emotional support should be provided through sensitive and clear explanations of brain death, complex medical information, the purpose of particular tests, and confirmation of their understanding of their loved one’s condition.

Participants stated that nursing staff were also important sources of emotional support.

**Environmental**

The need for privacy during donation discussion was almost universally seen as critically important. Many participants in both groups commented on the uncomfortable and unsuitable spaces in which such discussions had to take place.

The idea of the ‘all-in-one’ birthing room concept was mentioned as beneficial for families considering the donation option, affording the family a comfortable place where they could continuously be with their loved one. Good lighting, comfortable furniture, and music were some specific ideas proposed.

**Spiritual**

Faith and spiritual support was important to nearly all donor families members but less so to non-donor group participants.
In some cases, hospital clergy was present, while in others, members of the families’ own religious communities were called.

<table>
<thead>
<tr>
<th>Study type</th>
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<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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<tbody>
<tr>
<td>ID: 290</td>
<td>N/A</td>
<td></td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The wider research objective was to conduct a sociological investigation into the experiences, attitudes, and belief systems of donor and non-donor families. Semi structured interviews over a 2-year period was conducted. The interviews were conducted at a time and place that suited the respondents.</td>
<td>N/A</td>
<td>Respondents’ understanding of Brain-Death Tests</td>
</tr>
<tr>
<td>Author: Haddow (2004)</td>
<td></td>
<td></td>
<td>Characteristics of cases: Not mentioned</td>
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<tr>
<td>Study type: Qualitative retrospective study</td>
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<td>Baseline Measurements: Not mentioned</td>
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<td>Study group: Donor families-19</td>
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<td>Non-donor families-4</td>
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<td>Control group: N/A</td>
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<tr>
<td>Study period: Not mentioned</td>
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<tr>
<td>Setting: Scotland</td>
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</table>

**Brain Death: The Role of Healthcare Professional Communication**

**Direct Information**

Allowing an optimum amount of time, clear information was also alluded to as being crucial during the initial stages of diagnosis. The majority of respondents in both groups said healthcare professionals mentioned the term brain stem death.

There is a requirement for the language to be understandable to the lay person, free from medical jargon and containing concepts familiar to the respondent.

**Tacit Feeling Displayed by Healthcare**

All respondents reported that 2 different healthcare professionals carried out the tests. Most donor and non-donor next of kin claimed that they were unaware of what the procedures involved (n = 18, 78%).

**The impact of time**

An important factor aiding understanding of the brain death diagnosis was said to be the availability of time.

For e.g.: A donor spouse claimed she was unaware her husband was dead when asked for her lack of objection to remove organs: "[I thought], 'Yes, I'll sign the kidney donation form and if anything happens, if he dies, they can have his kidneys.' I didn't realize that it set the whole process in motion."
Professionals

Essentially, both donor and non-donor relatives searched for, assessed, interpreted, and examined available information, directly provided or otherwise, enabling them to make their own judgment regarding the potential outcome for the patient.

Organ request

Most respondents said that a consultant had made the request following the results of the brain-death tests, generally with some degree of privacy, although 1 donor family complained it was made in a public place.

Also, because transplant coordinators did not wear a uniform, donor families mentioned it was easier to speak to them.

Respect for deceased's body

Inappropriate usage of words like "harvesting" caused the next of kin some anxiety. In one case, treating the deceased as a resource for organs, along with an assumption that healthcare professionals could "presume" donation was reported as highly distressing.

For donor relatives, issues arose regarding a discernible moment of death, because they were not present when mechanical ventilation was removed.

Follow-up care

A third of donor respondents agreed that follow-up care might be generally beneficial, because it allowed them the opportunity to ask questions and was said to make the donation seem more sincere and personal. Respondents who had received a home visit articulated this thought.

Conversely, responses from other donor respondents who
Additional comments:
A warning regarding the bias nature of the sample toward donor families might be noted and that "saturation" was not reached with the non-donor families. Comparisons are therefore made with other research conducted in the area. Equally, given the scope of this paper, the discussion does not address why donor and non-donor families refused or agreed to donation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
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<th>Results</th>
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</thead>
<tbody>
<tr>
<td>ID: 199</td>
<td></td>
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<td></td>
<td></td>
<td>Several physicians stressed the importance of “making everything right when determining death.” “There must be no question at all about it.”</td>
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<tr>
<td>Author: Sanner et. al (2007)</td>
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<tr>
<td>Study type: Qualitative study</td>
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<tr>
<td>Level of evidence: (-)</td>
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</tr>
<tr>
<td>Study group: 20 relatives (donors and non-donors) 25 physicians</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>Relative and physicians understood cases where organ donation had been requested and what factors were salient for the decision on donation.</td>
<td></td>
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</tr>
<tr>
<td>Control group: N/A</td>
<td></td>
<td>Characteristics of cases: Not mentioned</td>
<td>Relatives were mostly interviewed in their homes, but in some cases in our offices. Physicians were either interviewed by telephone or in their offices.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study period: Not mentioned</td>
<td></td>
<td>Baseline Measurements: Not mentioned</td>
<td>An open interview method was chosen to allow informants to speak freely about their experiences, although predetermined issues were also covered.</td>
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<tr>
<td>Setting: Sweden</td>
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</table>

**Semantic obscurity**

There was some confusion concerning terminology and semantics, which was demonstrated by both physicians and relatives. The terms used by professionals were adopted by relatives. They said for instance mostly that the patient "was declared dead" or "was declared brain dead" instead of "had died" or "was dead." Also, many physicians alternated between the terms *brain dead* and *dead*. The most difficult act to denominate was what happened when the ventilator was removed.

**Conflicts in task of procuring organs**

More than half the physicians found the request for organ donation stressful and demanding determination, concentration, and timing. They underscored the importance of relatives being convinced that everything was done to save the patient in the first place and not to procure organs.

**Accepting or declining request**

**Donation**

In 4 cases, relatives at first impulsively declined the request, initially reacting with uneasiness and felt too exhausted to make a decision. However, the physicians gave time for discussion, gently pointed out the benefits of a donation, and introduced the perspective of recipients. The initial uneasiness subsided when relatives had time to start cognitive operations and consider rational and altruistic ideas in their deliberations. They were also encouraged to...
Non donation
In one case, the closest relative did not want the deceased's organs to live on in strangers while the rest of his body was buried. The physician did not intervene in the family conversation.

In another case, the adult children were convinced that all organs of the deceased were unsuitable as transplants because the deceased was old and ill. The physician had not been successful in informing the family about possible benefits of the donation and what organs and tissue could be useful.

The relative thought it awful to cut into the deceased's body after death. The conversation with the physician had been conducted solely by telephone.

The relative had no opportunity to discuss the issue with other family members. She was uncertain of the deceased's opinion and thought it difficult to "decide for him." She also felt a little uneasy at the thought of having him cut up. The physician said that he regarded the informant as an old, fragile lady that should not be pressed further in this issue.

In 2 cases, no relatives were found but the physician thought that relatives were in shock and not capable of fully understanding information. His impression was that the family did not want the body to be cut into.

**Title:** The instability of organ donation decisions by next-of-kin and factors that predict it.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 72</td>
<td>Study group: 285 next-of-kin donors 147-donors 138-non-donors</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned Characteristics of cases: Age: 49.3±13.2 yrs 52% registered organ donors Spouse:36% Parent:26% Adult child:21% Sibling: 10% Other:7% Baseline Measurements: NA</td>
<td>N/A</td>
<td>Decision instability was more likely when the deceased had not previously discussed organ donation with the next-of-kin (p&lt;0.01) Next-of-kin donors were more likely to consent to donation when the person who first mentioned donation at the time of their loved one’s death was a non OPO (organ procurement organization) professional, such as physician, nurse, clergy, or social worker (p&lt;0.01). Also when they perceived the timing of donation discussion to be poor (p&lt;0.001). Were not told of their loved one’s death before the first mention of donation (p&lt;0.0001) Did not feel they were given enough time to discuss their donation decision with others (p&lt;0.006). These variables were statistically significant predictors of decision instability among next-of-kin non-donors in a logistic regression model.</td>
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</tr>
<tr>
<td>Author: Rodrigue et. al (2008)</td>
<td>Study type: Retrospective study</td>
<td>Control group: N/A</td>
<td>Study period: Jul 2001- Feb 2004</td>
<td>Setting: Gainesville, Florida</td>
<td>N/A</td>
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<td>Level of evidence: (-)</td>
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**Additional comments:**

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</table>
| ID: 477    | Study group: 225 individuals donating families | N/A | Inclusion/Exclusion(study group): Families who had actual potential, medically acceptable donor family members. Tissue donors were not included. Characteristics of cases: Mean age: 48.01 years (SD: 14.63) 78-men 157-women Baseline Measurements: Not applicable. | The aim was to examine the psychological consequences of consenting or refusing donation of the organs or tissue of a dying family member. Participants were interviewed using the same phone survey instrument. Four groups were identified: Group 1: nondonors who would make the same decision again Group 2: nondonors who would not make the same decision again Group 3: donors who would make the same decision again Group 4: donors who would not make the same decision again | N/A | Demographic factors African-Americans were less likely to donate than Caucasians (p < 0.001) Individuals with more formal education were more likely to donate than individuals with less formal education (p < 0.001) Individuals who were married were more satisfied with their decision than individuals who were single, divorced, or widowed (p < 0.01) Past behaviors of the donor family The act of signing a donor card, discussing organ donation, and contributing money to charities, were all associated with the decision to donate organs or tissues (p < 0.01). Medical/Hospital factors Satisfaction was higher whenever the donation took place in a hospital that the family typically used for family care (p < 0.01) Families were more satisfied with their decision when the deceased died at a medical centre that they considered to highly regarded (p < 0.01) Whenever approach was made in large university medical centre, families were less satisfied than when the request was made at a...
community hospital, regardless of the community hospital's size (p < 0.01).

Previous knowledge about transplantation
Families who considered transplantation to be a proven procedure and believed that it had a high success rate were more likely to donate than families who did not hold these beliefs (p < 0.01).

Donation was more likely if the family personally knew someone who had received an organ or tissue (p < 0.01).

Families who understood the term brain death and who had its meaning explained were more likely to become satisfied donors (p < 0.05).

Request process
Individuals who felt pressured to donate were less likely to do so than individuals who did not feel pressured (p < 0.05).

Religion
Individuals for whom religion did not play a major role were more likely to indicate that they would now donate if given the opportunity (p < 0.01).

Donation rates were higher for individuals for whom belief in life after death did not pose a problem for donation (p < 0.01).

Individuals who attended religious services frequently were less likely to have donated and been satisfied (p < 0.05).
Reference: Burroughs, TE, Hong, BA, Kappel, DF, Freedman, BK The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosomatic Medicine* 1998; 60: 156-62.
<table>
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<tr>
<th>Study type</th>
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<tbody>
<tr>
<td>Study group: 815 approachable families</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The aim was to evaluate the success rates of convincing the relatives of the documented brain-dead organ donors who were suitable for donation of organs to consent for donation.</td>
<td>N/A</td>
<td>There were no significant changes in the rates of success of obtaining consent for donation in the male (41%) and female (27%) groups</td>
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</tbody>
</table>

**Study type:** Retrospective study (audit)

**Level of evidence:** (-)

**Study group:**

- **Control group:** N/A
- **Study period:** 1986 to 1994
- **Setting:** Saudi Arabia

**Inclusion/Exclusion (study group):** Not mentioned

**Characteristics of cases:**
- 689-males
- 126-females

**Baseline Measurements:** Not applicable.

**Additional comments:**

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<th>Study type</th>
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<tbody>
<tr>
<td>ID: 789</td>
<td>Study group: 435 potential organ donors monitored</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>The aim was to identify reasons given by family at bedside when a request for donation was refused.</td>
<td>N/A</td>
<td>Traditional cultural beliefs on keeping the body intact was the most common reason for refusal (54.2%)</td>
</tr>
<tr>
<td>Author: Yong et. al (2000)</td>
<td>Control group: N/A</td>
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<td>Characteristics of cases: Not mentioned</td>
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<td></td>
<td>12% expressed fear that donation would increase the sufferings of the patient.</td>
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<tr>
<td>Study type: Prospective study (survey)</td>
<td>Study period: 1996 to 1998</td>
<td>Setting: Hong Kong Hospital Authority Transplant Registry</td>
<td>Baseline Measurements: Not applicable.</td>
<td></td>
<td></td>
<td>Uncertainty about relatives’ wishes and patients’ objection to donation when alive accounted for 8%</td>
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<td>Level of evidence: (-)</td>
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<td></td>
<td>Emotional reluctance to accept death-5%</td>
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<td>Lack of family consensus and family being ‘upset’-3%</td>
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</table>

**Title:** Factors influencing families’ consent for donation of solid organs for transplantation.

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<tr>
<td><strong>ID:</strong> 387</td>
<td><strong>Author:</strong> Siminoff et al (2001)</td>
<td><strong>Study type:</strong> Retrospective study (chart review and interviews)</td>
<td><strong>Control group:</strong> N/A</td>
<td><strong>Study group:</strong> 420 cases 238 donors 182 non-donors</td>
<td><strong>Study period:</strong> Jan 1994 to Dec 1999</td>
<td><strong>Setting:</strong> 9 trauma hospitals, Southwestern Pennsylvania and Northeastern Ohio</td>
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</table>
donation (p- <0.001).

No association was found between the decision to donate and the hospital environmental variables or HCPs' sociodemographic characteristics and HCPs' attitude towards organ donation.

**Donation decisions and decision process variable.**

Families who believed that 1 or more HCPs involved in their relatives' care were not caring or concerned were somewhat less likely to donate (p- 0.04).

Families who were surprised to be asked about organ donation were less likely to donate than families who were not (p- <0.001).

Families who felt harassed or pressured to make a decision were also less likely to donate (p- 0.002).

HCPs correct assessment of a family's initial reaction to the issue of organ donation was strongly associated with the donation decision.

Families who were congruent with HCPs concerning the initial reaction to the donation request were more likely to donate (p- <0.001).

Rates of consent were not different when a physician, nurse, social worker, or OPO staff member made the initial request (p- 0.30).

However, when a hospital-based HCP
(but not a physician) broached the possibility of organ donation, followed by a meeting with an OPO staff person, the donation rate exceeded that of any other discussion pattern (p <0.001).

Talking to an OPO staff person before being asked to make a donation decision (p <0.001), and spending more time with an OPO staff person (p <0.001) were both factors strongly associated with donation.

A salient feature of consent would be a family understands that the patient was indeed dead.

Certain topics such as costs of donation, the impact of donation on funeral arrangements, disfigurement of the body and assurances that the family had a choice about which organs to donate correlated with organ donation decisions (p <0.001).

When HCPs told families they were required to ask about donation, families were less likely to donate (p < 0.002).

However, when HCPs mentioned that donation had the potential to help others, families were more likely to donate (p < 0.001).

Having more discussions about donation itself, discussing more topics of concern to the families, and having more questions answered were all associated with consent to donate (p < 0.001).
### Title: Donor Families' Attitude Toward Organ Donation.

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<tr>
<td>ID: 1558</td>
<td>Study group: 20 families</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>Characteristics of cases: Not mentioned</td>
<td>The aim of our study was to investigate the psychological mechanisms related to the family's decision to consent to organ donation. The research consisted of two parts: first, a preliminary survey was carried out on 20 families who had given their consent to organ removal from a relative deceased from 6 to 12 months previously. The second part of the research was carried out by means of a questionnaire which included different areas of interest, filled in by one of the doctors of the ICU medical staff at the end of the clinical event, either in case of a consent to donation or refusal.</td>
<td>N/A</td>
<td>Beyond the generally defined &quot;humanitarian&quot; reason for donation, there was a latent yet quite explicit longing to keep the deceased relative alive by identifying him or her with the patients into whom the organs were transplanted. Noticed an increase in consent to organ removal when the persistent beating of the heart was justified to the donors' relatives. Breathing movement induced by artificial ventilation, body temperature, and persistent heart beat are the main reasons for not accepting brain death as real death. Refusal rate is higher in families with a low socio-cultural level.</td>
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<tr>
<td>Author: La Spina et al (1993)</td>
<td>Study group: Control group: N/A</td>
<td>Study period: Not mentioned</td>
<td>Setting: Italy</td>
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<td>Study type: Retrospective study</td>
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<td>ID: 686</td>
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<td>N/A</td>
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<tr>
<td>Author: Pike et. al (1990)</td>
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<td>Study type: Retrospective study (audit)</td>
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<td>Level of evidence: (-)</td>
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**Study group:**
- 566 potential donors referred
- Control group: N/A
- Study period: Jan 1984 to Jun 1989
- Setting: Groote Schuur Hospital, Cape Town.

**Characteristics of cases:**
- 424 males
- 137 females
- Mean age: 28 years
- Baseline Measurements: Not mentioned

**Methods:**
To determine whether there were any factors that influenced families to give consent for organ donation.

This retrospective study examined the records of all cadaver donor referrals to the renal and cardiac transplant units.

Potential organ donors were identified and certified brain dead (irreversible loss of all brain function) by the doctor in charge of the patient. Once certified brain dead, the patient was immediately referred to the transplant coordinators attached to the renal and cardiac transplant units.

**Results:**

**Age of donor**
Families of donors aged < 10 years gave consent more frequently than those in all other age groups (P < 0.02). The largest group of donors were those between the ages of 21 years and 30 years. In this group consent was obtained in 78.5% of cases.

**Sex of donor**
The sex of the potential donor did not influence the decision of the family about organ donation.

**Race of donor**
Of the 127 white families approached, 91% gave consent. Of the 189 families of mixed race who were approached, 74% consented and 42% of the 50 black families who were approached for consent agreed.

These differences in consenting to organ donation were statistically significant when all the race groups were compared (p < 0.000002).

When consent from black families was compared with consent from both white and mixed families the differences remained statistically significant (p<0.0004).

**Cause of death**
| Additional comments: |  |  |  | There was no difference in the frequency of consent for organ donation between these groups. |

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<tbody>
<tr>
<td>Study group: 300 interviews</td>
<td>Study group: N/A</td>
<td>Inclusion/Exclusion(study group): Brain dead patients. Characteristics of cases: 200 males 100 females Baseline Measurements: Not mentioned</td>
<td>To assess the conditions under which relatives were informed, and to determine the criteria that would improve the rate of consent. After patient information had been obtained, a questionnaire was filled in by the doctor.</td>
<td>N/A</td>
<td>In two thirds of the cases the family had been informed when brain death occurred, before the information about organ and tissue donation. The shifts dwelled on the fact that the patients were dead (252 of 300 cases), with explanations about cerebral death in 230 cases. When the family was reticent, the rate of agreement was very low. The frequency of the refusals decreased with age, that is, 35% before 18, 28% between 19 and 50, and 13% after 50. Rates of agreement were not influenced by sex nor by the causes of cerebral death.</td>
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<td>Study group:</td>
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<td>Inclusion /Exclusion(study group):</td>
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<tr>
<td>Author: Brown et. al (2010)</td>
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<tr>
<td>Study type: Retrospective study</td>
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<td>ID: 1143</td>
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<td>The average time from declaration of brain death to approach by TOSA was 213 minutes ± 958 minutes.</td>
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<td>Study group: 827 potential organ donor referrals</td>
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<td>471 families consented to donation 356 declined donation</td>
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<td>Control group: N/A</td>
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<td>Consent rates were lower in the Hispanic (46%) and African American (33%) populations, than among Caucasian (75%) potential donors (p &lt; 0.001).</td>
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<td>Study period: 2004 to 2007</td>
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<td>The decline group more often had an approach initiated independently by a healthcare provider (15% vs. 8%, p - 0.001).</td>
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<td>Setting: USA</td>
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<td>Families approached at the time of or within 1 hour of brain death consented to organ donation in 61% of cases, but if approached &gt;3 hours after brain death consent rates dropped to 51% (p &lt; 0.001).</td>
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<td></td>
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<td>Characteristics of cases:</td>
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<td>Consen rates were significantly lower for medical (51%) patients than for trauma (67%&gt;) patients (p &lt; 0.001).</td>
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<td>Average age- 39±18 yrs 467 males</td>
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<td>Similarly, older patients (aged 50 years or older) had a lower consent rate than younger</td>
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<td>Baseline Measurements: Not mentioned</td>
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patients (51% vs. 61%, p = 0.006).

Potential donor characteristics independently predictive of failure to consent for organ donation include:

Medical brain death (OR - 1.6 (1.2-2.4), p - 0.005)
Ethnicity (OR - 5.4 (1.6-18.5), p - 0.007)
Independent member of the healthcare team approach (OR - 1.9 (1.2-3.2), p - 0.01) and
Aged 50 years or older (OR - 1.4 (1.0-2.0), p - 0.05).

Additional comments:

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<tr>
<td>Author: Siminoff et. al (2000)</td>
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<td>Study type: Prospective study</td>
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<tr>
<td>Study group:</td>
<td>827 potential organ donor referrals</td>
<td>N/A</td>
<td>Inclusion /Exclusion(study group): Not mentioned</td>
<td>The purpose of this study is to identify those factors that enhance or inhibit donation in a sample of 23 hospitals in two states. Each week, the medical charts of all patient deaths (both in-patient and emergency room) at each hospital were reviewed to determine eligibility for organ, tissue, or cornea donation. Interviews were conducted with HCPs, including physicians, nurses, and others (generally medical social workers and clergy), who either spoke with the family after the patient's death or discussed donation with the family.</td>
<td>N/A</td>
<td>Multiple logistic regressions demonstrated that the best and strongest predictor of consent or refusal to donate was the family's initial response to the donation request, as reported by the HCP. Those who expressed an initially favorable response to the donation request discussed more issues about donation than those who did not. The mean number of total discussion items was 10.55 for families who were initially favorable toward the donation request, 5.95 items for undecided families, and 5.63 items for families who were not favorably disposed to the request for donation (p&gt; 0.001). The process of procurement was explained to 19.9% of families who were favorable, but to only 3.0% of the undecided, and 1.9% of the unfavorable families. HCPs told 62.2 and 64.4% of the undecided and unfavorable families that they were required by law to ask about donation, but made this statement to only 49.8% of the families who responded favorably to the donation request. Undecided responses to the donation request were almost three times as likely to occur when HCPs told families they were required to ask about donation (OR = 2.71, p &lt; 0.002). More detailed information was provided to the favorable families as compared to the other two groups concerning the effect of donation on funeral arrangements and costs. Families were 6 times as likely to be undecided when funeral arrangements were not discussed and 4 times as likely to be undecided when no assurances were provided that the funeral wouldn't be delayed as a result of donating.</td>
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</table>
Patients of families who were initially opposed to donation were least likely to be cared for in a pediatric hospital. Lack of specificity when discussing donation was also associated with unfavorable responses to the donation request. For example, when the rules and procedures for the distribution of donated organs were not discussed, families were 11 times as likely to respond negatively to the request.

In addition, when requesters reported a general attitude of no confidence in the willingness of families to donate, their requests were more likely to evoke a response of indecision by the families (OR = 2.19, p<0.018).

Additional comments:

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<th>ID: 530</th>
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<tr>
<td>Author: Siminoff et al (2002)</td>
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<tr>
<td>Study type: Retrospective study (survey)</td>
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<tr>
<td>Study group: 420 individuals</td>
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<td>Control group: N/A</td>
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<td>Study period: 1994 to 1998</td>
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<tr>
<td>Setting: 9 trauma hospitals in southwest Pennsylvania and northeast Ohio</td>
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Inclusion/Exclusion (study group): Only patients 16 years of age or older were included. Failure to request organ donation excluded the family from the interview portion of this study.

Characteristics of cases: 59.44% male 85% white Mean age - 45.4 yrs (16-86) Baseline Measurements: Not mentioned

The purpose of this study was to examine in detail the impact of knowledge of a donor-eligible patient's preferences on organ donation decisions.

Data collection included identification of all possible organ donor-eligible patients on the basis of a detailed chart review of all deceased patients; audiotaped telephone interviews with all health care providers (HCPs) and OPOs who spoke with donor-eligible patients' families about organ donation. The most frequently stated reasons not to donate were concerns about disfigurement and burial issues (66.7%); Feeling too overwhelmed emotionally and surprise at being asked to donate (58.3%); The process taking too long — either declaration of brain death or procurement (50.0%); and a feeling that the patient had “been through enough” (50.0%). Less frequently stated concerns were as follows: Against donation or had a prior negative experience with donation or transplantation (33.3%); Not liking the HCPs/OPOs or the hospital (33.3%); The family made their own assessment about eligibility to donate and thought the patient was ineligible (25.0%); Not wanting the patient to remain on mechanical supports (25.0%); Concerns that donation would be too distressing for another family member. | N/A |
The following were significantly related to deciding to donate when adjusting for other factors:

- Patient being white ($p = 0.034$),
- Patient being younger ($p = 0.001$),
- Family respondent being older ($p = 0.047$),
- Family having a middle income level compared with a higher income level ($p = 0.045$),
- Family being Protestant compared with religions other than Catholic ($p = 0.035$),
- and family considering how the patient felt about donation ($/? < 0.001$).
- Families who knew the patient's wishes ($p = 0.001$).

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 1527</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Author:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Pearson et. al (1995)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Study type: Retrospective study (survey)</td>
<td>211 brain dead patients</td>
<td>163 questionnaires sent out</td>
<td>69 replied</td>
<td>32 donor families</td>
<td>21 non-donor families</td>
<td>32 donor families</td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Study period:</td>
<td>Jan 1987 to Oct 1990</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
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</tr>
<tr>
<td>Setting:</td>
<td>Westmead Hospital ICU, Australia</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
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</tbody>
</table>

This study was designed to attempt an examination of the experiences of a group of families of patients declared brain dead, including those becoming organ donors, those where donation was refused, and those not asked about donation.

The study protocol required that families be contacted first by telephone to introduce the study and to request consent before questionnaires were mailed.

The odds of being asked about organ donation peaked in the group 30-39 years, and those who spoke English were significantly more likely to be asked (P=0.016).

Females were significantly less likely to donate than males (p=0.019), donors were of caucasoid ethnic origin (p=0.049) and English speaking (p=0.007).

**The initial period: Illness and treatment plan**

63% regarded the information as sufficient, most (83.5%) felt that the information was understandable but 36% were also confused through insufficient information, the use of overly complex medical terminology, the suddenness and their distress.

Thirty-six would have liked methods such as X-rays, diagrams, models or pictures used to explain the patient's brain injury.

22 families admitted that they experienced some rudeness or unpleasantness from staff at some stage of the hospital care. Nurses were more likely to be officious and impatient, while doctors were judged as cold and callous.

**Explanation of brain death**

Twenty per cent of families felt that brain death was poorly explained.
For seven families their distress interfered with their ability to understand what they were being told, for five the terminology was too complex, six felt that the explanation was insufficient.

Fifty-five per cent would have liked diagrams and pictures, X-rays and written material to aid understanding.

**The decision to donate**

The decision to decline organ donation was in response to the patient's wishes, or because they did not want the patient to suffer any further disturbance.

**When organ donation was requested**

Of those asked, 14 respondents reported that they still had doubts about whether their relative "was really dead".

Of the total, 74.5% felt that they were given enough time to make a decision and 74% felt they were given enough information to make an informed choice.

Pressure by staff was felt by nine respondents (without affecting their rate of agreement). These nine however also felt they were given insufficient time or information.

**After brain death**

The majority 86% felt that they had been given enough time with the patient before organ retrieval or the removal of the ventilator, and that they had not been hurried to say their goodbyes (88%).
Since the death
Of those agreeing to organ donation, 84% believed that organ donation had been helpful to the grieving process, principally because of the sense of having helped another person (14) or because they believed that their relative would have liked to have helped another (5), or that death was not just a waste (5).

Additional comments:

Title: Organ donation and family decision-making within the Spanish donation system.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
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<td>ID: 577</td>
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<tr>
<td>Author: Martinez et. al (2001)</td>
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<tr>
<td>Study type: Retrospective study</td>
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<tr>
<td>Level of evidence: (-)</td>
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</tbody>
</table>

- **Study group:** 68 cases
- **Control group:** N/A
- **Study period:** May 1994 to May 1995
- **Setting:** 13 Spanish hospitals

**Methods:**

- This study analyses the variables associated with the decisions made by families of potential organ donors to give or deny consent for the extraction of organs.
- Interviews and questionnaires were used.

**Reference standard:** N/A

**Reasons for refusal to consent for donation by families**

- Deceased's opposition to donation in life (n=6),
- Ignorance of the deceased's wishes about donation (n=5),
- Problems with appearance/integrity of deceased's body (n=5),
- Family disagreement in relation to donation (n=4),
- Doubts about relative's death (n=2),
- Complaints about medical attention (n=2),
- Social resentment (n=2),
- Absence of main decision-makers (n=1),
- Lack of respect for deceased by hospital staff (n=1),
- Religious problems (n=1),
- Desire to take deceased's body home (n=),
- Distrust of organ destination (n=1), and
- Complaints about personal treatment in the hospital (n=1).

**Opinions of transplant coordinators**

- The position of the family on donation maintains an important relation to the deceased's expressed wishes, and the deceased's wishes were more frequently respected when he/she had favored donation.
- There was a stronger tendency for the process to end in refusal when the deceased was a woman.
- Families that maintained "good relations" among their members tended to agree to donation whilst families that maintained relations perceived as "regular or poor" were disproportionately represented among the refusals.
- The data also reveal a tendency towards a greater presence of "close relatives and other people" (distant relatives, friends, etc.) in interviews resulting in concession of permission. Consent to donate was obtained in all of the consent interviews in which 3-6
people participated, whilst the presence of "two people" tended to be linked statistically much more often to refusal to donate.

In turn, families that expressed dissatisfaction with the medical attention received or gave no opinion on it showed a greater tendency to decline the coordinator's request; the same occurred with those families that complained about the personal treatment received, or gave no opinion on it. In contrast, those families that expressly manifested their satisfaction with these aspects tended to agree to donation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
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<th>Results</th>
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</thead>
<tbody>
<tr>
<td>ID: 1398</td>
<td>Study group: 269 interviews 248 valid reports 21 incomplete interviews</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>To evaluate the guidelines followed by the transplant coordinators during family interviews.</td>
<td>N/A</td>
<td>Notable differences in the latter two groups (refusal or indecision) included the low cultural level of the family, as perceived by the interviewers; The absence of the main decision-making members of the family (usually parents or spouse) during the first interview; And the attendance of a greater number of people at the interview.</td>
</tr>
<tr>
<td>Author: Frutos et. al (2002)</td>
<td>Control group: N/A</td>
<td>Study group: Jan 1995 to Dec 2000</td>
<td>Not mentioned</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Baseline Measurements: Not mentioned</td>
<td>Among the 146 initial interviews that authorized donation (group A), all except one resulted in donation, as one family changed their mind prior to organ retrieval. Of the 64 families who initially refused (group B), 13 (20%) changed their minds about donation, And among the 38 who were initially unsure (group C) 25 (65%) finally did authorize organ recovery.</td>
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<tr>
<td>Study type: Retrospective study</td>
<td>Setting: Spain</td>
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<td>Level of evidence: (-)</td>
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</table>

Additional comments:

### Title: Factors affecting cadaveric organ donation: A national survey of organ procurement coordinators.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
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<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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<tbody>
<tr>
<td>ID: 1725</td>
<td>Study group: 210 questionnaires mailed</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group):</td>
<td>The overall purpose of the present study was to conduct a national study of OPCs (organ procurement coordinators) in order to begin to validate on a large scale factors that affect families’ decisions regarding organ donation. A 21-item questionnaire was used as the data collection instrument.</td>
<td>N/A</td>
<td>Reasons for donations as perceived by the OPCs</td>
</tr>
<tr>
<td></td>
<td>Control group: N/A</td>
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<td>Subject selection criteria were as follows:</td>
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<tr>
<td></td>
<td>Study period: Not mentioned</td>
<td></td>
<td>(a) The individual was currently employed as an OPC in the United States as of December 1991</td>
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<td></td>
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<tr>
<td></td>
<td>Setting: USA</td>
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<td>(b) The OPC was a member of the North American Transplant Coordinators Organizations (NATCO), and</td>
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<td></td>
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<td>(c) The OPC was identified as being directly involved in organ donation requests in the NATCO directory.</td>
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<td>Characteristics of cases:</td>
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<td></td>
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<td></td>
<td>Not mentioned</td>
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<td></td>
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<td></td>
<td>Baseline Measurements:</td>
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<td></td>
<td></td>
<td></td>
<td>Not mentioned</td>
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<tr>
<td>Author: Douglas (1994)</td>
<td>Study type: Retrospective study</td>
<td></td>
<td>Level of evidence: (-)</td>
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<td></td>
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<td></td>
<td>Study period: Not mentioned</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Setting: USA</td>
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</tr>
</tbody>
</table>

### Study group:
- 210 questionnaires mailed
- 202 returned

### Control group:
- N/A

### Study period:
- Not mentioned.

### Setting:
- USA

### Inclusion/Exclusion (study group):
- Subject selection criteria were as follows:
  - (a) The individual was currently employed as an OPC in the United States as of December 1991
  - (b) The OPC was a member of the North American Transplant Coordinators Organizations (NATCO), and
  - (c) The OPC was identified as being directly involved in organ donation requests in the NATCO directory.

### Characteristics of cases:
- Not mentioned

### Baseline Measurements:
- Not mentioned

### Reasons for donations as perceived by the OPCs:
- The two most common reasons for donating given by families were:
  - (a) The family felt that the brain-dead relative would have wanted his/her organs donated (known preference) and
  - (b) The family felt that something positive would come from their loss.
- The next most common reasons reported by OPCs were:
  - (c) The family member would somehow live on, and
  - (d) Donating was seen as a good thing to do.

### Reasons for non-donations as perceived by the OPCs:
- OPCs reported that in their experience, the most common reason for not donating given by families was that families did not know if the donor would have wanted his/her organs to be donated.
- Other reasons reported by OPCs were:
  - (a) Concern by family about disfigurement of the body after death
  - (b) The family had a negative experience with health care personnel
  - (c) Religious/spiritual reasons.
(d) Fear that less than adequate medical care would be given, and  
(e) Fear that organs would be removed prematurely.

**Most important factors that influenced families’ decisions regarding organ donation**

1. “Giving the family time to accept death prior to the discussion of organ donation.”  
2. “How the family was treated by health care personnel.”  
3. "Knowledge of the loved one’s wishes" was the most important factor.”

Suggestions by OPCs about what HCPs could do to facilitate the donation request experience

1. "Decouple the brain death and organ donation discussion.”
2. “Ongoing communication with family members throughout the donation process.”  
3. ‘Leave the donation requesting to OPCs.”
4. "Informed, positive, and caring person request donation.”  
5. "Involving the OPC early on in the process.”

**Additional comments:**

Title: Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/Incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study group: 183 families approached</td>
<td>N/A</td>
<td>Inclusion /Exclusion(study group):</td>
<td>Objectives of the current study were to examine the relation between consenting to a post-mortem organ donation procedure and subsequent process of grief in the bereaved.</td>
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<tr>
<td>No. consented to participate 5 families excluded</td>
<td>N/A</td>
<td>95 study sample 36 donated 23 refused donation 36 not asked for donation</td>
<td>The instrument used was an elaborate structured interview containing pre-coded answering categories as well as open questions.</td>
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<tr>
<td>Control group: N/A</td>
<td>N/A</td>
<td>Characteristics of cases:</td>
<td>3 groups were identified:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study period: Not mentioned.</td>
<td>N/A</td>
<td>Not mentioned</td>
<td>ODC- organ donation consent ODR-organ donation refusal NDR-no donation request</td>
<td></td>
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<tr>
<td>Setting: 27 hospitals, Netherlands</td>
<td>N/A</td>
<td>Baseline Measurements:</td>
<td>Information</td>
<td></td>
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</table>

In the ODC group, 75% stated they thought they received adequate knowledge of the concept of brain death.

Although, sometimes the bereaved claimed that essential information about brain death or the donation procedure was never given.

When asked, half of the bereaved stated they would have appreciated a presentation of visual material (e.g., the results of the EEG) to clarify the situation of the deceased.

**Breaking the news of death and donation request**

In almost half of the cases (48%) the pronouncement of death and donation request were made in the same session with the bereaved. In 19% of the cases, donation had even been discussed preceding the death. To 18% of the ODC bereaved, it was not clear that their loved one had died at the time of the request.

Of the ODR group, 24% were dissatisfied with the way in which the donation question was posed to them. Amongst consenters (ODC) this percentage was lower (10%).

In a small minority of cases the bereaved experienced a disturbing lack of privacy at the time of death, as well as the request and decision to donate organs.
Care and well being

The subject of dissatisfaction was commonly a lack of attention or room for the bereaved family, and an impersonal, casual, or business-like approach.

Experiences with Hospital Staff: Some Problem Areas

In many cases, the bereaved reported they had not understood what was happening. They often had not had the courage to ask again for clearer info.

The use of unfamiliar technical medical terms was repeatedly mentioned.

Some bereaved also reported that the flow of information stopped as soon as they had given their response to the request: they felt superfluous and ignored afterward.

The desire to be informed about the results of the transplanted organs was strong in almost all bereaved.

Most bereaved judged medical staff to be quite friendly and benevolent. At the same time, it was clear that a number of physicians lacked time, basic social skills, and willingness to deal with the situation of the bereaved family members. The care by the nursing staff was often evaluated to be warmer and supportive.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
</table>
| ID: 115    | Study group: 26 relatives who declined donation  
Control group: N/A | N/A | Inclusion/Exclusion(study group): Not mentioned | Characteristics of cases: Age 26-75 years  
Baseline Measurements: Not mentioned | The aim was to explore the reasons family members declined organ donation. Face-to-face or telephone interviews were arranged. | N/A | 6 main themes that contributed to decision making about donation were identified |
| Author: Sque et al (2007) | Study type: Retrospective cross sectional qualitative study | | | | | |
| Level of evidence: (-) | Setting: 4 ICUs, UK | | | | | |

Additional comments:

**Title: Identification of variables that influence brain-dead donors’ family groups regarding refusal.**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 20</td>
<td>Study group: 186 family interviews</td>
<td>N/A</td>
<td>Inclusion / Exclusion (study group): Not mentioned</td>
<td>The aim was to identify the variables that influenced brain-dead donor family groups to refuse donation. A tool was designed to register all phases of family interview.</td>
<td>N/A</td>
<td><strong>Strategies used by transplant coordinators were:</strong></td>
</tr>
</tbody>
</table>
| Author: Sotillo et. al (2009) | Control group: N/A | | Characteristics of cases: Average age-27 years 71.11% male | | | - Setting a place for the interview  
- Asking open-ended questions  
- Listen actively  
- Identification of family grief  
- Reflexive answers  
- Donation as a way to improve the spiritual value of the dead donor  
- Donation as a loving act for others  
- Donation as a significant act of life |
| Study type: Retrospective descriptive study | Study period: 2007 | | Baseline Measurements: Not mentioned | | | **Reasons for denials from families include:** |
| Level of evidence: (-) | Setting: Venezuela | | | | | - Absolute denial  
- Family disagreement  
- Uncertainty about the destination of donated organs  
- Fears about deformation of the donor’s body  
- No acceptance of brain death |

**Additional comments:**

## Title: Obtaining consent for organ donation in 9 NSW metropolitan hospitals.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
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<td>ID: 138</td>
<td>N/A</td>
<td>N/A</td>
<td>Inclusion /Exclusion(study group):</td>
<td>N/A</td>
<td></td>
<td>Reasons for non-donation</td>
</tr>
<tr>
<td>Author: Chapman et. al (1995)</td>
<td>Study group: 177 potential donors 126 diagnosed as brain dead 112 considered for donation</td>
<td></td>
<td>Not mentioned</td>
<td></td>
<td></td>
<td>• Families gave no reason for refusal in about half of the cases</td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
<td>Control group: N/A</td>
<td></td>
<td>Characteristics of cases:</td>
<td></td>
<td></td>
<td>• Religious and cultural views</td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td>Study period: Apr 1991 to Mar 1992</td>
<td></td>
<td>Not mentioned</td>
<td></td>
<td></td>
<td>• Prevent mutilation of the body</td>
</tr>
<tr>
<td></td>
<td>Setting: 9 hospitals, NSW, Sydney</td>
<td></td>
<td>Baseline Measurements:</td>
<td></td>
<td></td>
<td>• Patients' wishes prior to death</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Not mentioned</td>
<td></td>
<td></td>
<td>• Refusal by one individual in a family group</td>
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</table>

### Additional comments:

**Title: The timing factor in the consent process.**

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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<tbody>
<tr>
<td>ID: 526</td>
<td></td>
<td>N/A</td>
<td>N/A</td>
<td>The aims were to examine who was initiating the topic of donation and the consent, view 'decoupling' and its effects, and identify when families were being asked for donation and the effects of timing on the consent rate. A data collection questionnaire, developed by OPO coordinators, was completed by one of three OPO coordinators receiving referral.</td>
<td>N/A</td>
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<tr>
<td>Author: Niles et. al (1996)</td>
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<tr>
<td>Study type: Retrospective study</td>
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<td>Level of evidence: (-)</td>
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<tr>
<td>Study group: 203 referrals 127 cases were suitable for family approach for consent</td>
<td>N/A</td>
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<tr>
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<tr>
<td>Study period: Jan 1994 to Nov 1995</td>
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<td>Setting: Dayton Regional Office, Ohio</td>
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<tr>
<td>Inclusion/Exclusion/study group:</td>
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<tr>
<td>Characteristics of cases:</td>
<td></td>
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<tr>
<td>Not mentioned</td>
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<tr>
<td>Baseline Measurements:</td>
<td></td>
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</tr>
<tr>
<td>Not mentioned</td>
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</tr>
</tbody>
</table>

**Table: Consent by request or role**

<table>
<thead>
<tr>
<th>Requestor</th>
<th>Requests</th>
<th>Consent obtained</th>
<th>Consent rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>82</td>
<td>40</td>
<td>49</td>
</tr>
<tr>
<td>Nurse</td>
<td>23</td>
<td>12</td>
<td>52</td>
</tr>
<tr>
<td>OPO coordinator</td>
<td>5</td>
<td>2</td>
<td>40</td>
</tr>
<tr>
<td>Family initiated</td>
<td>17</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>127</strong></td>
<td><strong>71</strong></td>
<td><strong>56</strong></td>
</tr>
</tbody>
</table>

Physicians asked 82 families and obtained 40 consents.

Nurses made 23 requests and acquired 12 consents.

OPO coordinators requested donation on 5 occasions and obtained 2 consents.

The family initiated discussion in 17 of the consents acquired.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 97</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Author: Siminoff et al (2002)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study group:</td>
<td>11 560 medical records of deceased</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The purpose of this study was to define what decoupling was and provide data from a large national study that examines a variety of factors to determine the value of decoupling.</td>
<td>The family has stronger pro-donation attitudes (p≤0.0001), and</td>
<td>There was a greater likelihood of the family donating if the patient was younger (p≤0.05)</td>
<td></td>
</tr>
<tr>
<td>Control group:</td>
<td>N/A</td>
<td>Characteristics of cases: Not mentioned</td>
<td>In-depth interviews were conducted with family members, healthcare professional and OPO staff involved in the process.</td>
<td>The family felt they had enough information about the patient’s wishes (p≤0.0001).</td>
<td>Donations was also associated with agreement between the healthcare professional and the family about the initial reaction regarding donation (p&lt;0.01)</td>
<td></td>
</tr>
<tr>
<td>Study period:</td>
<td>Jan 1994 to Dec 1999</td>
<td>Baseline Measurements: Not mentioned</td>
<td>An increased likelihood of donation was also associated with equating the patient’s death with brain death compared with family respondents who considered the patient dead only when the heart stopped beating.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting:</td>
<td>9 trauma hospitals, Southwest Pennsylvania and Northeast Ohio.</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Title: Donor families’ experience of organ donation.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study type</strong></td>
</tr>
<tr>
<td>ID: 97</td>
</tr>
<tr>
<td>Author: Douglass et. al (1995)</td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Study period: Jan 1991 to Dec 1992</td>
</tr>
<tr>
<td>Setting: Queensland, Australia</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Additional comments:**

### Study Group

**Study group:**
- 152 households
- 97 donors
- 55 non-donors

**Control group:**
- N/A

**Study period:**
- Jan 1990 to Jun 1992

**Setting:**
- USA

### Patient Characteristics

**Characteristics of cases:**
- Not mentioned

**Baseline Measurements:**
- Not applicable.

### Methods

**The purpose was to improve understandings of why parents do or do not consent to donate their child’s organs.**

**It was a survey by mailed questionnaire and no family was contacted until at least 9 months after the child’s death.**

### Reference Standard

N/A

### Results

**Opinions and general knowledge about organ transplantation**

Non donors were somewhat less likely to believe that doctors who determine brain death were not participants in the donation process (64% vs. 87%, $p = 0.056$).

**Parents’ perceptions about the hospital experience**

<table>
<thead>
<tr>
<th>Parents agreeing with statement</th>
<th>Donors (n=64) No. (%)</th>
<th>Non-Donors (n=14) No. (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was not happy with my child’s medical treatment</td>
<td>17 (27)</td>
<td>4 (29)</td>
<td>1.000</td>
</tr>
<tr>
<td>I knew enough about what was going on with my child</td>
<td>35 (55)</td>
<td>8 (62)</td>
<td>0.764</td>
</tr>
<tr>
<td>I felt supported by the hospital staff</td>
<td>48 (76)</td>
<td>11 (79)</td>
<td>1.000</td>
</tr>
<tr>
<td>The hospital did not let me spend enough time with my child</td>
<td>10 (16)</td>
<td>3 (21)</td>
<td>0.697</td>
</tr>
</tbody>
</table>

There was no statistical difference between donors and non-donor parents in their perception about in-hospital experience surrounding their child’s critical illness and death.

**The consent process**

Non-donor parents were significantly more dissatisfied with the consent process (50% vs. 8%, $p = 0.002$).

One parent said: ‘the doctor was so angry when I said no that I wondered if he or the hospital were going to make money...’
from my son’s organs-like he had already sold them or something.’

Non-donor parents were also significantly less likely to feel they had been given enough information to make an informed decision about organ donation (57% vs. 87%, p < 0.023)

Non-donor parents were somewhat less likely to feel the time they were asked about organ donation was the best time (50% vs. 77%, p < 0.057).

Parents’ reasons for not donating their child’s organs

The most prevalent reasons mentioned by non-donor parents were:

My child had already been through enough (79%)
I don’t like the idea of my child being cut for organs (71%)
Organ donation was too upsetting at the time to think about (62%).

Parents’ reasons for donating their child’s organs

Donor parents reasons for donating were:

Donating organs helps other children live (85%)
If I or someone in my family needed a transplant, I would want someone to donate organs for us (90%)
Donating organs is the right thing to do (89%)
Donating organs makes me feel like part of my child is still living (70%)

Key results from telephone interview

Half of the undecided non-donor parents chose not to donate due to their perception of insensitivity, either on the part of the hospital staff involved in their child’s care or during the request for organ donation. The following statements were made:
'I am generally in favor of organ donation…but the staff changed my mind because of the way it was handled…all the doctor wanted to do was unplug my child'

'If we had been handled differently, we probably would have said yes…but the doctor was so cruel.'

'My child had wanted to donate. We talked about it as a family. It was definitely the way it was handled…they were circling over his body like a bunch of vultures.'

On the other side, the undecided donor parents specifically stated that their interactions with hospital personnel or the transplant coordinator positively influenced their decision to donate.

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 288</td>
<td>Study group: 250 deaths / 63 declared brain dead</td>
<td>N/A</td>
<td>Inclusion /Exclusion(study group): Not mentioned</td>
<td>To evaluate whether the odds of being approached for and obtaining consent to pediatric organ donation differed among Hispanic/Caucasian (H/C) and non-Hispanic/Caucasian (NH/C). H/C refers to people who have a Spanish background, including people from Central and South America and people from Spanish-speaking Caribbean countries. NH/C refers to all those who are not African American, Asian, Native American Indian, Middle Easterners, pacific Islanders, or those included in the description of H/C above.</td>
<td>N/A</td>
<td>100% of H/C families (n=22) were approached for organ donation 85% of NH/C families (n=41) were approached (p ≤0.08) 55% of NH/C consented to organ donation 27% of H/C families consented (p ≤0.03) The estimated odds ratio that an H/C family would consent was 0.31 compared to NH/C family (p ≤0.033)</td>
</tr>
<tr>
<td>Author: Pietz et al (2004)</td>
<td>Control group: N/A</td>
<td>Study period: 1990 to 1999</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Baseline Measurements: Not applicable.</td>
<td>Reference standard</td>
<td>N/A</td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
<td>Setting: 3 hospitals in San Antonio, Texas</td>
<td>No/</td>
<td></td>
<td></td>
<td>Additional comments:</td>
<td></td>
</tr>
</tbody>
</table>

Title: Parental Willingness To Donate the Organs of a Child.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 776</td>
<td>Study group: N/A</td>
<td>Inclusion/Exclusion(study group):</td>
<td>Not mentioned</td>
<td>The purpose of this study was to survey a randomly selected sample of adults in a large southeastern state to determine their attitudes toward organ donation for themselves, a spouse, if they were married, or a child, if they were parents. In the case of unwillingness to consent to organ donation of a child, the reasons were explored.</td>
<td>N/A</td>
<td>Table 1: Reasons for refusal of child organ donation</td>
</tr>
<tr>
<td>Author: Frauman et. al (1987)</td>
<td>Study group: N/A</td>
<td>Characteristics of cases:</td>
<td></td>
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</tr>
<tr>
<td>Study type: Retrospective study (survey)</td>
<td>Control group: N/A</td>
<td>Mean age: 47 years (19-91) 81%-white 18%-minority groups (blacks and native Americans)</td>
<td>Baseline Measurements: Not mentioned</td>
<td></td>
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<tr>
<td>Level of evidence: (-)</td>
<td>Study period: 1986</td>
<td></td>
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<tr>
<td>Setting: University of North Carolina</td>
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</tbody>
</table>

Additional comments:

| | Agreed with reason |
| | n (%) |
| Idea bothers me | 106 (74) |
| Body mutilation | 87 (61) |
| Might interfere with survival | 46 (32) |
| Don't understand the procedure | 46 (32) |
| Against religion | 33 (23) |

The reason most frequently agreed with was "the whole idea bothers me" (74%) followed by the reason "body mutilation" (62%).

A significantly (p < .05) higher percentage of minorities (36%) as compared to whites (17%) gave as their reason for refusal that organ donation was against their religious beliefs and that they were concerned that organ donation might interfere with survival (57% of minorities as compared with 33% of whites).

Significant relationships were found with income (p < .0001), gender (p<.04), and education (p<.002).
Reference: Frauman, AC, Miles, MS Parental willingness to donate the organs of a child. Anna Journal 1987; 14: 401-4.

Title: The decision-making process of parents regarding organ donation of their brain dead child: A Greek study.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 959</td>
<td>Study group:</td>
<td>29 Families of</td>
<td>N/A</td>
<td>N/A</td>
<td>The decision-making process with regard to organ donation</td>
<td></td>
</tr>
<tr>
<td>Author: Bellali et al (2006)</td>
<td>22 consented</td>
<td>children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td>(11 consents and 11 refusals)</td>
<td>9 declined participation</td>
<td>Inclusion/Exclusion(study group):</td>
<td>Not mentioned</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td>Control group:</td>
<td>N/A</td>
<td>Characteristics of cases:</td>
<td>Not mentioned</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting:</td>
<td>Pediatric</td>
<td>N/A</td>
<td>Baseline Measurements:</td>
<td>Not mentioned</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive care</td>
<td>units (PICUs),</td>
<td>Study period: 1995</td>
<td></td>
<td></td>
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<tr>
<td>Greece.</td>
<td>to 2002.</td>
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</table>

The purpose of this study was to explore the decision-making process of parents who were invited to donate the organs and tissues of their brain dead child. Participants were interviewed.

The decision-making process with regard to organ donation

Even though the final decision was made at a spousal level, in most cases, the extended family played a significant role in the decision-making process.

Whenever parents held an open, honest and trustful relationship with the ICU personnel, they were more likely to accept the finality of the child's condition and consent to the donation.

Factors affecting the decision toward organ donation

Personal factors

Perceived finality of the child’s death- When a parent accepted the irreversibility of death he or she tended to consent and vice versa.

The meaning attributed, to the act of donation- Several donor parents were prompted by altruistic motives and their desire to help another child live and/or relieve the suffering of other parents.

Child’s presumed desire- Even though organ donation was not discussed in any family prior to the child's death, they argued that donation reflected the child's desire to help other people and/or was in agreement with his or her personality.

Fear of mutilation or disrespect towards the child’s body.
Conditions of organ request

The large majority of donor and non-donor parents described in detail how physicians had informed them about the non-reversibility of the child’s condition and explained brain death to them. A few hours later the same physicians approached one or both parents and, in a private office, presented them with the option to donate the child’s organs.

Interestingly, before this formal request, quite often a member of the personnel approached a relative or family friend and informally suggested the possibility of organ donation, which was subsequently communicated to parents through their kin. This 'indirect approach' was welcomed by parents and seemed to have a positive effect upon their decision to donate the child's organs.

In fact, the time to reflect allowed them to feel more prepared to consider the physician's request for organ donation.

The relationship that parents developed with the ICU staff was important to their decision. When they were informed about the child's condition and shared an honest and trustful relationship, they were more likely to consent.

Some parents declined organ donation mostly because of the unsatisfactory relationship they held with health professionals, and the inappropriate manner by which they were informed and pressured to decide.

Prior knowledge and experience with regard to donation and illness

Parents were likely to decline if they had no prior knowledge about organ donation, and/or wanted to know personally the recipient.

When a child's brain death occurred after a long illness, parents were less likely to consent to organ donation because they felt they did not want to subject their child to ‘a new
ordeal', even though they were aware that he or she was not alive.

**Interpersonal factors**

A critical variable affecting the final decision was the process by which the decision was made among people who were involved in the process. All donor parents decided by consensus with their spouse to donate the organs.

### Reference

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 138</td>
<td>Study group: 22 families</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): The principal inclusion criterion was that the child met the medical criteria of suitability for donation at the time of death from any cause (accidental or non-accidental).</td>
<td>The aim of the study was to describe the challenges donor and non-donor parents encounter before, during, and after the organ donation decision, and to identify parents' needs and expectations from health care professionals. Parents were classified in two groups: Group A (donor parents) - 11 parents who consented to organ donation, and Group B (non-donor parents) 11 parents who refused both organ and tissue donation.</td>
<td>N/A</td>
<td>The pre-donation period</td>
</tr>
<tr>
<td>Author: Bellali et al (2007)</td>
<td>Control group: N/A</td>
<td>Study period: 1995 to 2002</td>
<td>Characteristics of cases: Not mentioned</td>
<td><strong>Personal challenges</strong>&lt;br&gt;&lt;br&gt;Personal challenges comprised the parent's ambivalence towards donation, which was affected by one's struggle to understand, assimilate, and accept the child's brain death. Both donor and non-donor parents had great difficulty to accept the finality of the child's death. Those who were ultimately unable to cognitively and emotionally accept the irreversibility of the child's condition, declined organ donation, since they hoped for a miracle until the very last moment. Another major difficulty was parents' reluctance to assume the responsibility to decide over somebody else's organs. Deciding on whether to donate all or few of the organs was another challenge for both donor and non-donor parents. The fear of body mutilation or disfigurement along with fantasies about a traumatic appearance following organ removal caused increased distress to some donor parents. Before they were able to decide, they requested detailed information and reassurance that the child's body would be respected by health care professionals during organ retrieval.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td>Setting: Pediatric intensive care units (PICUs), Greece.</td>
<td>Baseline Measurements: Not mentioned</td>
<td></td>
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<td></td>
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<tr>
<td>Level of evidence: (-)</td>
<td></td>
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</tbody>
</table>
Parents who lacked knowledge on the issue of organ donation or who were unaware of the church's position on the subject, experienced considerable difficulties throughout the decision making process.

**Conditions of organ request**

Parents, who felt that their hospitalised child was inappropriately cared for, declined organ donation.

Moreover, when the PICU staff did not facilitate parents' presence at the child's bedside, they experienced increased distress and were reluctant to accept the donation request.

Increased distress was also experienced by parents when staff members did not take the time to provide information about the child's condition, to discuss the odds of survival, and explain the concept of brain death.

The insensitive manner by which some parents were approached with the organ donation request, the limited information they received, and the pressure that was exercised upon them to reach a decision, contributed to their refusal.

**Interpersonal challenges**

The large majority of non-donor parents attributed their refusal to donate the child's organs to spousal disagreement, spousal unavailability (due to physical or mental condition), or to their reluctance to inform their mate about the option of organ donation.

**The post-donation period**
Many donor parents reported challenges after consenting to organ donation because they felt at a loss, unsupported, and with no guidance. No one ever told them if they had to stay at the hospital during organ retrieval, whether they would see their child after surgery, and how to handle burial procedures.

Some parents reported that everything happened so fast, that they did not have the opportunity or option to see their child and share their farewells following organ retrieval. This caused increased distress throughout the course of their bereavement.

Moreover, several donor parents were disappointed by the lack of information about the transplantation outcomes, the identity of the recipient, and the possibility of making contact with him or her.

Donor parents in particular, expressed resentment and anger at health care professionals who never expressed concern about their well-being during the period following the child's death. They felt that their act was not socially recognized, that they were quickly forgotten, and few even believed that they had been exploited.

### Title: Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief?

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 174</td>
<td>Study group: 22 families</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The purpose of this study was to investigate the grieving process of parents who were faced with the dilemma of donating organs and tissues of their underage brain dead child, and to explore the impact of their decision on their grief process. Parents were classified in two groups: Group A (donor parents) - 11 parents who consented to organ donation, and Group B (non-donor parents) 11 parents who refused both organ and tissue donation.</td>
<td>N/A</td>
<td>MEANING ATTRIBUTED TO THE ACT OF ORGAN DONATION</td>
</tr>
</tbody>
</table>

- The majority of donor parents believed that the donation eased their grief, but for different reasons.

  - Some felt relieved because they had helped another human being to live, whereas others were content that their child remained "alive" through the organ recipient.

  - The meaning they attributed to such "aliveness" affected their grief in positive or negative ways. Parents who referred to the child's aliveness or continued existence in symbolic terms were able to grieve over their loss.

  - Parents who lacked information about the transplantation outcomes experienced an unsettling and stress inducing effect throughout their grief. Some desperately sought information about the recipients' health condition in order to confirm the worthiness of the donation act.

Additional comments:

# Title: Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 20</td>
<td>Study group: 43 deaths 33 suitable for donation</td>
<td>N/A</td>
<td>Inclusion (Exclusion [study group]: Not mentioned</td>
<td>Characteristics of cases: Age of donors: 1 month to 18 years 27 boys 6 girls</td>
<td>Pediatric surgeons had a 17 of 22 (77%) success rate in obtaining consent for donation, whereas transplant surgeon had a 1 of 1, neurosurgeons a 1 of 3, adult trauma surgeons a 1 of 6, and pediatric intensivists a 0 of 1 success rate.</td>
<td></td>
</tr>
<tr>
<td>Author: Vane et. al (2001)</td>
<td>Study type: Retrospective study</td>
<td>Level of evidence: (-)</td>
<td>Study period: Jan 1993 to Aug 1999</td>
<td>Setting: USA</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

**Review Question 3:** When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?

**Title:** The timing factor in the consent process.

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<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Study group: 203 referrals 127 cases were suitable for family approach for consent</td>
<td>Control group: N/A</td>
<td>Inclusion /Exclusion(study group): Not mentioned</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Baseline Measurements: NA</td>
<td>The aims were to examine who was initiating the topic of donation and the consent, view ‘decoupling’ and its effects, and identify when families were being asked for donation and the effects of timing on the consent rate.</td>
<td>N/A</td>
<td>Before group (n=52)</td>
<td>32 (62%) families gave consent for donation.</td>
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<td>A data collection questionnaire, developed by OPO coordinators, was completed by one of three OPO coordinators receiving referral.</td>
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<td></td>
<td>Families who were approached for donation were divided in to 3 subcategories:</td>
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<td></td>
<td>1. Those who were approached for donation before death had occurred (‘before’-n= 52).</td>
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<td>2. Those who were asked for donation at the same time they were being told of the death (‘same’-n=12).</td>
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<td>3. Those families who were asked for donation after they had been told of the death (‘after’-n= 63).</td>
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</table>

**Additional comments:**

### Title: Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 20</td>
<td>N/A</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The purpose of this study was to ascertain a strategy for maximizing parental consent for organ donation in traumatically injured children suffering from brain death.</td>
<td>N/A</td>
<td>When time to initiation of brain death protocol was examined, success was obtained when a mean delay of 15.5 hours was respected vs. a mean delay of 7.0 hours when donation was requested but denied (p&lt;0.03)</td>
</tr>
<tr>
<td>Author: Vane et. al (2001)</td>
<td>Study group: 43 deaths 33 suitable for donation</td>
<td>Study group: N/A</td>
<td>Control group: N/A</td>
<td>Study period: Jan 1993 to Aug 1999</td>
<td>Setting: USA</td>
<td></td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
<td>Level of evidence: (-)</td>
<td>Characteristics of cases: Age of donors-1month to 18 years 27 boys 6 girls</td>
<td>Baseline Measurements: Not mentioned</td>
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</table>

<table>
<thead>
<tr>
<th>Study type</th>
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<th>Results</th>
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<tbody>
<tr>
<td><strong>ID: 97</strong></td>
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<tr>
<td><strong>Author:</strong> Siminoff et. al (2002)</td>
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<tr>
<td><strong>Study type:</strong> Retrospective study</td>
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<tr>
<td><strong>Level of evidence:</strong> (-)</td>
<td></td>
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<tr>
<td>Study group: 11 560 medical records of deceased</td>
<td>N/A</td>
<td>Inclusion</td>
<td>Not mentioned</td>
<td>The purpose of this study was to define what decoupling was and provide data from a large national study that examines a variety of factors to determine the value of decoupling.</td>
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<tr>
<td>Control group: N/A</td>
<td></td>
<td>Exclusion (study group):</td>
<td>Not mentioned</td>
<td>In-depth interviews were conducted with family members, healthcare professional and OPO staff involved in the process.</td>
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<tr>
<td>Study period: Jan 1994 to Dec 1999</td>
<td></td>
<td>Characteristics of cases:</td>
<td>Not mentioned</td>
<td>Families were most commonly asked about organ donation concurrent with their loved one’s death (40.9%) and had donation rates of 51.2%</td>
<td></td>
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<tr>
<td>Setting: 9 trauma hospitals, Southwest Pennsylvania and Northeast Ohio.</td>
<td></td>
<td>Baseline Measurements:</td>
<td>Not mentioned</td>
<td>Followed by before death (39.3%) with donation rates of 63%</td>
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<tr>
<td></td>
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<td>Followed by after death with donation rates of 56.6%</td>
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</tbody>
</table>

### Title: Increasing the availability of cadaveric organs for transplantation maximizing the consent rate.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 97</td>
<td>Study group: 212 BSD patient’s families</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned</td>
<td>The purpose of this study was to analyze the variables to determine what, if any, factor (timing) affected the consent rate and might be effectively managed to increase donation rates.</td>
<td>N/A</td>
<td>If the request for donation was made following notification of death as opposed to before or simultaneously with notification of death, the family was more likely to grant consent for donation. This trend appeared to hold true regardless of who made the request for donation.</td>
</tr>
<tr>
<td>Author: Cutler et. al (1993)</td>
<td>Control group: N/A</td>
<td>Study group: N/A</td>
<td>Study period: 1990 to 1991</td>
<td>Setting: USA</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Baseline Measurements: Not mentioned</td>
</tr>
<tr>
<td>Study type: Retrospective study</td>
<td>Level of evidence: (-)</td>
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</tbody>
</table>

# Title: A qualitative examination of the needs of families faced with the option of organ donation.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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<tbody>
<tr>
<td>ID: 234</td>
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<tr>
<td>Author: Jacoby et al (2005)</td>
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<tr>
<td>Study type: Qualitative study (interviews)</td>
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<td>Level of evidence: (-)</td>
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<td>Study group: 98 potential participants</td>
<td>50 donor family</td>
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<tr>
<td></td>
<td>48 non-donor family</td>
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<tr>
<td></td>
<td>33/50 refused in donor group</td>
<td>42/48 refused in non-donor group</td>
<td>11 finally participated from donor group</td>
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<td></td>
<td>5 from non donor group</td>
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<tr>
<td>Control group: N/A</td>
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<tr>
<td>Setting: 3 sites in New York</td>
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<tr>
<td>Inclusion/Exclusion (study group): Eligible legal next of kin who consented or refused donation of their loved one’s organs.</td>
<td>Baseline Measurements: Age range- 31-65 years (mean-43 yrs)</td>
<td>Not mentioned</td>
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<tr>
<td>The objective was to examine donor and non-donor family members’ perceived needs for support while in the hospital intensive care setting and to gain an in-depth understanding of specific support considerations on the basis of a theoretical framework.</td>
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<td>Timing of approach</td>
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<tr>
<td>The research questions were: 1. How do donor and non-donor families describe and interpret the communication and behaviors of people they interacted with during the donation process and how do these descriptions differ?</td>
<td>2. What can we learn from families’ accounts of their perceived need for support in relation to their donation decision and how do the 2 groups differ in this respect?</td>
<td>3. What are the implications for care and interventions that would effectively address families’ perceived needs for support?</td>
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<tr>
<td>Families in the non-donor group felt they had not been adequately prepared for the request for organ donation. They also felt they had not been clearly informed that their loved one was brain dead before being approached about organ donation. In contrast, donor families depicted the timing of the approach ‘as good as could have been’ and no one described problems with the manner of the approach by staff members.</td>
<td></td>
<td>Being given the time and opportunity to spend time with their loved one and to ‘say goodbye’ was a recurring theme among donor families.</td>
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</tbody>
</table>

**Reference:** Jacoby, LH, Breitkopf, CR, Pease, EA A qualitative examination of the needs of families faced with the option of organ donation. *DCCN - Dimensions of Critical Care Nursing* 2005; 24: 183-89.
<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td>ID: 290</td>
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<td></td>
<td></td>
<td>N/A</td>
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<tr>
<td>Author: Haddow (2004)</td>
<td></td>
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<td></td>
<td>N/A</td>
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<tr>
<td>Study type: Qualitative retrospective study</td>
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<td>N/A</td>
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<tr>
<td>Level of evidence: (-)</td>
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<td></td>
<td>N/A</td>
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</tbody>
</table>

**Study group:**
- Donor families-19
- Non-donor families-4

**Control group:**
- N/A

**Study period:**
- Not mentioned

**Setting:**
- Scotland

**Inclusion/Exclusion (study group):**
- Not mentioned

Characteristics of cases:
- Not mentioned

**Baseline Measurements:**
- Not mentioned

**The wider research objective was to conduct a sociological investigation into the experiences, attitudes, and belief systems of donor and non-donor families.**

Semi structured interviews over a 2-year period was conducted in. The interviews were conducted at a time and place that suited the respondents.

**The impact of time**

An important factor aiding understanding of the brain death diagnosis was said to be the availability of time.

For e.g.: A donor spouse claimed she was unaware her husband was dead when asked for her lack of objection to remove organs: "[I thought], 'Yes, I'll sign the kidney donation form and if anything happens, if he dies, they can have his kidneys." I didn't realize that it set the whole process in motion."

**Organ request**

Most respondents said that a consultant had made the request following the results of the brain-death tests, generally with some degree of privacy, although 1 donor family complained it was made in a public place.

Also, because transplant coordinators did not wear a uniform, donor families mentioned it was easier to speak to them.

**Additional comments:**
A warning regarding the bias nature of the sample toward donor families might be noted and that "saturation" was not reached with the non-donor families. Comparisons are therefore made with other research conducted in the area. Equally, given the scope of this paper, the discussion does not address why donor and non-donor families refused or agreed to donation.

<table>
<thead>
<tr>
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<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 199</td>
<td>Study group: 20 relatives (donors and non-donors) 25 physicians</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>The aim was to explore how relatives and physicians understood cases where organ donation had been requested and what factors were salient for the decision on donation.</td>
<td>N/A</td>
<td>Accepting or declining request</td>
</tr>
<tr>
<td>Author: Sanner et. al (2007)</td>
<td>Control group: N/A</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Relatives were mostly interviewed in their homes, but in some cases in our offices. Physicians were either interviewed by telephone or in their offices.</td>
<td>Donations</td>
<td>Not mentioned</td>
<td>An open interview method was chosen to allow informants to speak freely about their experiences, although predetermined issues were also covered.</td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td>Study period: Not mentioned</td>
<td>Baseline</td>
<td></td>
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<tr>
<td>Level of evidence: (-)</td>
<td>Setting: Sweden</td>
<td>Measurements: Not mentioned</td>
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</table>

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Prevalence/ incidence</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 959</td>
<td>Study group: 29 Families of children 22 consented (11 consents and 11 refusals) 9 declined participation</td>
<td>N/A</td>
<td>Inclusion/Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned</td>
<td>The purpose of this study was to explore the decision-making process of parents who were invited to donate the organs and tissues of their brain dead child. Participants were interviewed.</td>
<td>N/A</td>
<td>Factors affecting the decision toward organ donation</td>
</tr>
<tr>
<td>Author: Bellali et. al (2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Personal factors</td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>Perceived finality of the child's death- When a parent accepted the irreversibility of death he or she tended to consent and vice versa.</td>
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<td></td>
<td>The large majority of donor and non-donor parents described in detail how physicians had informed them about the non-reversibility of the child's condition and explained brain death to them. A few hours later the same physicians approached one or both parents and, in a private office, presented them with the option to donate the child's organs.</td>
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<td>Interestingly, before this formal request, quite often a member of the personnel approached a relative or family friend and informally suggested the possibility of organ donation, which was subsequently communicated to parents through their kin. This 'indirect approach' was welcomed by parents and seemed to have a positive effect upon their decision to donate the child's organs.</td>
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<td>In fact, the time to reflect allowed them to feel more prepared to consider the physician's request for organ donation.</td>
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</table>

Additional comments:

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
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<th>Patient characteristics</th>
<th>Methods</th>
<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 138</td>
<td>Study group: 22 families</td>
<td>N/A</td>
<td>Inclusion /Exclusion(study group):</td>
<td>The aim of the study was to describe the challenges donor and non-donor parents encounter before, during, and after the organ donation decision, and to identify parents’ needs and expectations from health care professionals.</td>
<td>N/A</td>
<td>The pre-donation period</td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td>Setting: Pediatric intensive care units (PICUs), Greece.</td>
<td></td>
<td>Characteristics of cases:</td>
<td>Personal challenges</td>
<td>Personal challenges comprised the parent's ambivalence towards donation, which was affected by one's struggle to understand, assimilate, and accept the child's brain death. Both donor and non-donor parents had great difficulty to accept the finality of the child's death.</td>
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<tr>
<td>Level of evidence: (-)</td>
<td></td>
<td></td>
<td>Not mentioned</td>
<td>Conditions of organ request</td>
<td>The insensitive manner by which some parents were approached with the organ donation request, the limited information they received, and the pressure that was exercised upon them to reach a decision, contributed to their refusal.</td>
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<tr>
<td></td>
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<td></td>
<td>Baseline Measurements:</td>
<td>Interpersonal challenges</td>
<td>The large majority of non-donor parents attributed their refusal to donate the child's organs to spousal disagreement, spousal unavailability (due to physical or mental condition), or to their reluctance to inform their mate about the option of organ donation.</td>
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<tr>
<td></td>
<td></td>
<td>Not mentioned</td>
<td></td>
<td>The post-donation period</td>
<td>Some parents reported that everything happened so fast, that they did not have</td>
<td></td>
</tr>
</tbody>
</table>
the opportunity or option to see their child and share their farewells following organ retrieval. This caused increased distress throughout the course of their bereavement.

**Additional comments:**

**Reference:** Bellali, T, Papazoglou, I, Papadatou, D Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive & Critical Care Nursing* 2007; **23**: 216-25.
### Title: Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief?

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
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<th>Reference standard</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 174</td>
<td>Study group: 22 families</td>
<td>N/A</td>
<td>Inclusion/Exclusion (study group): Not mentioned</td>
<td>The purpose of this study was to investigate the grieving process of parents who were faced with the dilemma of donating organs and tissues of their underage brain dead child, and to explore the impact of their decision on their grief process.Parents were classified in two groups: Group A (donor parents) - 11 parents who consented to organ donation, and Group B (non-donor parents) 11 parents who refused both organ and tissue donation.</td>
<td>N/A</td>
<td>MEANING ATTRIBUTED TO THE ACT OF ORGAN DONATION</td>
</tr>
<tr>
<td>Author: Bellali et. al (2007)</td>
<td>Control group: N/A</td>
<td>Study period: 1995 to 2002.</td>
<td>Characteristics of cases: Not mentioned</td>
<td>Parents were classified in two groups: Group A (donor parents) - 11 parents who consented to organ donation, and Group B (non-donor parents) 11 parents who refused both organ and tissue donation.</td>
<td>Study groups: N/A</td>
<td></td>
</tr>
<tr>
<td>Study type: Qualitative study</td>
<td>Setting: Pediatric intensive care units (PICUs), Greece.</td>
<td></td>
<td>Baseline Measurements: Not mentioned</td>
<td>The majority of donor parents believed that the donation eased their grief, but for different reasons. Some felt relieved because they had helped another human being to live, whereas others were content that their child remained &quot;alive&quot; through the organ recipient. The meaning they attributed to such &quot;aliveness&quot; affected their grief in positive or negative ways. Parents who referred to the child's aliveness or continued existence in symbolic terms were able to grieve over their loss. Parents who lacked information about the transplantation outcomes experienced an unsettling and stress inducing effect throughout their grief. Some desperately sought information about the recipients' health condition in order to confirm the worthiness of the donation act.</td>
<td>N/A</td>
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<tr>
<td>Level of evidence: (-)</td>
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**Additional comments:**

Review Question 4: How should the care pathway of deceased organ donation be coordinated to improve potential donors giving consent?

Title: Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 226</td>
<td>Setting: 20 non-donor hospitals in US</td>
<td>Non-donor hospitals: • &gt;100 beds, • regional or community centres, • had ICUs, operating rooms, staff neurologists and anaesthesiologist • community based providing services to local residents</td>
<td>Placement of in-house co-ordinators Establishment of routine notification Free telephone service In-service training Date: 1995-7</td>
<td>Pre-introduction practice Date: 1991-3</td>
<td>24 months</td>
<td>Results were:</td>
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<tr>
<td></td>
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<td>1991-3 1995-7 Increase (%)</td>
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<td></td>
<td>22 121 450</td>
</tr>
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<td>13 19 46</td>
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<td>2.67 10 275</td>
</tr>
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<td>3 5 67</td>
</tr>
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<td></td>
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<td></td>
<td>8.01 33 312</td>
</tr>
</tbody>
</table>

Additional comments: Limited number of data points. Complex intervention, so not able to attribute changes to single factor. Introduction into non-donor hospitals, so not able to estimated impact in hospitals with existing donor programmes.

## Title: Increasing organ recovery from level I trauma centers: The in-house coordinator intervention

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Patient Population/ Characteristics</th>
<th>Selection/Inclusion criteria</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Follow-up</th>
<th>Outcome and Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 284</td>
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</tr>
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<td>Level of evidence: ()</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Study type: Observational</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Authors: Shafer et al (2004)</td>
<td></td>
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</tr>
</tbody>
</table>

Results in the abstract are described as follows:

‘Comparison data were obtained on 83 level I trauma centers nationally. Data from 1999 to 2000 were compared with data from 2001 to 2002. Results - Despite demographic differences, the 8 centers with in-house coordinators had higher consent rates (60% vs 53%) and conversion rates (55% vs 45%) than centers without them. Conversion of potential to actual donors was 22% higher in centers with in-house coordinators than in centers without them. Donation rates were affected by donor age, ethnicity, previous family discussion of donation, the family’s initial reaction to the request (favorable, unfavorable, undecided), amount of time family spent with the in-house coordinator, presence of the in-house coordinator during explanation of brain death, whether the request was made at the same time as the brain-death explanation, and, in cases where donation was mentioned to the family before the formal request, who first mentioned donation to the family.’

However, methods were reported poorly and results not clear.

Overall, results were

<table>
<thead>
<tr>
<th></th>
<th>Centres with in-house co-ordinators (n=8)</th>
<th>Centres without in-house co-ordinators (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent rate (%)</td>
<td>60</td>
<td>53</td>
</tr>
<tr>
<td>Conversion rate (%)</td>
<td>55</td>
<td>48</td>
</tr>
</tbody>
</table>

**Additional comments:** Poorly reported study, with information from other published studies included? Also not possible to relate results in the abstract to those presented in the paper.

Title: Cadaveric organ donor recruitment at Los Angeles county hospital; improvement after formation of a structured clinical educational and administrative service.

<table>
<thead>
<tr>
<th>Study type</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID: 62</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study type: Observational study</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting: USA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of evidence: (-)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Study group: Not mentioned
Control group: N/A
Study period: 1996 to 2001

Inclusion/Exclusion (study group):
- Not mentioned

Characteristics of cases:
- Not mentioned

Baseline Measurements:
- NA

The aims were to examine who was initiating the topic of donation and the effect of a new approach had on organ donation.

Key components of the new approach/programme were:
1. A full time in-house transplant nurse coordinator from the local organ procurement organization (OPO) was stationed at LAC-UC. Functions of the coordinator included interacting and educating hospital personnel, coroner’s representatives, and approaching the families of potential donors.
2. The combined service strictly enforced this donation approach within the hospital.
3. Trauma and critical care services took the role of identifying, stabilizing and managing potential organ donors.
4. A resuscitation protocol was developed to provide standardized care for trauma patients with intracranial injuries in the pre-admission ward and in the ICU.
5. Biweekly multidisciplinary donor management conferences were instituted to review the management of every patient who suffered brain death to determine any deficiencies in administrative, clinical, or legal procedure that resulted in a failure of donation. Corrective actions were taken depending on the deficiencies identified.

Two phases were compared.
Phase I-1996 to 1998 where no institutional programme

Table 1: Comparison of organ donation between the 2 time periods

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Statistic</th>
<th>1996-98</th>
<th>1999-01</th>
<th>% change</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient referrals for organ donation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean per year ± SD</td>
<td></td>
<td>85 ± 9</td>
<td>124 ± 30</td>
<td>+46%</td>
<td>0.0495</td>
</tr>
<tr>
<td>Suitable donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean per year ± SD</td>
<td></td>
<td>52 ± 1</td>
<td>63 ± 10</td>
<td>+23%</td>
<td>0.1046</td>
</tr>
<tr>
<td>Actual donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean per year ± SD</td>
<td></td>
<td>15 ± 2</td>
<td>26 ± 5</td>
<td>+67%</td>
<td>0.0495</td>
</tr>
<tr>
<td>Actual organs donated</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean per year ± SD</td>
<td></td>
<td>52 ± 7</td>
<td>89 ± 24</td>
<td>+70%</td>
<td>0.0495</td>
</tr>
</tbody>
</table>

It is noteworthy that total hospital admissions declined slightly during the time period from phase I to phase II.

In a comparison of Phase I and Phase II, there was a 46% increase in referrals to the OPO, a mean of 86 vs. 124 per year (p<0.0495).

There was a significant increase in the mean number of actual donors (15/year vs. 26/year, p<0.0495) from phase I to phase II.
This difference was also noted in the mean number of organs donated (52/year vs. 89/year, \( p = 0.0495 \)).

The significant increases noted are to a greater level of awareness and coordination.

Additional comments:

Title: Improving organ donation in Central Saudi Arabia.

<table>
<thead>
<tr>
<th>Study type: Observational study</th>
<th>No. of people</th>
<th>Patient characteristics</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study group: Not mentioned</td>
<td>Inclusion/Exclusion/study group: Not mentioned</td>
<td>2 in-house coordinators were employed in order to facilitate the logistics of the organ donation pathway. Their work was supervised by a physician forming a donor action team, which helps to coordinate the effort in organ donation at all stages. Data were gathered between Oct 2003 to Dec 2003 (after employing 2 in-house coordinators) and these were compared to similar data collected from Jan 2003 until Sept 2003 (no in-house coordinators existed).</td>
<td>From Jan 2003 to Sept 2003 (no in-house coordinators existed), only 10 patients became actual donors which equates to 11% yield from total number reported to the Saudi Center for Organ Transplantation. While from Oct 2003 until end of Dec 2003, 6 patients became actual donors which equates to 32% yield from total number reported to the Saudi Center for Organ Transplantation.</td>
<td></td>
</tr>
<tr>
<td>Control group: N/A</td>
<td>Characteristics of cases: Not mentioned</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study period: Jan 2003 to Dec 2003</td>
<td>Baseline Measurements: NA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting: 3 hospitals in Riyadh, Saudi Arabia</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Additional comments:


Review question 5:

What key skills and competencies are important for healthcare professionals to improve the structures and processes for identifying potential DBD and DCD; to improve structures and processes for obtaining consent; and to effectively coordinate the care pathway from identification to obtaining consent?

As noted above, evidence from other questions was used to inform recommendations on skills and competencies needed. There are therefore no evidence tables for this question.
Appendix F List of excluded studies

Review question 1
Aaronson, KD, Schwartz, JS, Chen, TM, Wong, KL, Goin, JE, Mancini, DM
Ref ID: 247
**Reason for Exclusion:** looking at survival in ambulatory patients referred for cardiac transplant evaluation

Abbud-Filho, M, Ramalho, H, Pires, HS, Silveira, JA
Ref ID: 1522
**Reason for Exclusion:** surveyed population are not health care professionals

Al Sebayel, MI, Khalaf, H
Ref ID: 424
**Reason for Exclusion:** looking at attitudes towards organ donation

Al-Mousawi, M, Abdul-Razzak, M, Samhan, M
Ref ID: 575
**Reason for Exclusion:** considered for q5

Antommaria, AH, Bratton, SL
Ref ID: 161
**Reason for Exclusion:** considered for q5

Baines, LS, Joseph, JT, Jindal, RM
Ref ID: 550
**Reason for Exclusion:** looking at views on organ donation and how to promote it in the Asian community

Barber, K, Falvey, S, Hamilton, C, Collett, D, Rudge, C
Ref ID: 295
**Reason for Exclusion:** looks at why potential donors couldn’t end up as actual donors
Ref ID: 248
**Reason for Exclusion: not using clinical triggers or required referral to identify potential donors**

Ref ID: 1079
Reason for Exclusion: not a study

Ref ID: 112
Reason for Exclusion: considered for q5

Bledsoe, CM Factors influencing the decision of families to donate organs. jj 1994; -NaN.
Ref ID: 1726
Reason for Exclusion: BL can't find it

Ref ID: 356
Reason for Exclusion: considered for q5

Ref ID: 78
**Reason for Exclusion: looking at definitive diagnostic tests to confirm BSD**

Ref ID: 1143
Reason for Exclusion: considered for q2

Ref ID: 631
Reason for Exclusion: considered for q2
Ref ID: 1220
Reason for Exclusion: looking at using criteria to identify potential donors

Cherkassky, L Presumed consent in organ donation: is the duty finally upon us? European Journal of Health Law 2010; 17: 149-64.
Ref ID: 12
Reason for Exclusion: general background

Ref ID: 677
Reason for Exclusion: considered for q2

Ref ID: 317
Reason for Exclusion: not using clinical triggers or required referral in the study

Childress, JF The failure to give: reducing barriers to organ donation. Kennedy Institute of Ethics Journal 2001; 11: 1-16.
Ref ID: 558
Reason for Exclusion: general background

Ref ID: 1407
Reason for Exclusion: considered for q2

Ref ID: 1633
Reason for Exclusion: BL can't find it

Ref ID: 785
Reason for Exclusion: looking at organ retrieval rather than identification

Ref ID: 1000
Reason for Exclusion: not a study
Denny, DW Now more than ever, doctors must help in finding organ donors. Medical World News 1983; 24: 110.
Ref ID: 1031
Reason for Exclusion: not a study

Ref ID: 185
Reason for Exclusion: looking at using specific criteria to predict death within 60 minutes after withdrawal of life support

DeVita, MA, Snyder, JV Development of the University of Pittsburgh Medical Center policy for the care of terminally ill patients who may become organ donors after death following the removal of life support. Kennedy Institute of Ethics Journal 1993; 3: 131-43.
Ref ID: 297
Reason for Exclusion: description of services and not evaluation

Ref ID: 1437
Reason for Exclusion: general background

Ref ID: 313
Reason for Exclusion: survey of nurses but not on clinical triggers or care pathway

Ref ID: 1725
Reason for Exclusion: considered for q2

Ref ID: 93
Reason for Exclusion: looks at identification of potential donors after DCD


Ref ID: 640
Reason for Exclusion: doesn’t show how to increase donor identification

Ref ID: 1398
Reason for Exclusion: considered for q2

Ref ID: 1551
Reason for Exclusion: not a study

Ref ID: 713
Reason for Exclusion: not a study

Ref ID: 1349
Reason for Exclusion: looking at living donors which is not part of our population

Ref ID: 1543
Reason for Exclusion: not a study

Ref ID: 256
Reason for Exclusion: not using clinical triggers or required referral in the study

Gronda, EG, Barbieri, P, Frigerio, M, Mangiavacchi, M, Oliva, F, Quaini, E, Andreuzzi, B, Garascia, A, De, VC, Pellegrini, A Prognostic indices in heart transplant candidates after the first hospitalization triggered by the need for intravenous pharmacologic circulatory support. Journal of Heart & Lung Transplantation 1999; 18: 654-63.
Ref ID: 208
Reason for Exclusion: looking at interventions to improve outcomes in patients with endstage heart failure

Ref ID: 22

**Reason for Exclusion:** not looking at clinical triggers but rather change in processes to increase identification


Ref ID: 200

**Reason for Exclusion:** letter to editor


Ref ID: 259

**Reason for Exclusion:** not looking at clinical triggers and no baseline comparison


Ref ID: 236

**Reason for Exclusion:** looking at benefits of educating staff to increase identification


Ref ID: 1507

**Reason for Exclusion:** for q2


Ref ID: 541

**Reason for Exclusion:** looking at attitudes of the public towards organ donation


Ref ID: 324

**Reason for Exclusion:** not using clinical triggers or required referral in the study

Ref ID: 50
**Reason for Exclusion: BL can't find it**

Koenig, BA Dead donors and the "shortage" of human organs: are we missing the point? American Journal of Bioethics 2003; 3: 26-27.
Ref ID: 500
Reason for Exclusion: not a study

Ref ID: 755
Reason for Exclusion: not a study

Ref ID: 986
Reason for Exclusion: describes the process of organ donation

Ref ID: 35
**Reason for Exclusion: general background**

Ref ID: 1558
Reason for Exclusion: considered for q2

Ref ID: 1058
Reason for Exclusion: general background

Leslie, GD The "Spanish Model"--an initiative aimed at increasing organ donation rates in Australia. Australian Critical Care 1995; 8: 33-34.
Ref ID: 266
**Reason for Exclusion: general background**

Ref ID: 927
Reason for Exclusion: looks at organ procurement rather than identification

[Care pathway: co-ordination]
Ref ID: 577
Reason for Exclusion: considered for q2

Ref ID: 148
Reason for Exclusion: looking at implementing better processes to improve identification

Ref ID: 1715
Reason for Exclusion: considered for q5

Ref ID: 263
Reason for Exclusion: not using clinical triggers or required referral in the study

Ref ID: 1244
Reason for Exclusion: letter to editor

Ref ID: 879
Reason for Exclusion: general background

Ref ID: 1527
Reason for Exclusion: considered for q2

Ref ID: 334
Reason for Exclusion: not a study

Quaghebeur, B, van, GF, Roels, L, Daenen, W, van den Berghe, G Potential for Hb and nHb organ donation: a retrospective medical record review on 7 critical care units in a 1900 bed hospital. CONNECT: The World of Critical


Ref ID: 1150
Reason for Exclusion: considered for q2

Ref ID: 14
Reason for Exclusion: duplicate

Ref ID: 961
Reason for Exclusion: not a study

Ref ID: 170
Reason for Exclusion: looking at identifying potential donors using counselling and education services

Ref ID: 229
Reason for Exclusion: looking at liking organ donation failure and a national programme

Ref ID: 111
Reason for Exclusion: not a study

Ref ID: 340
Reason for Exclusion: looking at using specific criteria to identify donors for kidney transplantation

Ref ID: 132
Reason for Exclusion: looking at implementing better management of potential donors to increase donation rather than clinical triggers
Ref ID: 199
Reason for Exclusion: considered for q2

Ref ID: 243
Reason for Exclusion: a report on a paper

Ref ID: 209
Reason for Exclusion: comment on another study

Ref ID: 775
Reason for Exclusion: general background

Ref ID: 262
Reason for Exclusion: background

Ref ID: 277
Reason for Exclusion: not using clinical triggers or required referral in the study

Ref ID: 1452
Reason for Exclusion: considered for q2

Ref ID: 530
Reason for Exclusion: considered for q2
Ref ID: 29
**Reason for Exclusion: looking at barriers to organ donation**

Ref ID: 712
Reason for Exclusion: considered for q5

Ref ID: 266
Reason for Exclusion: looks at time interval for retrieval of organs

Ref ID: 1582
Reason for Exclusion: general background

Ref ID: 419
Reason for Exclusion: general background

Ref ID: 1239
Reason for Exclusion: duplicate

Sullivan, H, Blakely, D, Davis, K An in-house coordinator program to increase organ donation in public teaching hospitals. *Journal of Transplant Coordination* 1998; **8**: 40-42.
Ref ID: 232
**Reason for Exclusion: BL can't find it**

Ref ID: 164
**Reason for Exclusion: a report**

Ref ID: 109
Reason for Exclusion: not using clinical triggers or required referral in the study

Ref ID: 1185
Reason for Exclusion: expert comment on a study

Ref ID: 904
Reason for Exclusion: looking at viability of transplantable organs from different sources

Ref ID: 874
Reason for Exclusion: studying time intervals between retrieval and identification of organs

Wight, C Two initiatives designed to maximize the potential for organ donation from intensive care units. Annals of Transplantation 1998; 3: 13-17.
Ref ID: 672
Reason for Exclusion: considered for q5

Ref ID: 686
Reason for Exclusion: considered for q5

Ref ID: 506
Reason for Exclusion: not a study

Review question 2

Ref ID: 182
Reason for Exclusion: not a study

Brain death cases reported, medically documented, families approached, consented for donation and harvested from different hospitals in Saudi Arabia in 2006. Saudi Journal of Kidney Diseases & Transplantation 2007; 18: 287-
98.
Ref ID: 139
**Reason for Exclusion: not a study**

Ref ID: 608
**Reason for Exclusion: general background**

Ref ID: 184
**Reason for Exclusion: general background**

Ref ID: 696
**Reason for Exclusion: general background**

Ref ID: 113
**Reason for Exclusion: general background**

Ref ID: 1180
**Reason for Exclusion: looks at identification rather than consent**

Aksoy, S A critical approach to the current understanding of Islamic scholars on using cadaver organs without prior permission. *Bioethics* 2001; **15**: 461-72.
Ref ID: 373
**Reason for Exclusion: general background**

Ref ID: 494
**Reason for Exclusion: looking at views of Muslim scholars towards organ donation and not consent**

Ref ID: 25
**Reason for Exclusion: general background**
Ref ID: 192

Reason for Exclusion: looks at potential for organ donation and not consent

Beaulieu, D Organ donation: the family’s right to make an informed choice. [Review] [25 refs]. Journal of Neuroscience Nursing 1999; 31: 37-42.
Ref ID: 433

Reason for Exclusion: literature search

Ref ID: 714

Reason for Exclusion: looking at presumed consent law which is not practiced in UK

Ref ID: 1037

Reason for Exclusion: report of a conference

Bledsoe, CM Factors influencing the decision of families to donate organs. jj 1994; -NaN.
Ref ID: 1726

Reason for Exclusion: BL can’t find it

Ref ID: 264

Reason for Exclusion: general background

Ref ID: 237

Reason for Exclusion: BL can’t find it

Ref ID: 334

Reason for Exclusion: a symposium presentation

[Care pathway: co-ordination]
Ref ID: 98
**Reason for Exclusion:** looking at effects of family advocates on recovery of organs

Ref ID: 1147
**Reason for Exclusion:** looking at tissue donation

Cheng, B, Ho, C-P, Ho, S, Wong, A An overview on attitudes towards organ donation in Hong Kong. *Hong Kong Journal of Nephrology* 2005; **7**: 77-81.
Ref ID: 1050
**Reason for Exclusion:** looking at general attitudes towards organ donation rather than consent

Ref ID: 1729
**Reason for Exclusion:** looking at cultural differences in attitude towards organ donation

Ref ID: 597
**Reason for Exclusion:** general background

Ref ID: 887
**Reason for Exclusion:** looking at honouring patient’s wishes rather than asking for permission from relatives which is not practiced in the UK

Chrysler, GR Consent for cadaver organ and tissue donation. *Journal of Transplant Coordination* 1998; **8**: 72-73.
Ref ID: 465
**Reason for Exclusion:** letter to editor

Chung, CS, Lehmann, LS Informed consent and the process of cadaver donation. *Archives of Pathology & Laboratory Medicine* 2002; **126**: 964-68.
Ref ID: 354
**Reason for Exclusion:** setting is medical school and not hospitals

Chung, CS, Lehmann, LS Informed consent and the process of cadaver donation. *Archives of Pathology and Laboratory Medicine* 2002; **126**: 964-68.
Ref ID: 1407
Reason for Exclusion: setting is medical school and not hospitals and duplicate

Collins, M Consent for organ retrieval cannot be presumed. *HEC Forum* 2009; **21:** 71-106.
Ref ID: 61

**Reason for Exclusion: general background**

Dimond, B Law concerning organ transplants and dead donors in the UK. [Review] [4 refs]. *British Journal of Nursing* 2005; **14:** 47-48.
Ref ID: 249

**Reason for Exclusion: not a study**

Ref ID: 765

**Reason for Exclusion: general background**

Ref ID: 594

**Reason for Exclusion: not a study**

Floden, A, Kelvered, M, Frid, I, Backman, L Causes why organ donation was not carried out despite the deceased being positive to donation. [Review] [20 refs]. *Transplantation Proceedings* 2006; **38:** 2619-21.
Ref ID: 169

**Reason for Exclusion: literature search**

Ref ID: 1719

**Reason for Exclusion: looks at religious attitudes towards organ donation and not consent**

Gallagher, C Religious attitudes regarding organ donation. [Review] [17 refs]. *Journal of Transplant Coordination* 1996; **6:** 186-90.
Ref ID: 524

**Reason for Exclusion: looks at religious attitudes towards organ donation and not consent**

Ref ID: 1543

**Reason for Exclusion: not a study**

Ref ID: 209
**Reason for Exclusion: looking at identification of donors**


Ref ID: 15
**Reason for Exclusion: general background**


Ref ID: 955
**Reason for Exclusion: letter to editor**


Ref ID: 97
**Reason for Exclusion: general background**


Ref ID: 954
**Reason for Exclusion: not a study**


Ref ID: 963
**Reason for Exclusion: looking at effects of best practices on conversion of potential donors becoming actual donors rather than obtaining consent**


Ref ID: 33
**Reason for Exclusion: literature search**


Ref ID: 417
**Reason for Exclusion: general background**


Ref ID: 375
**Reason for Exclusion: general background**

Ref ID: 521
**Reason for Exclusion: general background**


Ref ID: 1239

**Reason for Exclusion: general background**


Ref ID: 824

**Reason for Exclusion: general background**


Ref ID: 1035

**Reason for Exclusion: general background**


Ref ID: 965

**Reason for Exclusion: general background**


Ref ID: 170

**Reason for Exclusion: general background**


Ref ID: 1007

**Reason for Exclusion: general background and duplicate**


Ref ID: 214

**Reason for Exclusion: conference findings**


Ref ID: 792

**Reason for Exclusion: general background**

Ref ID: 1284
**Reason for Exclusion: general background**

Morgan, SE, Harrison, TR, Long, SD, Afifi, WA, Stephenson, MT, Reichert, T
Ref ID: 231
**Reason for Exclusion: setting is not hospitals but rather homes**

Ref ID: 274
**Reason for Exclusion: not a study**

Ref ID: 587
**Reason for Exclusion: complete results not reported**

Ref ID: 680
**Reason for Exclusion: not a study**

Ref ID: 1016
**Reason for Exclusion: looking at identification of potential donors rather than obtaining consent**

Ref ID: 689
**Reason for Exclusion: not a study**

Ref ID: 891
**Reason for Exclusion: general background**

Ref ID: 1051
**Reason for Exclusion: general background**
Ref ID: 1286
**Reason for Exclusion: general background**

Ref ID: 1197
**Reason for Exclusion: literature search**

Ref ID: 191
**Reason for Exclusion: practices looked at are not used in UK**

Ref ID: 1731
**Reason for Exclusion: looks at association between funeral aid and donation**

Ref ID: 1732
**Reason for Exclusion: looks at association between funeral aid and donation and duplicate**

Ref ID: 508
**Reason for Exclusion: comment on a study**

Saunders, B Normative consent and opt-out organ donation. *Journal of Medical Ethics* 2010; **36**: 84-87.
Ref ID: 12
**Reason for Exclusion: general background**

Shafer, TJ Improving relatives' consent to organ donation. *BMJ* 2009; **338**: 1023.
Ref ID: 882
**Reason for Exclusion: literature search**

Ref ID: 547
Reason for Exclusion: results incomplete and causes of refusal to consent not mentioned

Ref ID: 552

Reason for Exclusion: looking at medical causes of failure to obtain consent

Ref ID: 1246

Reason for Exclusion: not a study

Ref ID: 120

Reason for Exclusion: general background

Ref ID: 151

Reason for Exclusion: general background

Ref ID: 255

Reason for Exclusion: BL can't find it

Ref ID: 1297

Reason for Exclusion: general background

Ref ID: 652

Reason for Exclusion: not a study

Ref ID: 1230

Reason for Exclusion: general background

Ref ID: 71

Reason for Exclusion: not a study
Ref ID: 808

**Reason for Exclusion: not a study**

Ref ID: 69

**Reason for Exclusion: looking at association between depression and organ donation**

Ref ID: 57

**Reason for Exclusion: looking at consent for autopsy research purposes**

Valapour, M Donation after cardiac death: consent is the issue, not death. *Journal of Clinical Ethics* 2006; **17**: 137-38.
Ref ID: 180

**Reason for Exclusion: not a study**

Webster, PA, Markham, L Pediatric organ donation: a national survey examining consent rates and characteristics of donor hospitals. *Pediatric Critical Care Medicine* 2009; **10**: 500-504.
Ref ID: 45

**Reason for Exclusion: looking at relationship between identification and consent rates and no reasons stated for low consent rates**

Ref ID: 395

**Reason for Exclusion: doesn’t describe the consent process or factors influencing them**

Ref ID: 361

**Reason for Exclusion: literature search**

Ref ID: 341

**Reason for Exclusion: general background**
Wilkinson, TM Individual and family consent to organ and tissue donation: is the current position coherent?. [Review] [16 refs]. *Journal of Medical Ethics* 2005; 31: 587-90.  
Ref ID: 224  
**Reason for Exclusion: general background**

Ref ID: 379  
**Reason for Exclusion: general background**

Ref ID: 1735  
**Reason for Exclusion: general background**

**Review question 3**

Ref ID: 8  
**Reason for Exclusion: general background**

Ref ID: 137  
**Reason for Exclusion: general background**

Ref ID: 68  
**Reason for Exclusion: looking at entire donation process rather than timing for consent**

Ref ID: 28  
**Reason for Exclusion: not a study**

Ref ID: 27  
**Reason for Exclusion: looking at success of heart transplantation in children**

Bousso, RS The family decision-making process concerning consent for donating their child's organs: a substantive theory [Portuguese]. *Texto &
Ref ID: 4
**Reason for Exclusion:** considered for q2

Ref ID: 32
**Reason for Exclusion:** considered for q2

Ref ID: 138
**Reason for Exclusion:** considered for q2

Ref ID: 165
**Reason for Exclusion:** looking at obtaining kidneys only from donors

Ref ID: 12
**Reason for Exclusion:** looking at wishes recorded after autopsy and not donation

Ref ID: 240
**Reason for Exclusion:** looking at effects of new criteria to diagnose BSD and transplantation

Ref ID: 277
**Reason for Exclusion:** general background

Ref ID: 248
Reason for Exclusion: looking at observations made to confirm brain death

Ref ID: 299

Reason for Exclusion: considered for q2

Ref ID: 286

Reason for Exclusion: looking at identification of potential kidney donors

Ref ID: 80

Reason for Exclusion: considered for q2

Ref ID: 133

Reason for Exclusion: looking at tissue donation and nor organ donation

Ref ID: 131

Reason for Exclusion: looking at effect of NHBD programme at identification of potential kidney donors

Ref ID: 74

Reason for Exclusion: looking at identification rather than timing

Ref ID: 197

Reason for Exclusion: considered for q2

Lawlor, M, Kerridge, I Registering wishes about organ and tissue donation: Personal discussion during licence renewal may be superior to online registration. *Internal Medicine Journal* 2009; 39: 835-37.
Ref ID: 215

Ref ID: 198

Ref ID: 161

Ref ID: 101

Ref ID: 118

Ref ID: 179

Ref ID: 266

Ref ID: 25
Ref ID: 75
**Reason for Exclusion:** looking at identification of donors

Ref ID: 102
**Reason for Exclusion:** considered for q2

Ref ID: 112
**Reason for Exclusion:** looking at identification of potential donors

Siminoff, AL, Robertson, LC, Barber, VS, Young, JD Modifiable factors influencing relatives' decision to offer organ donation: systematic review. [Review] [7 refs]. *BMJ* 2009; 338: b991.
Ref ID: 20
**Reason for Exclusion:** literature search

Ref ID: 297
**Reason for Exclusion:** BL can't find it

Ref ID: 5
**Reason for Exclusion:** considered for q2

Ref ID: 270
**Reason for Exclusion:** general background

Ref ID: 98
**Reason for Exclusion:** literature search
Review question 4
Ref ID: 89
**Reason for Exclusion: BL can’t find it**

Ref ID: 308
**Reason for Exclusion: not looking at specific role of SNOD in the organ donation care pathway**

Arbour, R Clinical management of the organ donor. [Review] [86 refs]. *AACN Clinical Issues* 600; 16: 551-80.
Ref ID: 42
**Reason for Exclusion: general background**

Ref ID: 436
**Reason for Exclusion: BL can’t find it**

Ref ID: 122
**Reason for Exclusion: general background**

Ref ID: 357
**Reason for Exclusion: general background**

Ref ID: 124
**Reason for Exclusion: narrative review**

Ref ID: 18
**Reason for Exclusion: looking at attitudes of HCPs towards organ donation**

D’Alessandro, AM Current results of an organ procurement organization effort to increase utilization of donors after cardiac death. *Transplantation* 2006; 81: 15.
Ref ID: 249
**Reason for Exclusion: expert opinion**

Ref ID: 191
**Reason for Exclusion: looking at increasing knowledge and providing support to HCPs to increase DCD**

Ref ID: 17
**Reason for Exclusion: looks at overall barriers with DCD donation**

Ref ID: 126
**Reason for Exclusion: general background**

Ref ID: 130
**Reason for Exclusion: general background**

Ref ID: 374
**Reason for Exclusion: general background**

Ref ID: 218
**Reason for Exclusion: general background on ethics for the critical care nurse**

Ref ID: 6
**Reason for Exclusion: general background**

Ref ID: 221
**Reason for Exclusion: general background**

Edwards, J, Mulvania, P, Robertson, V, George, G, Hasz, R, Nathan, H, D'Alessandro, A Maximizing organ donation opportunities through donation
after cardiac death. *Critical Care Nurse* 2006; **26**: 101-16.
Ref ID: 435
**Reason for Exclusion: general background**

Ref ID: 168
**Reason for Exclusion: BL can't find it**

Ref ID: 22
**Reason for Exclusion: implementation of a regional network**

Ref ID: 373
**Reason for Exclusion: looks at procurement strategies for obtaining lungs as organs**

Frontera, JA How i manage the adult potential organ donor: Donation after cardiac death (Part 2). *Neurocritical Care* 2010; **12**: 111-16.
Ref ID: 137
**Reason for Exclusion: expert opinion**

Frontera, JA, Kalb, T How I manage the adult potential organ donor: donation after neurological death (part 1). *Neurocritical Care* 2010; **12**: 103-10.
Ref ID: 4
**Reason for Exclusion: expert opinion**

Ref ID: 83
**Reason for Exclusion: general background**

Holmquist, M Organ donor Care MAP: a multidisciplinary approach. [Review] [4 refs]. *Journal of Transplant Coordination* 1996; **6**: 101-4.
Ref ID: 101
**Reason for Exclusion: looking at role of ICU nurses after consent has been obtained**

Ref ID: 412
**Reason for Exclusion: looking at effects of establishing family support programs**
Ref ID: 110
**Reason for Exclusion:** description of a Spanish model but not evaluation

Ref ID: 19
**Reason for Exclusion:** looks at educational and other needs of nurses in the OD process

Ref ID: 90
**Reason for Exclusion:** general background

Ref ID: 442
**Reason for Exclusion:** BL can’t find it

Ref ID: 58
**Reason for Exclusion:** a guideline

Ref ID: 46
**Reason for Exclusion:** general background

Ref ID: 65
**Reason for Exclusion:** looks at the effects of implementing a new process to increase identification of donors and not looking at role of SNOD in the care pathway

Ref ID: 238
**Reason for Exclusion:** the paper looks at increasing identification rates rather than the role of SNOD in the care pathway
Ref ID: 359
*Reason for Exclusion: not looking at the specific role of SNOD in the OD care pathway*

Ref ID: 195
*Reason for Exclusion: general background*

**Review question 5**

As noted above, evidence from other questions was used to inform recommendations on skills and competencies needed. There are therefore no excluded studies for this question.