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

NICE guideline

Guideline Appendices

Content

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'.

Terms used in this scope	
Brain-stem death	Death diagnosed after irreversible cessation of brain stem function and confirmed using neurological criteria. The diagnosis of death is made while the body of the person is attached to an artificial ventilator and the heart is still beating.
Cardiac death	Death diagnosed and confirmed by a doctor after cardiorespiratory arrest.
Potential donors	People for whom brain-stem death or cardiac death has been diagnosed and active treatment is planned to be withdrawn, and who have no medical contraindications to solid organ donation.
See Department of Health (2008) Organs for transplants: a report from the Organ Donation Taskforce. Available from www.dh.gov.uk/en/Publicationsandstatistics/Publications	

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 awaiting 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.

[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 under taken 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 How this guideline was developed

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.

Guidance/guidelines	Systematic reviews/economic evaluations
British Medical Association Canadian Medical Association Infobase Clinical Knowledge Summaries Department of Health Donor Family Network European Transplant Co-ordinators Organisation General Medical Council Guidelines International Network (GIN) Human Tissue Authority National Guideline Clearing House (US) National Health and Medical Research Council (Australia) National Institute for Health and Clinical Excellence (NICE) – guidance published & in development National Institute for Health and Clinical Excellence (NICE) – topic selection	Clinical Evidence Cochrane Database of Systematic Reviews (CDSR) Database of Abstracts of Reviews of Effects (DARE) Health Economic Evaluations Database (HEED) Health Technology Assessment (HTA) Database NHS Economic Evaluation Database (NHS EED) NHS R&D Service Delivery and Organisation (NHS SDO) Programme National Institute for Health Research (NIHR) Health Technology Assessment Programme TRIP Database

NHS Blood and Transplant NHS Confederation NHS Evidence New Zealand Guidelines Group Royal College of General Practitioners Royal College of Pathologists Scottish Intercollegiate Guidelines Network (SIGN)	

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

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

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

9 7 or 8

10 Decision Making/

11 (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.

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 clinical triggers for referral to organ donation team

1 exp "Tissue and organ procurement"/ or Tissue donors/
2 ((don* or procur*) adj3 (tissue* or organ*)).ti,ab.
3 1 or 2
4 trigger*.tw.
5 "Referral and Consultation"/
6 Models, Organizational/
7 ("task force" or "taskforce" or "task-force").ti,ab.
8 or/4-7
9 3 and 8
10 animals/ not humans/
11 9 not 10
12 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 approv* 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

17 Animals/ not Humans/

18 16 not 17

19 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 (pharmaco 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

Key Clinical Issues	Review Questions
• Structures and processes including timing for referral and criteria for consideration for identifying potential DBD and DCD donors • Structures and processes for obtaining consent for cadaveric organ donation for transplantation, including the optimum timing for approaching the families about consent. • Coordination of the care pathway for conversion of potential donors to actual donors. • Competencies of healthcare professionals involved in the activities described above.	***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?* ***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?* ***Review question 3:*** *When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?* ***Review question 4:*** *How the care pathway of deceased organ donation should be coordinated to improve potential donors giving consent?* ***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?*

Review Protocols

	Details	Notes & Status
1. 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?*	
2. Objectives	To identify all relevant literature on structures and processes including timing for referral and criteria for consideration for identifying potential DBD and DCD donors.	
3. Language	*English only*	
4. Study design	*No restrictions.*	
5. Status	*Published papers (full papers only)*	
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.*	

	Details	Notes & Status
1. 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?*	
2. Objectives	To identify all relevant literature on structures and processes for obtaining consent for deceased organ donation for transplantation.	
3. Language	*English only.*	
4. Study design	*No restrictions.*	
5. Status	*Published papers (full papers only)*	
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	
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 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.*	

	Details	**Notes & Status**
1. Review question 3	*When is the optimal time for approaching the families, relatives and legal guardians of potential DBD and DCD donors for consent?*	
2. Objectives	To identify all relevant literature on optimum timing for approaching the families about consent.	
3. Language	*English only*	
4. Study design	*No restrictions.*	
5. Status	*Published papers (full papers only)*	
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	
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 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.*	

	Details	Notes & Status
1. Review question 4	*How the care pathway of deceased organ donation should be coordinated to improve potential donors giving consent?*	
2. Objectives	To identify all the relevant literature on structures and processes for the coordination of the care pathway from identification to consent.	
3. Language	*English only*	
4. Study design	*No restrictions.*	
5. Status	*Published papers (full papers only)*	
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	
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 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 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.*	

	Details	Notes & Status
1. 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 donors; to improve structures and processes for obtaining consent; and to effectively coordinate the care pathway from identification to obtaining consent?*	
2. Objectives	To identify all the relevant literature on the competencies of healthcare professionals involved in the activities described above.	
3. Language	*English only*	
4. Study design	*No restrictions.*	
5. Status	*Published papers (full papers only)*	
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	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	
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:* • *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.*	

Excluded studies

Review question 1

Aaronson, KD, Schwartz, JS, Chen, TM, Wong, KL, Goin, JE, Mancini, DM Development and prospective validation of a clinical index to predict survival in ambulatory patients referred for cardiac transplant evaluation. *Circulation* 1997; 95: 2660-2667.

Reason for Exclusion: looking at survival in ambulatory patients referred for cardiac transplant evaluation

Abbud-Filho, M, Ramalho, H, Pires, HS, Silveira, JA Attitudes and awareness regarding organ donation in the western region of Sao Paulo, Brazil. Transplantation Proceedings 1995; 27: 1835.

Reason for Exclusion: surveyed population are not health care professionals

Al Sebayel, MI, Khalaf, H Knowledge and attitude of intensivists toward organ donation in Riyadh, Saudi Arabia. Transplantation Proceedings 2004; 36: 1883-84.

Reason for Exclusion: looking at attitudes towards organ donation

Al-Mousawi, M, Abdul-Razzak, M, Samhan, M Attitude of ICU staff in Kuwait regarding organ donation and brain death. Transplantation Proceedings 2001; 33: 2634-35.

Reason for Exclusion: for q5

Antommaria, AH, Bratton, SL Nurses' attitudes toward donation after cardiac death: implications for nurses' roles and moral distress. Pediatric Critical Care Medicine 2008; 9: 339-40.

Reason for Exclusion: for q5

Baines, LS, Joseph, JT, Jindal, RM A public forum to promote organ donation amongst Asians: the Scottish initiative. Transplant International 2002; 15: 124-31.

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 Potential for organ donation in the United Kingdom: audit of intensive care records. BMJ 2006; 332: 1124-27.

Reason for Exclusion: looks at why potential donors couldn't end up as actual donors

Beasley, CL, Capossela, CL, Brigham, LE, Gunderson, S, Weber, P, Gortmaker, SL The impact of a comprehensive, hospital-focused intervention to increase organ donation. *Journal of Transplant Coordination* 1997; 7: 6-13.

Reason for Exclusion: not using clinical triggers or required referral to identify potential donors

Belzer, FO, Kountz, SL Criteria for selection of cadaver donors. Transplantation Proceedings 1972; 4: 591-93.

Reason for Exclusion: not a study

Bener, A, El-Shoubaki, H, Al-Maslamani, Y Do we need to maximize the knowledge and attitude level of physicians and nurses toward organ donation and transplant? Experimental & Clinical Transplantation: Official Journal of the Middle East Society for Organ Transplantation 2008; 6: 249-53.

Reason for Exclusion: for q5

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

Reason for Exclusion: British Library can't find it

Bogh, L, Madsen, M Attitudes, knowledge, and proficiency in relation to organ donation: a questionnaire-based analysis in donor hospitals in northern Denmark. Transplantation Proceedings 2005; 37: 3256-57.

Reason for Exclusion: for q5

Bohatyrewicz, R, Walecka, A, Bohatyrewicz, A, Zukowski, M, Kepinski, S, Marzec-Lewenstein, E, Sawicki, M, Kordowski, J Unusual movements, "spontaneous" breathing, and unclear cerebral vessels sonography in a brain-dead patient: a case report. *Transplantation Proceedings* 2007; 39: 2707-8.

Reason for Exclusion: looking at definitive diagnostic tests to confirm BSD

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.

Reason for Exclusion: for q2

Caballero, F, Lopez-Navidad, A, Leal, J, Garcia-Sousa, S, Soriano, JA, Domingo, P The cultural level of cadaveric potential organ donor relatives determines the rate of consent for donation. Transplantation Proceedings 1999; 31: 2601.

Reason for Exclusion: for q2

Cameron, AM, Ghobrial, RM Utilization of extended criteria donors. Current Opinion in Organ Transplantation 2007; 12: 119-24.

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.

Reason for Exclusion: general background

Cheung, AH, Alden, DL, Wheeler, MS Cultural attitudes of Asian-Americans toward death adversely impact organ donation. Transplantation Proceedings 1998; 30: 3609-10.

Reason for Exclusion: for q2

Cheung, AH, Luna, GK Cadaveric organ donor availability: regional trauma center vs. community hospital. *Journal of Trauma-Injury Infection & Critical Care* 1990; 30: 1366-71.

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.

Reason for Exclusion: general background

Chung, CS, Lehmann, LS Informed consent and the process of cadaver donation. Archives of Pathology and Laboratory Medicine 2002; 126: 964-68.

Reason for Exclusion: for q2

Coleman, N, Brieva, J, Crowfoot, E Identification of a realistic donation after cardiac death (DCD) donor: predicting time of death within 60 minutes following withdrawal of futile life sustaining treatment. Transplant Nurses' Journal 2008; 17: 22-26.

Reason for Exclusion: British Library can't find it

Colpart, JJ, Bouttin, B, Guillot, B, Maillefaud, B, Marion, A, Saury, G, Leone, C, Minarro, D, Moskovtchenko, JF Logistics and management for improvement of multiorgan procurement from potential brain-dead donors. Transplantation Proceedings 1996; 28: 264-65.

Reason for Exclusion: looking at organ retrieval rather than identification

Criteria for organ donors. IMJ - Illinois Medical Journal 1987; 171: 309-10.

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.

Reason for Exclusion: not a study

DeVita, MA, Brooks, MM, Zawistowski, C, Rudich, S, Daly, B, Chaitin, E Donors after cardiac death: validation of identification criteria (DVIC) study for predictors of rapid death. American Journal of Transplantation 2008; 8: 432-41.

Reason for Exclusion: looking at using specific criteria to predict death within 60minutes 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.

Reason for Exclusion: description of services and not evaluation

DeVita, MA, Webb, SA, Hurford, WE, Truog, RD, Wlody, GS, Hayden, CT, Sprung, CL, Brilli, RJ, Beals, DA, Rothenberg, DM, Friedman, AL, Silverstein, DS, Kaufman, DC, Perkin, RM, Rosenbaum, SH, Cist, AFM, Samotowka, M, Teres, D, Unkle, DW, Burns, JP, Wallace, TE Recommendations for nonheartbeating organ donation. Critical Care Medicine 2001; 29: 1826-31.

Reason for Exclusion: general background

DeYoung, S, Temmler, L, Adams, EF, Just, G Organ referrals--would nurses do more if they knew more? *Journal of Continuing Education in Nursing* 1991;

22: 219-21.

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

Douglas, S Factors affecting cadaveric organ donation: a national survey of organ procurement coordinators. Journal of Transplant Coordination 1994; 4: 96-103.

Reason for Exclusion: for q2

Durall, AL, Laussen, PC, Randolph, AG Potential for donation after cardiac death in a children's hospital. *Pediatrics* 2007; **119:** e219-e224.

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

Edwards, J, Mulvania, P, Robertson, V, George, G, Hasz, R, Nathan, H, D'Alessandro, A Maximizing organ donation opportunities through donation after cardiac death. [Review] [25 refs]. Critical Care Nurse 2006; 26: 101-15.

Reason for Exclusion: general background

Edwards, JM, Hasz, RD, Jr., Robertson, VM Non-heart-beating organ donation: process and review. [Review] [21 refs]. AACN Clinical Issues 1999; 10: 293-300.

Reason for Exclusion: general background

Ehrle, R Timely referral of potential organ donors. [Review] [36 refs][Reprint in Prog Transplant. 2008 Mar;18(1):17-21; PMID: 18429577]. *Critical Care Nurse* 2006; 26: 88-93.

Reason for Exclusion: general background

Ehrle, RN, Shafer, TJ, Nelson, KR Referral, request, and consent for organ donation: best practice--a blueprint for success. [Review] [66 refs]. *Critical Care Nurse* 1932; 19: 21-30.

Reason for Exclusion: British Library can't find it

Evans, RW, Orians, CE, Ascher, NL The potential supply of organ donors. An assessment of the efficacy of organ procurement efforts in the United States. JAMA 1992; 267: 239-46.

Reason for Exclusion: used certain criteria to identify donors and also looked at donor procurement

Fecteau, A, Atkinson, P, Grant, D Early referral is essential for successful pediatric small bowel transplantation: The Canadian experience. *Journal of Pediatric Surgery* 2001; 36: 681-84.

Reason for Exclusion: looking at outcomes of patients who undergo small bowel transplantation

Ferguson, M, Zuk, J Organ donation after cardiac death: A new trend in pediatrics. Journal of Pediatric Gastroenterology and Nutrition 2003; 37: 219-20.

Reason for Exclusion: not a study

Freebury, DR The psychological implications of organ transplantation. A selective review. [Review] [16 refs]. Canadian Psychiatric Association Journal 1974; 19: 593-97.

Reason for Exclusion: literature search

Frezza, EE, Krefski, LR, Valenziano, CP Factors influencing the potential organ donation: a 6-yr experience of the New Jersey Organ and Tissue Sharing Network. Clinical Transplantation 1999; 13: 231-40.

Reason for Exclusion: doesn't show how to increase donor identification

Frutos, MA, Ruiz, P, Requena, MV, Daga, D Family refusal in organ donation: Analysis of three patterns. Transplantation Proceedings 2002; 34: 2513-14.

Reason for Exclusion: for q2

Gabel, H Continuous registration of potential cadaveric donors in Sweden, May 1989- December 1991. Journal of Transplant Coordination 1993; 3: 134-38.

Reason for Exclusion: not a study

Gabel, H, Roels, L Legislative initiatives to increase donation. Transplantation Proceedings 1997; 29: 3223.

Reason for Exclusion: not a study

Garcia, VD, Garcia, CD, Keitel, E, Santos, AF, Bianco, PD, Bittar, AE, Neumann, J, Campos, HH, Pestana, JOM, Abbud-Filho, M Expanding criteria for the use of living donors: What are the limits? Transplantation Proceedings 2004; 36: 808-10.

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

Glasson, J, Plows, CW, Tenery, J, Clarke, OW, Ruff, V, Fuller, D, Kliger, CH, Wilkins, J, Cosgriff, J, Orentlicher, D, Harwood, K, Leslie, J Strategies for cadaveric organ procurement: Mandated choice and presumed consent. Journal of the American Medical Association 1994; 272: 809-12.

Reason for Exclusion: not a study

Gravel, MT, Szeman, P Increasing referrals and donations using the Transplant Center Development Model. *Journal of Transplant Coordination* 1996; 6: 32-36.

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.

Reason for Exclusion: looking at interventions to improve outcomes in patients with endstage heart failure

Hagan, ME, McClean, D, Falcone, CA, Arrington, J, Matthews, D, Summe, C Attaining specific donor management goals increases number of organs transplanted per donor: a quality improvement project. *Progress in Transplantation* 2009; 19: 227-31.

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

Hardison, J, Schears, RM Organ donation after cardiac death: a reexamination of healthcare provider attitudes. Critical Care Medicine 2007; 35: 2666-67.

Reason for Exclusion: letter to editor

Hassan, TB, Joshi, M, Quinton, DN, Elwell, R, Baines, J, Bell, PR Role of the accident and emergency department in the non-heart-beating donor programme in Leicester. *Journal of Accident & Emergency Medicine* 1996; 13: 321-24.

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

Henderson, SO, Chao, JL, Green, D, Leinen, R, Mallon, WK Organ procurement in an urban level I emergency department. *Annals of Emergency Medicine* 1998; 31: 466-70.

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

Jouan, MC, Decaris, J, Bicocchi, C, Joseph, L, Claquin, J, Villiers, S Analysis of organ donation refusal. Transplantation Proceedings 1996; 28: 388-89.

Reason for Exclusion: for q2

Keenan, SP, Hoffmaster, B, Rutledge, F, Eberhard, J, Chen, LM, Sibbald, WJ Attitudes regarding organ donation from non-heart-beating donors. Journal of Critical Care 1937; 17: 29-36.

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

Kittur, DS, McMenamin, J, Knott, D Impact of an organ donor and tissue donor advocacy program on community hospitals. *American Surgeon* 1990; 56: 36-39.

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

Kmietowicz, Z Taskforce rejects system of presumed consent for organ donation in UK. *BMJ* 2008; 337: a2621.

Reason for Exclusion: British Library 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.

Reason for Exclusion: not a study

Kowalski, AE, Light, JA, Ritchie, WO, Sasaki, TM, Callender, CO, Gage, F A new approach for increasing the organ supply. Clinical Transplantation 1996; 10: t-7.

Reason for Exclusion: not a study

Kozlowski, LM Case study in identification and maintenance of an organ donor. Heart & Lung 1988; 17: 366-71.

Reason for Exclusion: describes the process of organ donation

Kwek, TK, Lew, TW, Tan, HL, Kong, S The transplantable organ shortage in Singapore: has implementation of presumed consent to organ donation made a difference?. [Review] [30 refs]. *Annals of the Academy of Medicine, Singapore* 2009; 38: 346-48.

Reason for Exclusion: general background

La, SF, Sedda, L, Pizzi, C, Verlato, R, Boselli, L, Candiani, A, Chiaranda, M, Frova, G, Gorgerino, F, Gravame, V, Mapelli, A, Martini, C, Pappalettera, M, Seveso, M, Sironi, PG Donor families' attitude toward organ donation. Transplantation Proceedings 1993; 25: 1699-701.

Reason for Exclusion: for q2

Lawton, RL, Davis, J Importance of recent legislation regarding the recognition of brain death, and the identification of organ donors. Journal of

the Iowa Medical Society 1977; 67: 11-13.

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.

Reason for Exclusion: general background

Mackersie, RC, Bronsther, OL, Shackford, SR Organ procurement in patients with fatal head injuries. The fate of the potential donor. Annals of Surgery 1991; 213: 143-50.

Reason for Exclusion: looks at organ procurement rather than identification

Martinez, JM, Lopez, JS, Martin, A, Martin, MJ, Scandroglio, B, Martin, JM Organ donation and family decision-making within the Spanish donation system. Social Science & Medicine 2001; 53: 405-21.

Reason for Exclusion: for q2

Matesanz, R, Bozzi, G, Saviozzi, AR, Ferrini, PL, Cardone, A, Tuscany Nurse, TC How to evaluate organ donation: the quality programme in Tuscany. *Edtna-Erca Journal* 2004; 30: 38-41.

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

Molzahn, AE Knowledge and attitudes of critical care nurses regarding organ donation. Canadian Journal of Cardiovascular Nursing 1997; 8: 13-19.

Reason for Exclusion: for q5

O'Brien, RL, Serbin, MF, O'Brien, KD, Maier, RV, Grady, MS Improvement in the organ donation rate at a large urban trauma center. *Archives of Surgery* 1996; 131: 153-59.

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

Opdam, HI, Silvester, W Erratum: "Potential for organ donation in Victoria: An audit of hospital deaths" (Medical Journal of Australia (2006) vol. 185 (250-254)). Medical Journal of Australia 2006; 185: 408.

Reason for Exclusion: letter to editor

Pearson, IY The potential organ donor. Medical Journal of Australia 1993; 158: 45-47.

Reason for Exclusion: general background

Pearson, IY, Bazeley, P, Spencer-Plane, T, Chapman, JR, Robertson, P A survey of families of brain dead patients: Their experiences, attitudes to organ donation and transplantation. Anaesthesia and Intensive Care 1995; 23: 88-95.

Reason for Exclusion: /for q2

Prottas, J Shifting responsibilities in organ procurement: a plan for routine referral. *JAMA* 1988; 260: 832-33.

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 Care Nursing 2005; 4: 85-87.

Reason for Exclusion: British Library can't find it

Ranjan, D, Schmonsky, K, Johnston, T, Jeon, H, Bouneva, I, Erway, E Financial analysis of potential donor management at a medicare-approved transplant hospital. American Journal of Transplantation 2006; 6: 199-204.

Reason for Exclusion: looking at financial incentives and organ donation

Razek, T, Olthoff, K, Reilly, PM Issues in potential organ donor management. [Review] [75 refs]. Surgical Clinics of North America 2000; 80: 1021-32.

Reason for Exclusion: general background

Rios, A, Conesa, C, Ramirez, P, Galindo, PJ, Rodriguez, JM, Rodriguez, MM, Martinez, L, Parrilla, P, Redes Tematicas de Investigacion Cooperativa: Estrategias para Optimizar los Resultados en Donacion Attitudes of resident doctors toward different types of organ donation in a Spanish transplant hospital. Transplantation Proceedings 2006; 38: 869-74.

Reason for Exclusion: looks at attitudes of resident doctors towards organ donation

Rios, A, Lopez-Navas, A, Ayala, MA, Sebastian, MJ, Martinez-Alarcon, L, Ramirez, EJ, Munoz, G, Camacho, A, Lopez-Lopez, A, Rodriguez, JS, Martinez, MA, Nieto, A, Ramirez, P, Parrilla, P Attitudes of Spanish and Mexican resident physicians faced with solid organ donation and transplantation. Transplantation Proceedings 2010; 42: 233-38.

Reason for Exclusion: looks at attitudes towards organ donation and not identification

Rios, ZA, Ramirez, P, Martinez, L, Montoya, MJ, Lucas, D, Alcaraz, J, Rodriguez, MM, Rodriguez, JM, Parrilla, P Are personnel in transplant hospitals in favor of cadaveric organ donation? Multivariate attitudinal study in

a hospital with a solid organ transplant program. Clinical Transplantation 2006; 20: 743-54.

Reason for Exclusion: for q5

Roth, BJ, Sher, L, Murray, JA, Belzberg, H, Mateo, R, Heeran, A, Romero, J, Mone, T, Chan, L, Selby, R Cadaveric organ donor recruitment at Los Angeles County Hospital: improvement after formation of a structured clinical, educational and administrative service. *Clinical Transplantation* 2003; 17: Suppl-7.

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

Roza, BA, Pestana, JO, Barbosa, SF, Schirmer, J Organ donation procedures: an epidemiological study. Progress in transplantation (Aliso Viejo, Calif) 2010; 20: 88-95.

Reason for Exclusion: for q2

Roza, BA, Pestana, JO, Barbosa, SF, Schirmer, J Organ donation procedures: an epidemiological study. Progress in Transplantation 2010; 20: 88-95.

Reason for Exclusion: duplicate

Rutter, N, Mann, NP, Watson, AR Organ donation. Archives of Disease in Childhood 1989; 64: 875-78.

Reason for Exclusion: not a study

Sade, RM, Kay, N, Pitzer, S, Drake, P, Baliga, P, Haines, S Increasing organ donation: a successful new concept. *Transplantation* 2002; 74: 1142-46.

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

Saeed, B, Derani, R, Hajibrahim, M, Roumani, J, Al-Shaer, MB, Saeed, R, Damerli, S, Al-Saadi, R, Kayyal, B, Haddad, M Organ failure in Syria: initiating a national deceased donation program. [Review] [34 refs]. Saudi Journal of Kidney Diseases & Transplantation 2007; 18: 270-276.

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

Saeed, B, Derani, R, Hajibrahim, M, Roumani, J, Al-Shaer, MB, Saeed, R, Damerli, S, Al-Saadi, R, Kayyal, B, Haddad, M Volume of organ failure in Syria and obstacles to initiate a national cadaver donation program. Iranian journal of Kidney Diseases 2008; 2: 65-71.

Reason for Exclusion: not a study

Salih, MA, Harvey, I, Frankel, S, Coupe, DJ, Webb, M, Cripps, HA Potential availability of cadaver organs for transplantation. BMJ 1991; 302: 1053-55.

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

Salim, A, Velmahos, GC, Brown, C, Belzberg, H, Demetriades, D Aggressive organ donor management significantly increases the number of organs available for transplantation. *Journal of Trauma-Injury Infection & Critical Care* 2005; 58: 991-94.

Reason for Exclusion: looking at implementing better management of potential donors to increase donation rather than clinical triggers

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.

Reason for Exclusion: for q2

Shafer, T, Hueneke, M, Wolff, S, Davis, K, Ehrle, R, Van, BC, Orlowski, J, White, C The Texas Nondonor Hospital Project: a preliminary report on the impact of inhouse coordinators on organ donation rates in nondonor hospitals. *Transplantation Proceedings* 1997; 29: 3261-62.

Reason for Exclusion: a report on a paper

Shafer, TJ, Van Buren, CT, Andrews, CA Program development and routine notification in a large, independent OPO: a 12-year review. *Journal of Transplant Coordination* 1999; 9: 40-49.

Reason for Exclusion: comment on another study

Shaw, AB Non-therapeutic (elective) ventilation of potential organ donors: the ethical basis for changing the law. Journal of Medical Ethics 1996; 22: 72-77.

Reason for Exclusion: general background

Shemie, SD, Baker, AJ, Knoll, G, Wall, W, Rocker, G, Howes, D, Davidson, J, Pagliarello, J, Chambers-Evans, J, Cockfield, S, Farrell, C, Glannon, W, Gourlay, W, Grant, D, Langevin, S, Wheelock, B, Young, K, Dossetor, J National recommendations for donation after cardiocirculatory death in Canada: Donation after cardiocirculatory death in Canada. CMAJ Canadian Medical Association Journal 2006; 175: S1.

Reason for Exclusion: background

Shirley, S, Cutler, J, Heymann, C, Hart, M Narrowing the organ donation gap: hospital development methods that maximize hospital donation potential. *Journal of Heart & Lung Transplantation* 1994; 13: 817-23.

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

Siminoff, LA, Arnold, RM, Hewlett, J The process of organ donation and its effect on consent. Clinical Transplantation 2001; 15: 39-47.

Reason for Exclusion: for q2

Siminoff, LA, Lawrence, RH Knowing patients' preferences about organ donation: does it make a difference? Journal of Trauma-Injury Infection & Critical Care 2002; 53: 754-60.

Reason for Exclusion: for q2

Siminoff, LA, Traino, HM Improving donation outcomes: hospital development and the Rapid Assessment of Hospital Procurement Barriers in Donation. *Progress in Transplantation* 2009; 19: 180-187.

Reason for Exclusion: looking at barriers to organ donation

Singer, P, Rachmani, R Improving attitude and knowledge of healthcare professionals towards organ donation in Israel: results of 12 European donor hospital education programs. Transplantation Proceedings 1997; 29: 3244-45.

Reason for Exclusion: for q5

Sohrabi, S, Navarro, A, Asher, J, Wilson, C, Sanni, A, Wyrley-Birch, H, Anand, V, Reddy, M, Rix, D, Jacques, B, Manas, D, Talbot, D Agonal period in potential non-heart-beating donors. Transplantation Proceedings 2006; 38: 2629-30.

Reason for Exclusion: looks at time interval for retrieval of organs

Soifer, BE, Gelb, AW The multiple organ donor: Identification and management. Annals of Internal Medicine 1989; 110: 814-23.

Reason for Exclusion: general background

Studer, SM, Orens, JB Cadaveric donor selection and management. [Review] [51 refs]. Respiratory Care Clinics of North America 2004; 10: 459-71.

Reason for Exclusion: general background

Studer, SM, Orens, JB Cadaveric donor selection and management. Seminars in Respiratory and Critical Care Medicine 2006; 27: 492-500.

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.

Reason for Exclusion: British Library can't find it

Sutherland, S Nurse coordinator--European experience organizing development in UK transplant--a nurse-based system. *Transplantation Proceedings* 2003; 35: 992-94.

Reason for Exclusion: a report

Tenn-Lyn, NA, Doig, CJ, Shemie, SD, Teitelbaum, J, Cass, DE Potential organ donors referred to Ontario neurosurgical centres. *Canadian Journal of Anaesthesia* 2006; 53: 732-36.

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

UNOS criteria identify candidates for organ donation after cardiac death. Nature Clinical Practice Nephrology 2008; 4: 242.

Reason for Exclusion: expert comment on a study

Waller, JA, Haisch, CE, Skelly, JM Potential availability of transplantable organs according to factors associated with type of injury event. Accident Analysis & Prevention 1992; 24: 193-200.

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

Waller, JA, Haisch, CE, Skelly, JM, Goldberg, CG Potential availability of transplantable organs and tissues in fatalities from injury and nontraumatic intracranial hemorrhage. Transplantation 1993; 55: 542-46.

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.

Reason for Exclusion: for q5

Wight, C, Cohen, B, Miranda, B, Fernandez, M, Beasley, C Hospital attitudes: preliminary findings from donor action pilot projects. Transplant International 1998; 11: Suppl-9.

Reason for Exclusion: for q5

Williams, MA, Lipsett, PA, Rushton, CH, Grochowski, EC, Berkowitz, ID, Mann, SL, Shatzer, JH, Short, MP, Genel, M, Council on Scientific Affairs, AMA The physician's role in discussing organ donation with families. [Review] [39 refs]. Critical Care Medicine 2003; 31: 1568-73.

Reason for Exclusion: not a study

Review question 2

Brain death cases reported, medically documented, families approached, consented for donation and harvested from different hospitals in Saudi Arabia in 2005. *Saudi Journal of Kidney Diseases & Transplantation* 2006; **17:** 262-70.

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.

Reason for Exclusion: not a study

Strategies for cadaveric organ procurement. Mandated choice and presumed consent. Council on Ethical and Judicial Affairs, American Medical Association. *JAMA* 1994; 272: 809-12.

Reason for Exclusion: general background

Abadie, A, Gay, S The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *Journal of Health Economics* 2006; 25: 599-620.

Reason for Exclusion: general background

Abbing, HD Organ donation, the legal framework. *Health Policy* 1990; 16: 105-15.

Reason for Exclusion: general background

Abouna, GM Organ shortage crisis: problems and possible solutions. *Transplantation Proceedings* 2008; 40: 34-38.

Reason for Exclusion: general background

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Reason for Exclusion: looks at identification rather than consent

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Reason for Exclusion: looking at tissue donation

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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.

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Reason for Exclusion: literature search

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

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

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: looks at association between funeral aid and donation

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Reason for Exclusion: general background

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

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Reason for Exclusion: not a study

Sheach Leith, VM Consent and nothing but consent? The organ retention scandal. *Sociology of Health & Illness* 2007; 29: 1023-42.

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Reason for Exclusion: British Library can't find it

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: not a study

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Reason for Exclusion: not a study

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

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Reason for Exclusion: looking at consent for autopsy research purposes

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Reason for Exclusion: not a study

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West, R, Burr, G Why families deny consent to organ donation. *Australian Critical Care* 2002; 15: 27-32.

Reason for Exclusion: literature search

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: general background

Review question 3

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Reason for Exclusion: general background

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Reason for Exclusion: general background

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Reason for Exclusion: looking at entire donation process rather than timing for consent

Bernat, JL The boundaries of organ donation after circulatory death. *New England Journal of Medicine* 2008; 359: 669-71.

Reason for Exclusion: not a study

Boucek, MM, Mashburn, C, Dunn, SM, Frizell, R, Edwards, L, Pietra, B, Campbell, D, Denver Children's Pediatric Heart Transplant Team Pediatric

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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 & Contexto Enfermagem* 2008; 17: 45-55.

Reason for Exclusion: not in English

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.

Reason for Exclusion: for q2

Caillouet-O'Neal, C, Booker, QG Converting family advocates to level 1 recovery coordinators. *Transplantation Proceedings* 2008; 40: 1041-43.

Reason for Exclusion: for q2

Chapman, JR, Hibberd, AD, McCosker, C, Thompson, JF, Ross, W, Mahony, J, Byth, P, MacDonald, GJ Obtaining consent for organ donation in nine NSW metropolitan hospitals. *Anaesthesia & Intensive Care* 1995; 23: 81-87.

Reason for Exclusion: for q2

Chatterjee, SN, Payne, JE, Berne, TV Difficulties in obtaining kidneys from potential postmortem donors. *JAMA* 1975; 232: 822-24.

Reason for Exclusion: looking at obtaining kidneys only from donors

Cohen, MC, Blakey, S, Donn, T, McGovern, S, Parry, L An audit of parents'/guardians' wishes recorded after coronial autopsies in cases of sudden unexpected death in infancy: issues raised and future directions. *Medicine, Science & the Law* 2009; 49: 179-84.

Reason for Exclusion: looking at wishes recorded after autopsy and not donation

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Reason for Exclusion: looking at effects of new criteria to diagnose BSD and transplantation

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Reason for Exclusion: general background

DeVita, MA, Snyder, JV, Arnold, RM, Siminoff, LA Observations of withdrawal of life-sustaining treatment from patients who became non-heart-beating organ donors. *Critical Care Medicine* 2000; 28: 1709-12.

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

Douglas, S Factors affecting cadaveric organ donation: a national survey of organ procurement coordinators. *Journal of Transplant Coordination* 1994; 4: 96-103.

Reason for Exclusion: for q2

Durall, AL, Laussen, PC, Randolph, AG Potential for donation after cardiac death in a children's hospital. *Pediatrics* 2007; 119: e219-eNaN.

Reason for Exclusion: looking at identification of potential kidney donors

Haddow, G Donor and nondonor families' accounts of communication and relations with healthcare professionals. *Progress in Transplantation* 2004; 14: 41-48.

Reason for Exclusion: for q2

Haire, MC, Hinchliff, JP Donation of heart valve tissue: seeking consent and meeting the needs of donor families. *Medical Journal of Australia* 1996; 164: 28-31.

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

Hassan, TB, Joshi, M, Quinton, DN, Elwell, R, Baines, J, Bell, PR Role of the accident and emergency department in the non-heart-beating donor programme in Leicester. *Journal of Accident & Emergency Medicine* 1996; 13: 321-24.

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

Helms, AK, Torbey, MT, Hacein-Bey, L, Chyba, C, Varelas, PN Standardized protocols increase organ and tissue donation rates in the neurocritical care unit. *Neurology* 2004; 63: 1955-57.

Reason for Exclusion: looking at identification rather than timing

Howard, DH, Siminoff, LA, McBride, V, Lin, M Does quality improvement work? Evaluation of the organ donation breakthrough collaborative. *Health Services Research* 2007; 42: 2160-2173.

Reason for Exclusion: 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.

Reason for Exclusion: general background

Marks, WH, Wagner, D, Pearson, TC, Orlowski, JP, Nelson, PW, McGowan, JJ, Guidinger, MK, Burdick, J Organ donation and utilization, 1995-2004: Entering the collaborative era. *American Journal of Transplantation* 2006; 6: 1101-10.

Reason for Exclusion: general background

Matesanz, R, Dominguez-Gil, B Strategies to optimize deceased organ donation. *Transplantation Reviews* 2007; 21: 177-88.

Reason for Exclusion: general background

Montefusco, CM, Levine, S, Goldsmith, J, Veith, FJ Obtaining consent for organ donation. *Hospital Physician* 1985; 21: 46-50.

Reason for Exclusion: general background

Neades, BL Organ donation in A&E: the legal and ethical implications for the A&E nurse. [Review] [76 refs]. *Accident & Emergency Nursing* 2001; 9: 109-22.

Reason for Exclusion: general background

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Reason for Exclusion: for q4

Reich, DJ, Mulligan, DC, Abt, PL, Pruett, TL, Abecassis, MMI, D'Alessandro, A, Pomfret, EA, Freeman, RB, Markmann, JF, Hanto, DW, Matas, AJ, Roberts, JP, Merion, RM, Klintmalm, GBG ASTS recommended practice guidelines for controlled donation after cardiac death organ procurement and transplantation. *American Journal of Transplantation* 2009; 9: 2004-11.

Reason for Exclusion: general background

Robinette, MA Organ donation: Resource requirements and consent for donation. *Anesthesiology Clinics of North America* 1994; 12: 635-42.

Reason for Exclusion: general background

Rodrigue, JR, Cornell, DL, Howard, RJ The instability of organ donation decisions by next-of-kin and factors that predict it. *American Journal of Transplantation* 2008; 8: 2661-67.

Reason for Exclusion: for q2

Shafer, TJ, Ehrle, RN, Davis, KD, Durand, RE, Holtzman, SM, Van Buren, CT, Crafts, NJ, Decker, PJ Increasing organ recovery from level I trauma centers: the in-house coordinator intervention. *Progress in Transplantation* 2004; 14: 250-263.

Reason for Exclusion: looking at identification of donors

Shih, FJ, Lai, MK, Lin, MH, Lin, HY, Tsao, CI, Duh, BR, Chu, SH The dilemma of "to-be or not-to-be": needs and expectations of the Taiwanese cadaveric organ donor families during the pre-donation transition. *Social Science & Medicine* 2001; 53: 693-706.

Reason for Exclusion: for q2

Siminoff, LA, Nelson, KA The accuracy of hospital reports of organ donation eligibility, requests, and consent: a cross-validation study. *Joint Commission Journal on Quality Improvement* 1999; 25: 129-36.

Reason for Exclusion: looking at identification of potential donors

Simpkin, 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.

Reason for Exclusion: literature search

Siminoff, LA Withdrawal of treatment and organ donation. *Critical Care Nursing Clinics of North America* 1997; 9: 85-96.

Reason for Exclusion: British Library can't find it

Sotillo, E, Montoya, E, Martinez, V, Paz, G, Armas, A, Liscano, C, Hernandez, G, Perez, M, Andrade, A, Villasmil, N, Mollegas, L, Hernandez, E, Milanes, CL, Rivas, P Identification of variables that influence brain-dead donors' family groups regarding refusal. *Transplantation Proceedings* 2009; 41: 3466-70.

Reason for Exclusion: for q2

Spital, A Consent for organ donation: Time for a change. *Clinical Transplantation* 1993; 7: 525-28.

Reason for Exclusion: general background

West, R, Burr, G Why families deny consent to organ donation. *Australian Critical Care* 2002; 15: 27-32.

Reason for Exclusion: literature search

Review question 4

How to manage vital-organ donors. *Nursing* 1999; 29: 32cc11-13.

Reason for Exclusion: British Library can't find it

Abdo, A, Ugarte, JC, Castellanos, R, Gonzalez, L, Lopez, O, Hernandez, JC, Valdivia, J, Almora, E, Suarez, O, Diaz, J, Collera, S, Enamorado, A, Vazquez, A, Benite, P, Dominguez, J, Wilford, M, Falcon, J The transplantation donation process in the Centro de Investigaciones Medico Quirurgicas of Cuba: 1999-2002. *Transplantation Proceedings* 2003; 35: 1636-37.

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.

Reason for Exclusion: general background

Austen, D Establishing a Queensland wide network for the holistic approach to organ donation and transplantation: the Link Nurse phenomenon. *Transplant Journal of Australasia* 2005; 14: 10-15.

Reason for Exclusion: British Library can't find it

Bodenham, A, Park, GR Care of the multiple organ donor. [Review] [56 refs]. *Intensive Care Medicine* 1989; 15: 340-348.

Reason for Exclusion: general background

Brody, B What can and cannot be learned from the Pittsburgh experience. *Critical Care Medicine* 2000; 28: 2134-35.

Reason for Exclusion: general background

Brown, ME Clinical management of the organ donor. [Review] [25 refs]. *DCCN - Dimensions of Critical Care Nursing* 1989; 8: 134-41.

Reason for Exclusion: narrative review

Cohen, J, Ami, SB, Ashkenazi, T, Singer, P Attitude of health care professionals to brain death: influence on the organ donation process. *Clinical Transplantation* 2008; 22: 211-15.

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.

Reason for Exclusion: expert opinion

D'Alessandro, AM, Peltier, JW, Phelps, JE Increasing organ donations after cardiac death by increasing DCD support among health care professionals: A case report. *American Journal of Transplantation* 2008; 8: 897-904.

Reason for Exclusion: looking at increasing knowledge and providing support to HCPs to increase DCD

D'Alessandro, AM, Peltier, JW, Phelps, JE Understanding the antecedents of the acceptance of donation after cardiac death by healthcare professionals. *Critical Care Medicine* 2008; 36: 1075-81.

Reason for Exclusion: looks at overall barriers with DCD donation

Darby, JM, Stein, K, Grenvik, A, Stuart, SA Approach to management of the heartbeating 'brain dead' organ donor. [Review] [71 refs]. *JAMA* 1989; 261: 2222-28.

Reason for Exclusion: general background

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Reason for Exclusion: general background

Delmonico, FL, Reese, JC Organ donor issues for the intensive care physician. *Journal of Intensive Care Medicine* 1998; 13: 269-79.

Reason for Exclusion: general background

DeVeaux, TE Non-heart-beating organ donation: Issues and ethics for the critical care nurse. *Journal of Vascular Nursing* 2006; 24: 17-21.

Reason for Exclusion: general background on ethics for the critical care nurse

Dictus, C, Vienenkoetter, B, Esmaeilzadeh, M, Unterberg, A, Ahmadi, R Critical care management of potential organ donors: our current standard. [Review] [81 refs]. *Clinical Transplantation* 2009; 23: Suppl-9.

Reason for Exclusion: general background

DuBois, JM, DeVita, M Donation after cardiac death in the United States: How to move forward. *Critical Care Medicine* 2006; 34: 3045-47.

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.

Reason for Exclusion: general background

Fidler, SA Implementing donation after cardiac death protocols. *Journal of health & life sciences law* 2008; 2: 123, 125-23, 149.

Reason for Exclusion: British Library can't find it

Filipponi, F, De, SP, Rossi, E The Tuscany model of a regional transplantation service authority: Organizzazione Toscana Trapianti. *Transplantation Proceedings* 2007; 39: 2953-60.

Reason for Exclusion: implementation of a regional network

Follette, D, Rudich, S, Bonacci, C, Allen, R, Hoso, A, Albertson, T Importance of an aggressive multidisciplinary management approach to optimize lung donor procurement. *Transplantation Proceedings* 1999; 31: 169-70.

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.

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.

Reason for Exclusion: expert opinion

Holmquist, M, Chabalewski, F, Blount, T, Edwards, C, McBride, V, Pietroski, R A critical pathway: guiding care for organ donors. [Review] [36 refs]. *Critical Care Nurse* 1999; 19: 84-98.

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.

Reason for Exclusion: looking at role of ICU nurses after consent has been obtained

House, MA, Durham, J, Joyner, J An OPO's experience with a donor family support program. *Journal of Transplant Coordination* 1993; 3: 36-38.

Reason for Exclusion: looking at effects of establishing family support programs

Matesanz, R, Miranda, B, Felipe, C Organ procurement and renal transplants in Spain: the impact of transplant coordination. Spanish National Transplant

Organization (ONT). *Nephrology Dialysis Transplantation* 479; 9: 475-78.

Reason for Exclusion: description of a Spanish model but not evaluation

Meyer, K, Bjork, IT Change of focus: from intensive care towards organ donation. *Transplant International* 2008; 21: 133-39.

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

Noah, P, Morgan, S Organ/tissue donation request: a multidisciplinary approach. *Critical Care Nursing Quarterly* 1999; 22: 30-38.

Reason for Exclusion: general background

Petro, JA, Tack, CM, Groh, J Up close & clinical. A critical pathway for organ donation: one possible solution to a crucial need. *Nursing Spectrum -- Philadelphia Tri -- State Edition* 1997; 6: 10-12.

Reason for Exclusion: British Library can't find it

Powner, DJ, Darby, JM, Kellum, JA Proposed treatment guidelines for donor care. *Progress in Transplantation* 2004; 14: 16-26.

Reason for Exclusion: a guideline

Rayburn, AB A multipronged approach to addressing the organ shortage. *Journal of Cardiovascular Nursing* 2005; 20: Suppl-21.

Reason for Exclusion: general background

Rosendale, JD, Chabalewski, FL, McBride, MA, Garrity, ER, Rosengard, BR, Delmonico, FL, Kauffman, HM Increased transplanted organs from the use of a standardized donor management protocol. *American Journal of Transplantation* 2002; 2: 761-68.

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

Whiting, JF, Delmonico, F, Morrissey, P, Basadonna, G, Johnson, S, Lewis, WD, Rohrer, R, O'Connor, K, Bradley, J, Lovewell, TD, Lipkowitz, G Clinical results of an organ procurement organization effort to increase utilization of donors after cardiac death. *Transplantation* 2006; 81: 1368-71.

Reason for Exclusion: the paper looks at increasing identification rates rather than the role of SNOD in the care pathway

Wight, C, Cohen, B, Roels, L, Miranda, B Donor action: A quality assurance program for intensive care units that increases organ donation. *Journal of Intensive Care Medicine* 2000; 15: 104-14.

Reason for Exclusion: not looking at the specific role of SNOD in the OD care pathway

Zavotsky, KE, Tamburri, LM A Case in Successful Organ Donation: Emergency Department Nurses Do Make a Difference. *Journal of Emergency Nursing* 2007; 33: 235-41.

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.

Appendix C References of all included studies

Review question 1

Total number of studies retrieved from searches = 1523	
Selection based on title and abstract = 90 (full papers ordered)	**Excluded = 1433**
Selection based on full papers = 14	**Excluded = 76**
Total number of studies included = 14 13 studies part of evidence 1 study as supporting evidence	

Review question 2

Total number of studies retrieved from searches = 1298	
Selection based on title and abstract = 133 (full papers ordered)	**Excluded = 1165**
Selection based on full papers = 38	**Excluded = 95**
Total number of studies included = 38 5 studies duplicate	

Review question 3

Total number of studies retrieved from searches = 254	
Selection based on title and abstract = 48 (full papers ordered)	**Excluded = 206**
Selection based on full papers = 10	**Excluded =38**
Total number of studies included = 10	

Review question 4

Total number of studies retrieved from searches = 390	
Selection based on title and abstract = 40 (full papers ordered)	**Excluded = 350**
Selection based on full papers = 4	**Excluded =36**
Total number of studies included = 4	

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

Aubrey, P, Arber, S, Tyler, M The organ donor crisis: the missed organ donor potential from the accident and emergency departments. *Transplantation Proceedings* 2008; **40:** 1008-11.

Bair, HA, Sills, P, Schumacher, K, Bendick, PJ, Janczyk, RJ, Howells, GA Improved organ procurement through implementation of evidence-based practice. *Journal of Trauma Nursing* 2006; **13:** 183-85.
Ref ID: 96

Burris, GW, Jacobs, AJ A continuous quality improvement process to increase organ and tissue donation. *Journal of Transplant Coordination* 1996; **6:** 88-92.

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

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Gabel, H, Edstrom, B Number of potential cadaveric donors: reasons for nonprocurement and suggestions for improvement. *Transplantation Proceedings* 1993; **25:** 3136.

Gallagher, C Religious attitudes regarding organ donation. *Journal of Transplant Coordination* 1996; **6:** 186-91.

Gortmaker, SL, Beasley, CL, Brigham, LE, Franz, HG, Garrison, RN, Lucas, BA, Patterson, RH, Sobol, AM, Grenvik, NA, Evanisko, MJ Organ donor potential and performance: size and nature of the organ donor shortfall. *Critical Care Medicine* 1996; **24:** 432-39.

Graham, JM, Sabeta, ME, Cooke, JT, Berg, ER, Osten, WM A system's approach to improve organ donation. *Progress in Transplantation* 2009; **19:** 216-20.

Higashigawa, KH, Carroll, C, Wong, LL Organ procurement 1999-2000: how is Hawaii doing? *Hawaii Medical Journal* 2001; **60:** 314-17.

Higashigawa, KH, Carroll, C, Wong, LL, Wong, LM Organ donation in Hawaii: impact of the final rule. *Clinical Transplantation* 2002; **16:** 180-184.

Madsen, M, Bogh, L Estimating the organ donor potential in Denmark: a prospective analysis of deaths in intensive care units in northern Denmark. *Transplantation Proceedings* 2005; **37:** 3258-59.

Moller, C, Welin, A, Henriksson, BA, Rydvall, A, Karud, K, Nolin, T, Brorson, I, Nilsson, L, Lundberg, D, Swedish Council for Organ and Tissue Donation National survey of potential heart beating solid organ donors in Sweden. *Transplantation Proceedings* 2009; **41:** 729-31.

Molzahn, AE Knowledge and attitudes of physicians regarding organ donation. *Annals of the Royal College of Physicians & Surgeons of Canada* 1997; **30:** 29-32.

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

recommendations. *Anaesthesia* 2009; **64:** 822-28.

Opdam, HI, Silvester, W Identifying the potential organ donor: an audit of hospital deaths. *Intensive Care Medicine* 2004; **30:** 1390-1397.

Pearson, IY, Zurynski, Y A survey of personal and professional attitudes of intensivists to organ donation and transplantation. *Anaesthesia & Intensive Care* 1995; **23:** 68-74.

Petersen, P, Fischer-Frohlich, CL, Konigsrainer, A, Lauchart, W Detection of potential organ donors: 2-year analysis of deaths at a German university hospital. *Transplantation Proceedings* 2009; **41:** 2053-54.
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Ploeg, RJ, Niesing, J, Sieber-Rasch, MH, Willems, L, Kranenburg, K, Geertsma, A Shortage of donation despite an adequate number of donors: a professional attitude? *Transplantation* 2003; **76:** 948-55.

Pugliese, MR, Degli, ED, Dormi, A, Venturoli, N, Mazzetti, GP, Buscaroli, A, Petropulacos, K, Nanni, CA, Ridolfi, L Improving donor identification with the Donor Action programme. *Transplant International* 2003; **16:** 21-25.

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Review question 2

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

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.

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Review question 3

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Review question 4

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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

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
9 studies 3 x Audit retrospective studies-[A], [P], [Ma] 1 x Audit report-[G&E] 1 x Medical records retrospective review-[G] 3 x Survey	S (a)	NA	S (b)	S (c)	Studies showed that one of the factors for low identification rates were that healthcare professionals missed identifying potential donors.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
questionnaires- [O], [W], [M] 1 x Audit prospective study- [T]						
1 study 1 x Audit study- [Pu]	S (a)	NA	S (b)	S (c)	A study showed that there was an improvement in identification of potential donors in hospitals with a donor action programme implemented.	Very low
2 studies 1 x Audit retrospective study-[A] 1 x Survey using a questionnaire- [Mo]	S (a)	NA	S (b)	S (c)	Studies showed that 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.	Very low
2 studies 1 x Medical records retrospective reviews-[G] 1 x Survey questionnaire- [O]	S (a)	NA	S (b)	S (c)	Studies showed that health care professionals did not approach family members to make a decision about donation.	Very low
1 study 1 x Survey questionnaire- [Pe]	S (a)	NA	S (b)	S (c)	A study showed that health care staff felt that families were too stressed to be approached for organ donation.	Very low
1 study 1 x Audit retrospective study-[A]	S (a)	NA	S (b)	S (c)	A study showed the lack of available contact details of the DTC in emergency departments as a factor for lack of identification of potential donors.	Very low
1 study	S (a)	NA	S (b)	S (c)	A study showed the following personnel should be part of the identification process in the emergency department:	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 x Audit retrospective study-[A]					• Hospital consultants- A&E, anaesthetists and neuro-surgeons • Emergency trauma team • A&E nursing and medical staff	
1 study 1 x Audit retrospective study-[A]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Audit retrospective study-[A]	S (a)	NA	S (b)	S (c)	A study 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.	Very low
2 studies 1 x Audit retrospective study-[A] 1 x Survey questionnaire-[Pe]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Structured questionnaire- [Pl]	S (a)	NA	S (b)	S (c)	A study showed the following factors which influenced the decision to discuss with families regarding organ donation: • 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.	Very low
2 studies 1 x Medical records retrospective review-[G] 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.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 study 1 x Medical records retrospective review-[G]	S (a)	NA	S (b)	S (c)	A study showed that rates of organ donation were higher when the cause of death was a motor vehicle accident, a gunshot wound or stabbing, or other head trauma compared with cerebrovascular, asphyxiation, or cardiovascular events	Very low
1 study 1 x Survey questionnaire-[Pe]	S (a)	NA	S (b)	S (c)	A study showed that threats to staff from family members acted as a barrier to identification of potential donors.	Very low
1 study 1 x Survey questionnaire-[Pe]	S (a)	NA	S (b)	S (c)	A study showed that healthcare staff experienced language difficulties in explaining to families about organ donation which acted as a barrier to identification of potential donors.	Very low
1 study 1 x Survey using a questionnaire- [Mo]	S (a)	NA	S (b)	S (c)	A study showed that healthcare staff felt that approaching families for organ donation was too emotionally demanding and acted as a barrier to identification of potential donors.	Very low
1 study 1 x Survey using a questionnaire- [Mo]	S (a)	NA	S (b)	S (c)	A study showed that healthcare professional's fear of potential litigation was a factor for non identification and donation.	Very low
1 study 1 x Structured questionnaire- [Pl]	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

[A] = Aubrey et.al (2008)
[G&E] = Gabel and Edstrom (1993)
[P] = Petersen et.al (2009)
[G] = Gortmaker et.al (1996)
[O] = Opdham et.al (2004)

[T] = Thompson et.al (1995)
[W] = Wood et.al (2003)
[M] = Moller et.al (2009)
[Ma] = Madsen et.al (2006)
[Pu] = Pugliese et al (2003)
[Mo] = Molzahn et.al (1997)
[Pe] = Pearson et.al (1995)
[Pl] = Ploeg et.al (2003)
(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 2: Use of clinical triggers

<table>
<tr><th colspan="5">Study characteristics</th><th colspan="2">Summary of findings</th></tr>
<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>
<tr><td colspan="7">Conversion rate</td></tr>
<tr><td>1 study

1 x observational study- [B]</td><td>S (a)</td><td>NA</td><td>S (b)</td><td>S (c)</td><td><table><tr><td>Outcome</td><td>2004</td><td>2005</td><td>p value</td></tr><tr><td>Conversion rate</td><td>50%</td><td>80%</td><td>0.025</td></tr></table>
A study showed that the conversion rate statistically significantly increased when clinical triggers were used to screen all ICU patients.</td><td>Very low</td></tr>
<tr><td colspan="7">Number of organ donors</td></tr>
<tr><td>1 study

1 x observational study- [S]</td><td>S (a)</td><td>NA</td><td>S (b)</td><td>S (c)</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><td>Very low</td></tr>
<tr><td colspan="7">Number of potential and effective donors</td></tr>
<tr><td>2 studies</td><td>S</td><td>NA</td><td>S</td><td>S</td><td>The number of potential donors increased between 4% to 27.46%</td><td>Very</td></tr>
</table>

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
2 x observational studies- [Sh] and [V]	(a)		(b)	(c)	The number of effective donors increased by 22% to 30.86%.	low
Total number of referrals						
1 study 1 x observational study- [Sh]	S (a)	NA	S (b)	S (c)	Total referrals increased 26% in the project IHC LITCs vs. 14% in the comparison hospitals with no IHC LITCs	Very low

[B] = Bair et al (2006)
[S] = Shafer et al (2008)
[Sh] = Shafer et. al (2004)
[V] = Van gelder et. al (2006)
IHC-in-house cordinators
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

<table>
<tr><th colspan="5">Study characteristics</th><th colspan="2">Summary of findings</th></tr>
<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>
<tr><td colspan="7">Referral rate and number of potential donors</td></tr>
<tr><td>1 study

1 x observational study- [M]</td><td>S (a)</td><td>NA</td><td>No serious</td><td>S (c)</td><td>
<table>
<tr><td></td><td colspan="2">2006-7</td><td colspan="2">2007-8</td></tr>
<tr><td>Number</td><td>Heart beating donors</td><td>Non-heart beating donors</td><td>Heart beating donors</td><td>Non-heart beating donors</td></tr>
<tr><td>Referred</td><td>2</td><td>1</td><td>7</td><td>31</td></tr>
<tr><td>Accepted</td><td>1</td><td>1</td><td>6</td><td>7</td></tr>
</table>
There was an increase in referral rate.
There was an increase in the number of potential donors referred to the OPO representative.
</td><td>Low</td></tr>
<tr><td colspan="7">Referral rate and number of potential donors</td></tr>
<tr><td>5 studies

4 x observational studies- [H], [Hi], [R], and [S]

1 x retrospective study- [B]</td><td>S (a)</td><td>NA</td><td>S (b)</td><td>S (c)</td><td>There was an increase in referral rate of between 56% to 450%

There was an increase in the number of potential donors referred to the OPO representative of between 3% and 80%</td><td>Very low</td></tr>
<tr><td colspan="7">Number of donors</td></tr>
<tr><td>6 studies

3 x observational studies- [S], [R], and [Sh]

3 x retrospective studies- [B], [D], and [G]</td><td>S (a)</td><td>NA</td><td>S (b)</td><td>S (c)</td><td>Studies showed that there was an increase in the number of donors of between 24% and 275% from potential donors.</td><td>Very low</td></tr>
</table>

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Number of organs retrieved per donor						
1 study 1 x observational study- [S]	S (a)	NA	S (b)	S (c)	A study showed that there was an increase of 312% for the number of organs retrieved per donor.	Very low
Number of organs retrieved per donor						
1 study 1 x retrospective study-[G]	S (a)	NA	S (b)	S (c)	But one study showed that the overall number of organs per donor was essentially unchanged from the baseline year.	Very low

[M] = Murphy et al (2009)
[H] = Higashiwaga et al (2001)
[Hi] = Higashiwaga et al (2002)
[R] = Robertson et al (1998)
[S] = Shafer et al (1998)
[B] = Burris et. al (1996)
[Sh] = Shafer et al (2008)
[D] = Dickerson et. al (2002)
[G] = Graham et. al (2009)
(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

Quality assessment							Summary of findings			
							No of patients		Effect	Quality
No of studies	Design	Limitations	Inconsistency	Indirectness	Imprecision	Other considerations	Collaborative	Routine	Results (95% CI)	
Consent to organ donation (ITT)										
1 [Y]	RCT	S (a)	NS	NS	S (b)	none	57/100 (57.0%)	62/101 (61.4%)	OR- 0.83 (95% CI-0.47 to 1.46)	Low
Consent to organ donation (Adjusted for ethnicity, gender, and age)										
1 [Y]	RCT	S (a)	NS	NS	S (b)	none	57/100 (57%)	62/101 (61.4%)	OR- 0.80 (95% CI- 0.43 to 1.53, p- 0.49)	Low
Any solid organ retrieved from all patients (ITT)										
1 [Y]	RCT	S (a)	NS	NS	S (b)	none	45/100 (45.0%)	57/101 (56.4%)	OR- 0.63 (95% CI- 0.36 to 1.10)	Low
Any solid organ retrieved from patients who consented (ITT)										
1 [Y]	RCT	S (a)	NS	NS	S (b)	none	45/79 (57.0%)	57/92 (62.0%)	OR- 0.81 (95% CI- 0.44 to 1.50)	Low

[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

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Influence of staff involved in organ donation						
1 study 1 x Qualitative Study- [J]	S (a)	NA	S (b)	S (c)	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 s source of emotional support.	Very low
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Qualitative retrospective study- [H]	S (a)	NA	S (b)	S (c)	A study showed that donor families found it easier to talk to donor coordinators because they did not wear any uniform.	Very low
1 study 1 x Qualitative Study - [J]	S (a)	S (d)	S (b)	S (c)	A study showed that there were variations in the family experiences while being approached for consent on organ donation.	Very low
Continuity of care						
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	A study showed that families preferred continuity of care for their loved ones which was sometimes considered inadequate to increase consent for organ donation.	Very low
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	A study showed that families of potential donors preferred to interact with a single physician.	Very low
Quality of approach						
2 studies	S (a)	NA	S (b)	S (c)	Studies showed that both families of donors and non-donors wanted compassionate care of their loved one (potential donor) and their being treated with dignity and respect.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 x Qualitative retrospective study- [H] 1 x Qualitative Study - [J]						
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	A study showed that families wanted to be listened to by the staff and the staff to be there for them when needed.	Very low
Provision of information						
2 studies 2 x Qualitative Studies - [J] and [S]	S (a)	NA	S (b)	S (c)	Studies showed that both families of donors and non-donors wanted understandable, prompt, accurate, in-depth and consistent information.	Very low
2 studies 1 x Qualitative retrospective study- [H] 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	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.	Very low
Sources of support						
1 study	S (a)	NA	S (b)	S (c)	A study showed that families viewed nurses as a source of support during the discussion to gain consent for organ donation.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 x Qualitative Study - [J]						
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	A study showed that families of donors believed that 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.	Very low
1 study 1 x Qualitative retrospective study- [H]	S (a)	S (d)	S (b)	S (c)	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.	Very low
Views of physicians involved in organ donation						
1 study 1 x Qualitative Study - [S]	S (a)	NA	S (b)	S (c)	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.	Very low
Factors associated with decision stability or satisfaction						
1 study 1 x Retrospective study- [B]	S (a)	NA	S (b)	S (c)	A study showed that one factor associated with consent in potential adult donors was an understanding of the term brain death.	Very low
Factors associated with decision instability or dissatisfaction						
1 study 1 x Retrospective study- [R]	S (a)	NA	S (b)	S (c)	A study showed that the factors associated with denial of consent in potential adult donors were: • a lack of discussion of donation with the deceased • poor timing of donation discussion • not being told of the death before the first mention of donation • not being given enough time to discuss the donation decision with others	Very low
Factors associated with the decision to grant consent						
12 studies	S (a)	NA	S (b)	S (c)	Studies showed that the following factors were associated with families of potential donors granting consent to organ donation:	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
7 x Retrospective studies- [B], [Br], [M], [F], [D], [N], [Si & L] 1 x Retrospective study (chart review and interviews)- [Si-b] 2 x Retrospective studies (survey)- [Si], [P] 1 x Cross sectional survey- [C] 1 x Retrospective cross sectional qualitative study- [Sq]					• understanding that transplantation was a proven procedure had a high success rate, and knowledge of the benefits or organ donation • an understanding of the term brain death • acceptance of death, and confidence in the 'diagnosis of death' • consideration and knowledge of the deceased's wishes (through carrying a donor card or discussion) • earlier timing of request • involving more family members with the decision • the level of comfort with which the healthcare professional requested consent • good relationships between the family and the healthcare professionals • satisfaction with treatment (either of the family or the deceased) • congruence between the views of healthcare professionals and the families at initial approach • request for donation being initiated by a healthcare professional (not a physician) with further discussion with an organ donation professional • request by different healthcare professionals • more time spent with an organ donation professional • knowledge of the impact of donation on other processes, such as funeral arrangements • knowledge of the costs of donation • choice of organs for donation • families being able to discuss both specific and wider issues and getting answers to questions	
Factors associated with the decision to refuse consent						
18 studies 11 x Retrospective studies- [B], [Br], [M], [D], [Si & L], [La S], [No], [So], [Do], [Sh] and [Ch] 1 x Cross sectional survey- [C]	S (a)	NA	S (b)	S (c)	Studies showed that the following factors were associated with families of potential donors refusing consent to organ donation: • feelings of pressure to consent • feeling emotionally overwhelmed • feeling of surprise on being asked about consent • fear of causing more 'suffering' or disfigurement, and not wanting the deceased to have more medical intervention	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 x Retrospective cross sectional qualitative study- [Sq] 1 x Retrospective study (chart review and interviews)- [Si-b] 2 x Retrospective studies (survey)- [Si], [P] 1 x Prospective study- [Si-a]					• concern that donation may cause more distress to family members • uncertainty about the deceased's wishes • reluctance to accept the death • social resentment • lack of understanding and confidence in the concept of brain-stem death • lack of family consensus and the family being 'upset' • family reticence • making the decision before information was provided by a healthcare or organ donation professional • an absence of key decision makers • the length of the process • not liking the hospital or healthcare professionals • feeling that the medical care was not optimal • initial approach by a healthcare professional • perception that the healthcare professional did not care or was not concerned, or the healthcare professional showing a lack of respect • healthcare professionals stating that the request was required • lack of knowledge of the impact of donation on other processes, such as funeral arrangements • lack of detailed information on the process of organ donation, including the timing of retrieval and information on recipients • initial perception of healthcare professionals that the family were likely to refuse	
Other factors influencing consent for organ donation						
12 studies 7 x Retrospective studies- [B], [Br], [M], [Si & L], [La S], [F] and [No] 1 x Retrospective study (chart review and interviews)- [Si-b] 2 x Retrospective studies	S (a)	S (d)	S (b)	S (c)	Studies showed that other factors that influenced the families of potential donors in obtaining consent were: • donor ethnicity • donor age • donor sex • type of death (trauma or not) • familial (or consentor) • level of education	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
(survey)- [Si], [P] 1 x Prospective study (survey)- [Yo] 1 x Retrospective study (audit)- [Pi]					• socioeconomic status • marital status, previous examples of belief in or support for organ donation (such as carrying a donor card or donating to relevant charities) • religious, cultural or spiritual beliefs • personal experience or knowledge of transplantation • setting of donation or death However, some associations were not consistent across studies.	

[J] = Jacoby et al (2005)
[H] = Haddow (2004)
[S] = Sanner et. al (2007)
[B] = Burroughs et. al (1998)
[R] = Rodrigue et. al (2008)
[Si-b] = Siminoff et al (2001b)
[Br] = Brown et. al (2010)
[Si] = Siminoff et. al (2002)
[P] = Pearson et. al (1995)
[M] = Martinez et. al (2001)
[F] = Frutos et. al (2002)
[D] = Douglas (1994)
[C] = Cleiren and Van Zoelen (2002)
[Sq] = Sque et. al (2007)
[N] = Niles et. al (1996)
[Si & L] = Siminoff and Lawrence (2002)
[La S] = La Spina et. al (1993)
[No] = Noury et. al (1996)
[So] = Sotillo et. al (2009)
[Ch] = Chapman et. al (1995)
[Yo] = Yong et. al (2000)
[Pi] = Pike et. al (1990)
[Do] = Douglass et. al (1995)
[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

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Influence of staff involved in organ donation						
1 study 1 x qualitative study-[B], [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low
Influence of family members						
1 study 1 x qualitative study-[Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low
Factors related to consent						
1 study 1 x qualitative study-[B], [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x qualitative study-[B], [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x qualitative study-[B], [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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	Very low
1 study 1 x qualitative study-[Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Method of approach						
1 study 1 x qualitative study- [B]	S (a)	NA	S (b)	S (c)	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).	Very low
Quality of approach						
1 study 1 x qualitative study- [B], [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low
Provision of information						
1 study 1 x qualitative study- [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	A study showed that parents of potential paediatric donors requested the following information before giving consent for organ donation; • the process of organ retrieval • the outcomes of transplantation • the identity of the recipient • the possibility of making contact with him or her	Very low
1 study 1 x qualitative study- [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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; • the child's condition • the chance of survival of the child • the concept of brain death	Very low
1 study 1 x qualitative study- [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Factors associated with the decision to grant consent						
2 studies 1 x Retrospective study- [V] 1 x Retrospective study (survey)- [W]	S (a)	NA	S (b)	S (c)	Studies showed that the following factors were associated with families of potential paediatric donors granting consent to organ donation: • belief in the process of donation, and feeling that it was 'the right thing to do' • perception that the child would go on living in others • good interaction with healthcare professionals involved in organ donation • type of healthcare professional who asked for consent	Very low
Factors associated with the decision to refuse consent						
2 studies 2 x Retrospective studies (survey)- [W] and [F]	S (a)	NA	S (b)	S (c)	Studies showed that the following factors were associated with families of potential paediatric donors refusing consent to organ donation: • a perception that the doctors who determined death were not part of the organ donation process • lack of information • fear or lack of belief in organ donation • perception that timing of approach was not optimal • feeling that the child had been through enough and fear of further trauma • concern that donation would impact on survival • consideration of donation was too upsetting • poor interaction with healthcare professionals involved in organ donation, including a perception of insensitivity	Very low
Other factors influencing consent for organ donation						
2 studies 1 x Retrospective study (survey)- [F] 1 x Retrospective	S (a)	NA	S (b)	S (c)	Studies showed that other factors that influenced the families of potential paediatric donors in obtaining consent were: • donor ethnicity • familial (or consentor) ethnicity	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
study- [P]					• religious beliefs • previous examples of belief in or knowledge of transplantation	

[B] = Bellali et. al (2006)
[Be-a] = Bellali et. al (2007-a)
[Be-b] = Bellali et. al (2007-b)
[V] = Vane et. al (2001)
[W] = Weiss et. al (1997)
[F] = Frauman et. al (1987)
[P] = Pietz et . al (2004)
(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.

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Approach before death						
2 studies 2 x retrospective studies- [N] and [S]	S (a)	NA	S (b)	S (c)	Studies showed that when families of potential donors were asked about donation before death of their loved one, they tended to have a higher chance of giving consent than those asked at the time of death or after death.	Very low
Approach after death						
1 study 1 x retrospective study- [C]	S (a)	NA	S (b)	S (c)	A study also showed that when families of potential donors were asked about donation following notification of death of their loved one, as opposed to before or simultaneously with notification of death, they tended to have a higher chance of giving consent.	Very low
Time difference between approaches						
1 study 1 x retrospective study- [V]	S (a)	NA	S (b)	S (c)	A study showed that when time from admission 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.	Very low
Factors associated with optimal time to approach families of adult potential donors						
1 study 1 x Qualitative Study - [J]	S (a)	NA	S (b)	S (c)	A study showed that families who had denied consent had not been given enough time to prepare them for organ donation and had not been clearly informed that their loved one (potential donor) was brain dead.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
3 studies 2 x Qualitative Studies -[J] and [S] 1 x Qualitative retrospective study- [H]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x Qualitative Study- [J]	S (a)	NA	S (b)	S (c)	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	Very low
Factors associated with optimal time to approach families of paediatric potential donors						
1 study 1 x qualitative study- [B]	S (a)	NA	S (b)	S (c)	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.	Very low
1 study 1 x qualitative study- [Be-a], [Be-b]	S (a)	NA	S (b)	S (c)	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.	Very low

[N] = Niles et. al (1996)
[S] = Siminoff et. al (2002)
[C] = Cutler et. al (1993)
[V] = Vane et. al (2001)
[J] = Jacoby et al (2005)
[H] = Haddow (2004)
[S] = Sanner et. al (2007)
[B] = Bellali et. al (2006)
[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 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

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
Donor referrals						
2 studies 1 x Observational study- [S] 1 x Retrospective study- [R]	S (a)	NA	S (b)	S (c)	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	Very low
Consent rates						
1 study 1 x Observational study- [Sh]	S (a)	NA	S (b)	S (c)	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	Very low
Conversion rates and number of donors						
4 studies 2 x Observational studies- [S] and [Sh] 2 x Retrospective studies- [R] and [A]	S (a)	NA	S (b)	S (c)	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 275% in the number of donors when hospitals had in-house coordinators coordinating the process in hospitals compared to hospitals without in-house coordinators.	Very low
Number of organs recovered						
1 study 1 x Observational study- [S]	S (a)	NA	S (b)	S (c)	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.	Very low

Study characteristics					Summary of findings	
No. of studies	Limitation	Inconsistency	Indirectness	Other consideration	Analysis	Quality
1 x Retrospective study- [R]						

[S] = Shafer et al (1998)
[R] = Roth et. al (2003)
[Sh] = Shafer et al (2004)
[A] = Al-Sebayel et. al (2004)
(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.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 154 Author: Aubrey et. al (2008) Study type: Retrospective study (audit)	<u>Study group:</u> 770 deaths audited out of 1204 deaths <u>Control group:</u> N/A <u>Study period:</u> Oct. 2004 to Dec. 2005 <u>Setting:</u> 10 accident and emergency (A&E) departments in the North Thames region	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not applicable.	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 nondonation 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

						department. **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:						

Reference: Aubrey, P, Arber, S, Tyler, M The organ donor crisis: the missed organ donor potential from the accident and emergency departments. *Transplantation Proceedings* 2008; **40:** 1008-11.

Title: Number of potential cadaveric donors: reasons for nonprocurement and suggestions for improvement.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 865 Author: Gabel and Edstrom (1993) Study type: Audit report	Study group: Not reported Control group: N/A Study period: May 1989 to Dec. 1991 Setting: Sweden	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not applicable.	Performed continuous registration of potential cadaveric donors to assess donor availability and reasons for nonprocurement. Cases in which a diagnosis of total cerebral infarction was made were reported together with details of whether treatment was discontinued with adequate peripheral circulation. Information regarding suitability of the patient for organ donation and circumstances when suitable organs were not procured were also reported.	N/A	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.
Additional comments:						

Reference: Gabel, H, Edstrom, B Number of potential cadaveric donors: reasons for nonprocurement and suggestions for improvement. *Transplantation Proceedings* 1993; **25:** 3136.

Title: Detection of potential organ donors: a 2-year analysis of deaths at a German university hospital.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 56 Author: Petersen et. al (2009) Study type: Retrospective study	<u>Study group:</u> 1312 deaths <u>Control group:</u> N/A <u>Study period:</u> 2006-2007 <u>Setting:</u> Sweden	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not applicable.	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.	N/A	Among 1312 deaths, organ donation should have been considered in 114 cases, but was actauly 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.
<u>Additional comments:</u>						

Reference: Petersen, P, Fischer-Frohlich, CL, Konigsrainer, A, Lauchart, W Detection of potential organ donors: 2-year analysis of deaths at a German university hospital. *Transplantation Proceedings* 2009; **41:** 2053-54.

Title: Knowledge and attitudes of physicians regarding organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 746 Author: Molzahn (1997) Study type: Retrospective study	<u>Study group:</u> 2,400 questionnaires sent 831 physicians responded <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> Canada	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not applicable.	To describe Canadian physicians' knowledge, commitment, and professional involvement relating to organ donation, and to identify factors related to personal commitment and professional involvement. The questionnaire included sections on demographic characteristics, knowledge of and attitudes toward organ donation, willingness to facilitate the donation process, and experience with organ donation.	N/A	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. 95.4% of physicians strongly approved of organ donation 68.3% felt comfortable identifying organ donors 47.2% believed that brain death is difficult to explain to families. 57% agreed that they do not like to become involved in organ donation. 16% were concerned about potential liability 74.6% reported that organ donation was emotionally demanding 75% reported other health professionals were reluctant to approach families about organ donation. Strategies to improve organ donation 65.8% supported the idea that hospitals should be required to participate in organ donation 85.3% agreed that hospital protocols should be developed for assessing ventilated patients as potential organ donors.
<u>Additional comments:</u>						

Reference: Molzahn, AE Knowledge and attitudes of physicians regarding organ donation. *Annals of the Royal College of Physicians & Surgeons of Canada* 1997; **30:** 29-32.

Title: Shortage of donation despite an adequate number of donors: A professional attitude?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 486 Author: Ploeg et . al (2003) Study type: Prospective study	<u>Study group:</u> 5000 deceased patients 4877 filled D-forms 717 physicians <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> 11 hospitals in The Netherlands	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not applicable.	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. The donation form (D-form) was constructed to obtain information at the time of death of patients. In calculating the organ-donor potential in the hospitals included in the study, 3 possible scenarios were used: 1. Maximum potential: which included all deceased patients that had no specific contraindications and were below the proper age thresholds. 2. Optimistic potential: which included all deceased patients who had a diagnosis that could lead to brain death. 3. Realistic potential: the numbers obtained in the optimistic potential were used, with the addition of artificial respiration and brain death.	N/A	Maximum potential- 922 out of 4,877 deceased patients Optimistic potential- 205 Realistic potential- 61 out of 205 Out of 61, only in 42 (69%) was the topic of donation raised. 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: Medical contraindication-50% No time- 10% Did not think of it-5% Difficult situation- 4% Other reasons-18% In the multilevel analysis, the chance that a physician raises the donation request varies between 2% and 77% **Factors that had a strong and significant influence on whether or not the donation request was done were:** • Number of potential organs in a particular donor (p-0.000) • Knowledge of contraindications by physician (p-0.000) • Cause of death (p-0.026) with

						natural causes of death • Sex of the physician (p-0.035) female physicians are more likely to ask than male colleagues. **Factors that did not influence were :** • Sex of the patient • Time of death • Presence of a codicil Age of the physician • Position of the physician • Frequency with which the physician confirmed death.
Additional comments:						

Reference: Ploeg, RJ, Niesing, J, Sieber-Rasch, MH, Willems, L, Kranenburg, K, Geertsma, A Shortage of donation despite an adequate number of donors: a professional attitude? *Transplantation* 2003; **76:** 948-55.

<table>
<tr><th colspan="6">Title: Organ donor potential and performance: size and nature of the organ donor shortfall.</th></tr>
<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>
<tr>
<td>ID:
789

Author:
Gortmaker et. al (1996)

Study type:
Retrospective study (medical records review)</td>
<td><u>Study group:</u>
69 hospitals in a non random sample
956 medically suitable potential donors
40 records missing
916 complete data available

<u>Control group:</u>
N/A

<u>Study period:</u>
Jan 1990 to Dec. 1990

<u>Setting:</u>
USA</td>
<td>N/A</td>
<td><u>Inclusion /Exclusion(study group):</u>

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.

<u>Characteristics of cases:</u>
Not mentioned

<u>Baseline Measurements:</u>
Not applicable.</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)]

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-0.0001)

Donation was also lower among African American (22%) and Hispanic subjects (17%) compared with non-Hispanic white subjects (41%, p-<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- <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.

Table 1: Predictors of organd donation
<table>
<tr><th>Predictor variables</th><th>Multivariate Odds</th><th>95% CI</th><th>p value</th></tr>
<tr><td colspan="4">Age (years)</td></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-</td><td>0.0001</td></tr>
</table>
</td>
</tr>
</table>

								10.00	
						50-59	2.16	1.04-4.50	0.04
						≥60	1.00		
						ace/ thnicity			
						Africa American	0.38	0.23 0.63	0.0001
						Hispanic	0.26	0.13-0.49	0.0001
						White (non-Hispanic)	1.00		
						All other	0.25	0.11-0.57	0.0009
						Cause of Death			
						Gunshot wound/stabbing	2.70	1.58-4.62	0.0003
						Motor vehicle	2.22	1.40-3.51	0. 007
						Other head trauma	1.00		
						Cerebrovascular	1.33	0.84-2.10	0.22
						All other	1.23	0.66-2.30	0.52

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 aged0 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:						

Reference: Gortmaker, SL, Beasley, CL, Brigham, LE, Franz, HG, Garrison, RN, Lucas, BA, Patterson, RH, Sobol, AM, Grenvik, NA, Evanisko, MJ Organ donor potential and performance: size and nature of the organ donor shortfall. *Critical Care Medicine* 1996; **24:** 432-39.

<table>
<tr><th colspan="7">Title: A survey of personal and professional attitudes of intensivists to organ donation and transplantation.</th></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>ID:
819

Author:
Pearson et al (1995)

Study type:
Retrospective study</td><td><u>Study group:</u>
293 intensivists replied

<u>Control group:</u>
N/A

<u>Study period:</u>
1992

<u>Setting:</u>
Australia and New Zealand</td><td>N/A</td><td><u>Inclusion /Exclusion(study group):</u>

Not mentioned

<u>Characteristics of cases:</u>
Not mentioned

<u>Baseline Measurements:</u>
Not applicable.</td><td>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.</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.

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 al, that implied that only 40 had a policy in practice.

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

<table>
<tr><td>Reasons for not asking</td><td>Total</td></tr>
<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>
</table>
</td></tr>
<tr><td colspan="7"><u>Additional comments:</u></td></tr>
</table>

Reference: Pearson, IY, Zurynski, Y A survey of personal and professional attitudes of intensivists to organ donation and transplantation. *Anaesthesia & Intensive Care* 1995; **23:** 68-74.

Title: Improving donor identification with the Donor Action Programme.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 517 Author: Pugliese et al (2003) Study type: Retrospective study	Study group: 14 ICUs Control group: N/A Study period: July 1998 to Dec. 2000 Setting: Emilia Romagna region	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: The demographic characteristics of the study population, age and gender, remained stable in the analysed periods.	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 co-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.	N/A	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, χ^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, χ^2- 13.779) since the implementation of the DA project.
Additional comments:						

Reference: Pugliese, MR, Degli, ED, Dormi, A, Venturoli, N, Mazzetti, GP, Buscaroli, A, Petropulacos, K, Nanni, CA, Ridolfi, L Improving donor identification with the Donor Action programme. *Transplant International* 2003; **16:** 21-25.

Title: Identifying the potential organ donor; an audit of hospital deaths.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1244 Author: Opdam et. al (2004) Study type: Prospective study (medical record audit)	<u>Study group:</u> 12 Victorian hospitals 5551 deaths <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> Victorian Hospitals, Australia.	N/A	<u>Inclusion /Exclusion(study group):</u> Excluded those patients <1 year or >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. <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	To identify all potential donors (not just those in ICUs). The panel members discussed each case and classified according to the following categories: 1. Confirmed brain death 2. Likely to progress to brain death with 24h 3. Likely to progress to brain death with >24h but <72h 4. Not likely to progress to brain death within 72h or medically unsuitable for donation. Categories 1-3 were considered to be unrealized potential organ donors and category 4 was considered not to be potential organ donors.	N/A	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
<u>Additional comments:</u>						

Reference: Opdam, HI, Silvester, W Identifying the potential organ donor: an audit of hospital deaths. *Intensive Care Medicine* 2004; **30:** 1390-1397.

Title: Estimating the organ donor potential in Denmark: A prospective analysis of deaths in intensive care units in Northern Denmark.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 355 Author: Madsen et. al (2006) Study type: Prospective study	Study group: 15 ICUs 1655 deaths Control group: N/A Study period: Sept. 2000 to August 2002 Setting: Denmark	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	N/A	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%
Additional comments:						

Reference: Madsen, M, Bogh, L Estimating the organ donor potential in Denmark: a prospective analysis of deaths in intensive care units in northern Denmark. *Transplantation Proceedings* 2005; **37:** 3258-59.

Title: The identification of potential cadaveric organ donors.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 818 Author: Thompson et. al (1995) Study type: Prospective study (audit)	<u>Study group:</u> Phase 1: 6080 deaths Phase 2: 1326 deaths <u>Control group:</u> N/A <u>Study period:</u> Phase 1: April 1991 to March 1992 Phase 2: Aug. 1992 to Jul. 1993 <u>Setting:</u> NSW, Australia	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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 in 4 hospitals in country NSW.	N/A	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 48 resuscitation attempted but unsuccessful 63 refused permission for donation 49 became actual donors BUT 65 classified as ‘missed’ potential donors Phase 2: 1326 patients 103 potential donors 24 classified as unrealistic potential donors Another 14 became unrealistic 19 deemed medically unsuitable 46 realistic medically suitable potential donors

						15 resuscitation attempted but unsuccessful 9 refused permission for donation 11 became actual donors BUT 11 classified as 'missed' potential donors
Additional comments:						

Reference: Thompson, JF, McCosker, CJ, Hibberd, AD, Chapman, JR, Compton, JS, Mahony, JF, Mohacsi, PJ, Macdonald, GJ, Spratt, PM The identification of potential cadaveric organ donors. *Anaesthesia & Intensive Care* 1995; **23:** 75-80.

Title: Poisoned patients as potential organ donors; postal survey of transplant centers and intensive care units.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results

ID: 1387 Author: Wood et. al (2003) Study type: Retrospective study	<u>Study group:</u> 67 doctors total 35 surgeons 32 physicians 30 directors <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> United Kingdom	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> 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.
<u>Additional comments:</u>						

Reference: Wood, DM, Dargan, PI, Jones, AL Poisoned patients as potential organ donors: Postal survey of transplant centres and intensive care units. *Critical Care* 2003; **7:** 147-54.

Title: National survey of potential heart beating solid organ donors in Sweden.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 95 Author: Moller Et. al (2009) Study type: Retrospective study	Study group: 875 deaths Control group: N/A Study period: Last quarter of 2007 Setting: Sweden	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	The questionnaire consisted of 10 major questions concerning brain injury, mechanical ventilation, death diagnosis, and why donation did not take place among potential donors.	N/A	217 were on mechanical ventilation for at least 24 hours before death 65 declared brain dead 56 considered medically suitable Transplant coordinator contacted in 52 cases 29 patients had expressed their wishes about donation during their lifetime and consent was obtained in 18 of them.
Additional comments:						

Reference: Moller, C, Welin, A, Henriksson, BA, Rydvall, A, Karud, K, Nolin, T, Brorson, I, Nilsson, L, Lundberg, D, Swedish Council for Organ and Tissue Donation National survey of potential heart beating solid organ donors in Sweden. *Transplantation Proceedings* 2009; **41:** 729-31.

<table>
<tr><th colspan="7">Title: Improved organ procurement through implementation of evidence-based practice</th></tr>
<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>
<tr><td>ID: 96

Study type:
Observational

Authors:
Bair et al (2006)</td><td colspan="6">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><tr><th></th><th>2004</th><th>2005</th><th>p-value</th></tr><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></table>However, this was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.</td></tr>
<tr><td colspan="7">Additional comments: Not able to isolate the effect of clinical triggers. Limited number of data points.</td></tr>
</table>

Reference: H. A. Bair, P. Sills, K. Schumacher, P. J. Bendick, R. J. Janczyk, and G. A. Howells. Improved organ procurement through implementation of evidence-based practice. Journal of Trauma Nursing 13 (4):183-185, 2006.

Title: US organ donation breakthrough collaborative increases organ donation						
Level of Evidence	Patient Population/ Characteristics	Selection/Inclusion criteria	Intervention	Comparison	Follow-up	Outcome and Results
ID: 61 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 • teaching hospital staff clinical triggers for referral (GCS of 5) 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: T. J. Shafer, D. Wagner, J. Chessare, M. W. Schall, V. McBride, F. A. Zampiello, J. Perdue, K. O'Connor, M. J. Lin, and J. Burdick. US organ donation breakthrough collaborative increases organ donation. *Critical Care Nursing Quarterly* 31 (3):190-210, 2008.

Title: Implementation of an intervention plan designed to optimize donor referral in a donor hospital network.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 114 Author: Van gelder et. al (2006) Study type: Observational study	Study group: Not mentioned Control group: N/A Study period: Jan 1996 to Dec 2003 Setting: Belgium	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: NA	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. A multiple point plan was designed on the basis of 3 essential equal pillars; 1. Information on donation criteria 2. Facilitation of the donor procedure to reduce workload in the donor centre 3. Communication between the donor centre and the transplant centre to increase involvement of the donor teams in the transplant procedures. **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.	The number of potential donors increased by 27.46 %(324 in period 1 vs. 413 in period 2, p-<0.02). The number of effective donors increased by 30.86% (230 vs. 301, p-<0.05) from period 1 to period 2. The number of donor hospitals per year increased by 37% (16 in period 1 vs. 22 in period 2, p-<0.02).
Additional comments: This was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.				

Reference: Van, GF, Van, HD, de, RJ, Monbaliu, D, Aerts, R, Coosemans, W, Daenen, W, Pirenne, J Implementation of an intervention plan designed to optimize donor referral in a donor hospital network. *Progress in Transplantation* 2006; **16:** 46-51.

Title: Increasing organ recovery from level I trauma centers: the in-house coordinator intervention.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 143 Author: Shafer et. al (2004) Study type: Observational study	Study group: Not mentioned Control group: N/A Study period: 1999 to 2002 Setting: 8 LITCs in New York, Los Angeles, Houston, and Seattle.	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Age of donors-1month to 18 years 27 boys 6 girls Baseline Measurements: Not mentioned	The purpose of this study was to evaluate whether placement of OPO staff in Level I trauma centers (LITC) with large donor potential, to provide case management as well as donation system development, would result in a significant increase in organ donation, particularly among members of minority groups. Protocols were developed that outlined the role and activities of the IHC in 5 critical areas: Creating a positive environment for donation within the institution, providing support for potential donors families, obtaining consent, evaluating and managing donors, and evaluating the process.	**OPO Service area comparison** Total referrals increased 26% in the project IHC LITCs vs. 14% in the comparison hospitals. Potential donors increased 4% in IHC LITCs. Despite the fact that the project IHC LITCs had a higher minority population than the comparison hospitals, the consent rate was higher (55% vs. 44%) at IHC LITCs. The number of no consents decreased by 4% in the IHC LITCs despite the fact that the number of potential donors increased 4%. The consent and conversion rates in all ethnic groups were higher in the project IHC LITCs than in the comparison non-IHC centers. **National Comparison** Total referrals increased 26% in the IHC LITCs compared with 12% in the comparison LITCs. Potential donors increased in the 4% in the IHC LITCs vs. a 2% decrease in the comparison LITC. In the IHC LITCs the consent rate increased 13% vs. unchanged in the comparison group, no consents decreased 4% vs. 2% increase in comparison hospitals, the conversion rate increased 22% vs.2% increase, and the number of organs increased 26% vs. unchanged in the number of organs in comparison hospitals.
Additional comments: This was a hugely complex intervention, so it is not possible to attribute this to the use of clinical triggers alone.				

Reference: Shafer, TJ, Ehrle, RN, Davis, KD, Durand, RE, Holtzman, SM, Van Buren, CT, Crafts, NJ, Decker, PJ Increasing organ recovery from level I trauma centers: the in-house coordinator intervention. *Progress in Transplantation* 2004; **14:** 250-263.

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

Level of Evidence	Patient Population/ Characteristics	Selection/Inclusion criteria	Intervention	Comparison	Follow-up	Outcome and Results
ID: 188 and 182 Study type: Observational Authors: Higashiwaga et al (2001) Higashiwaga et al (2002)	Total no. of deaths: 4,679 (in 1999) and 4,730 (in 2000) Setting: 17 major acute care hospitals in Hawaii	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

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

Additional comments: Retrospective chart review.

Reference: K. H. Higashigawa, C. Carroll, and L. L. Wong. Organ procurement 1999-2000: how is Hawaii doing? *Hawaii Medical Journal* 60 (12):314-317, 2001.
K. H. Higashigawa, C. Carroll, L. L. Wong, and L. M. Wong. Organ donation in Hawaii: impact of the final rule. *Clinical Transplantation* 16 (3):180-184, 2002.

<table>
<tr><th colspan="6">Title: 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 recommendations</th></tr>
<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>
<tr><td>ID: 28

Study type: Observational

Authors: Murphy et al (2009)</td><td><u>Setting:</u>
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
<table>
<tr><td></td><td colspan="2">2006-7</td><td colspan="2">2007-8</td></tr>
<tr><td>Number</td><td>Heart beating donors</td><td>Non-heart beating donors</td><td>Heart beating donors</td><td>Non-heart beating donors</td></tr>
<tr><td>Referred</td><td>2</td><td>1</td><td>7</td><td>31</td></tr>
<tr><td>Accepted</td><td>1</td><td>1</td><td>6</td><td>7</td></tr>
</table>
[NOTE: read off graph in published paper]</td></tr>
<tr><td colspan="6"><u>Additional comments</u>: 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.</td></tr>
</table>

Reference: F. Murphy, D. Cochran, and S. Thornton. 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 recommendations. Anaesthesia 64 (8):822-828, 2009.

<table>
<tr><th colspan="7">Title: Concentrated professional education to implement routine referral legislation increases organ donation</th></tr>
<tr><td>Level of Evidence</td><td>Patient Population/ Characteristics</td><td>Selection/Inclusion criteria</td><td>Intervention</td><td>Comparison</td><td>Follow-up</td><td>Outcome and Results</td></tr>
<tr><td>ID: 239

Study type: Observational

Authors: Robertson et al (1998)</td><td><u>Setting:</u>
136 hospitals in a transplant programme in the US</td><td>Potential organ donors</td><td>Routine referral
Required due to legislation, and implemented through professional educational initiatives, provision of sample hospital policies, reallocation of resources</td><td>Pre-introduction of routine referral</td><td>24 months</td><td>Results were
<table>
<tr><th></th><th>1994</th><th>1996</th><th>Increase (%)</th></tr>
<tr><td>Referrals</td><td>528</td><td>824</td><td>56</td></tr>
<tr><td>Medically suitable referrals</td><td>342</td><td>427</td><td>25</td></tr>
<tr><td>Donors</td><td>175</td><td>217</td><td>24</td></tr>
</table></td></tr>
<tr><td colspan="7"><u>Additional comments:</u> Limited number of data points. Not clear if attributable to routine referral alone as part of complex educational initiative.</td></tr>
</table>

Reference: H V. M. Robertson, G. D. George, P. S. Gedrich, R. D. Hasz, R. A. Kochik, and H. M. Nathan. Concentrated professional education to implement routine referral legislation increases organ donation. *Transplantation Proceedings* 30 (1):214-216, 1998.

<table>
<tr><th colspan="6">Title: Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals</th></tr>
<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>
<tr>
<td>ID: 226

Study type: Observational

Authors: Shafer et al (1998)</td>
<td><u>Setting:</u>
20 non-donor hospitals in US</td>
<td><u>Non-donor hospitals:</u>
• >100 beds,
• regional or community centres,
• had ICUs, operating rooms, staff neurologists and an 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
<table>
<tr><th>.</th><th>1991-3</th><th>1995-7</th><th>Increase (%)</th></tr>
<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>
</table>
</td>
</tr>
<tr><td colspan="7"><u>Additional comments</u>: 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.</td></tr>
</table>

Reference: T. J. Shafer, R. Durand, M. J. Hueneke, W. S. Wolff, K. D. Davis, R. N. Ehrle, C. T. Van Buren, J. P. Orlowski, D. H. Reyes, R. T. Gruenenfelder, and C. K. White. Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals. *Journal of Transplant Coordination* 8 (3):146-152, 1998.

Title: US organ donation breakthrough collaborative increases organ donation						
Level of Evidence	Patient Population/ Characteristics	Selection/Inclusion criteria	Intervention	Comparison	Follow-up	Outcome and Results
ID: 61 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.						

Reference: T. J. Shafer, D. Wagner, J. Chessare, M. W. Schall, V. McBride, F. A. Zampiello, J. Perdue, K. O'Connor, M. J. Lin, and J. Burdick. US organ donation breakthrough collaborative increases organ donation. *Critical Care Nursing Quarterly* 31 (3):190-210, 2008.

Title: Organ donation rates in a neurosurgical intensive care unit.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 172 Author: Dickerson et. al (2002) Study type: Retrospective study	Study group: Not mentioned Control group: N/A Study period: 1996 to 1999 Setting: BGTH, Houston	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	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.
Additional comments:				

Reference: Dickerson, J, Valadka, AB, Levert, T, Davis, K, Kurian, M, Robertson, CS Organ donation rates in a neurosurgical intensive care unit. *Journal of Neurosurgery* 2002; **97:** 811-14.

Title: A system's approach to improve organ donation.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 24 Author: Graham et. al (2009) Study type: Retrospective study	Study group: Not mentioned Control group: N/A Study period: Not mentioned Setting: USA	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	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.
Additional comments:				

Reference: Graham, JM, Sabeta, ME, Cooke, JT, Berg, ER, Osten, WM A system's approach to improve organ donation. *Progress in Transplantation* 2009; **19:** 216-20.

Title: A continuous quality improvement process to increase organ and tissue donation.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 252 Author: Burris et. al (1996) Study type: Retrospective study	Study group: Not mentioned Control group: N/A Study period: Mar 1994 to Dec 1994 Setting: USA	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	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%).
Additional comments:				

Reference: Burris, GW, Jacobs, AJ A continuous quality improvement process to increase organ and tissue donation. *Journal of Transplant Coordination* 1996; **6:** 88-92.

Supporting evidence

Title: Religious attitudes regarding organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1719 Author: Gallagher (1996) Study type: Retrospective study	Study group: 183 responses Control group: N/A Study period: Not mentioned Setting: USA	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	A preliminary survey designed to ascertain beliefs held by religious leaders was designed.	N/A	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.
Additional comments:						

Reference: Gallagher, C Religious attitudes regarding organ donation. *Journal of Transplant Coordination* 1996; **6:** 186-91.

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?

<table>
<tr><td colspan="7">Title: Effect of ‘collaborative requesting’ on consent rate for organ donation: randomized controlled trial (ACRE trial)</td></tr>
<tr><td>Level of Evidence</td><td>Patient Population/ Characteristics</td><td>Selection/Inclusion criteria</td><td>Intervention</td><td>Comparison</td><td>Follow-up</td><td>Outcome and Results</td></tr>
<tr><td>ID: 896

Study type: RCT

Authors: Young et. al (2009)</td><td><u>Total no. of patients:</u>
Baseline = 317
Excluded- 116
Collaborative request group- 101
Routine request group- 100

<u>Baseline characteristics:</u>

There were no differences in the characteristics of donors between groups, and the relatives were matched,

<u>Setting:</u>
79 general, neuroscience, and paediatric intensive care units in UK.</td><td><u>Inclusion:</u>
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.

<u>Exclusion:</u>

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

<table><tr><td></td><td>All (n-201)</td><td>Routine request (n-101)</td><td>Collaborative request (n-100)</td></tr><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></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</td></tr>
</table>

						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.						

Reference: 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 (ACRE trial). *BMJ* 2009; **339:** 899-901.

Title: A qualitative examination of the needs of families faced with the option of organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 234 Author: Jacoby et al (2005) Study type: Qualitative study (interviews)	<u>Study group:</u> 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 <u>Control group:</u> N/A <u>Study period:</u> July 1998 to Dec. 2000 <u>Setting:</u> 3 sites in New York	N/A	<u>Inclusion /Exclusion(study group):</u> Eligible legal next of kin who consented or refused donation of their loved one's organs. <u>Characteristics of cases:</u> Age range- 31-65 years (mean-43 yrs) <u>Baseline Measurements:</u> Not mentioned	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?	N/A	**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.

						Examples: 'I had a fear of giving up too quickly,' 'We had the feeling the physicians wished we would give up now so somebody can stop waiting.' 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** **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.
Additional comments:						

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.

Title: Donor and non-donor families' accounts of communication and relations with healthcare professionals.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 290 Author: Haddow (2004) Study type: Qualitative retrospective study	<u>Study group:</u> Donor families-19 Non-donor families-4 <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> Scotland	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> 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.	N/A	**Respondents' understanding of Brain-Death Tests** 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." **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**

						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

						had not received a home visit suggested they could not see what they would gain from such a visit, although this does not subsequently imply that no support should be offered.

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.

Reference: Haddow, G Donor and nondonor families' accounts of communication and relations with healthcare professionals. *Progress in Transplantation* 2004; **14:** 41-48.

Title: Two perspectives on organ donation: experiences of potential donor families and intensive care physicians of the same event.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 199 Author: Sanner et. al (2007) Study type: Qualitative study	<u>Study group:</u> 20 relatives (donors and non-donors) 25 physicians <u>Control group:</u> N/A <u>Study period:</u> Not mentioned <u>Setting:</u> Sweden	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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. Relatives were mostly interviewed in their homes, but in some cases in our offices. Physicians were either interviewed by telephone or in their offices. An open interview method was chosen to allow informants to speak freely about their experiences, although predetermined issues were also covered.	N/A	Several physicians stressed the importance of "making everything right when determining death." "There must be no question at all about it." **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, concentra-tion, and timing. They under-scored 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

						talk with other close kin. **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 under-standing information. His impression was that the family did not want the body to be cut into.
Additional comments:						

Reference: 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.

Title: The instability of organ donation decisions by next-of-kin and factors that predict it.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 72 Author: Rodrigue et. al (2008) Study type: Retrospective study	Study group: 285 next-of-kin 147-donors 138-non-donors Each participant was paid $75.00 Control group: N/A Study period: Jul 2001- Feb 2004 Setting: Gainesville, Florida	N/A	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	The aims were to examine the instability of organ donation decisions made by next-of-kin and to identify factors that predict decision instability among non-donor next-of-kin. Semi-structured interviews were done within 4 weeks of the donation decision.	N/A	Decision instability was more likely when the deceased had not previously discussed organ donation with the next-of-kin (p-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-0.01). Also when they perceived the timing of donation discussion to be poor (p-0.001). Were not told of their loved one's death before the first mention of donation (p-0.0001) Did not feel they were given enough time to discuss their donation decision with others (p-0.006). These variables were statistically significant predictors of decision instability among next-of-kin non-donors in a logistic regression model.
Additional comments:						

Reference: Rodrigue, JR, Cornell, DL, Howard, RJ The instability of organ donation decisions by next-of-kin and factors that predict it. *American Journal of Transplantation* 2008; **8:** 2661-67.

Title: The stability of family decisions to consent or refuse organ donation: would you do it again?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 477 Author: Burroughs et. al (1998) Study type: Retrospective study	Study group: 225individuals 159-donating families 66-non donating families Control group: N/A Study period: 1988 to 1992 Setting: USA	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: Group1- nondonors who would make the same decision again Group2- 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 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).

Additional comments:

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.

Title: Trend of consents for donation by relatives of cadaveric donors in Kingdom of Saudi Arabia.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 548 Author: Shaheen et. al (1996) Study type: Retrospective study (audit)	<u>Study group:</u> 815 approachable families <u>Control group:</u> N/A <u>Study period:</u> 1986 to 1994 <u>Setting:</u> Saudi Arabia	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> 689-males 126-females <u>Baseline Measurements:</u> Not applicable.	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. The method of approaching the family for donation included: 1. The family was told about the diagnosis of brain death by the treating physician or intensive care unit physician. 2. A 'gap' for grief was given before requesting the consent for organ donation from them. This was usually 6-8 hours. 3. The convincing team showed sympathy, explained the concept of brain death in good terms, and supported their talks with explanation of the religious views about donation and brain death.	N/A	There were no significant changes in the rates of success of obtaining consent for donation in the male (41%) and female (27%) groups
<u>Additional comments:</u>						

Reference: Shaheen, FA, al-Khader, A, Souqiyyeh, MZ, Attar, MB, Ibrahim, S, Paul, TT, al-Swailem, AR Trend of consents for donation by relatives of cadaveric donors in the Kingdom of Saudi Arabia. *Transplantation Proceedings* 1996; **28:** 381.

Title: Refusal of consent for organ donation: from survey to bedside.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 789 Author: Yong et. al (2000) Study type: Prospective study (survey)	Study group: 435 potential organ donors monitored Control group: N/A Study period: 1996 to 1998 Setting: Hong Kong Hospital Authority Transplant Registry	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not applicable.	The aim was to identify reasons given by family at bedside when a request for donation was refused.	N/A	Traditional cultural beliefs on keeping the body intact was the most common reason for refusal (54.2%) 12% expressed fear that donation would increase the sufferings of the patient. Uncertainty about relatives' wishes and patients' objection to donation when alive accounted for 8% Emotional reluctance to accept death- 5% Lack of family consensus and family being 'upset'- 3%
Additional comments:						

Reference: Yong, BH, Cheng, B, Ho, S Refusal of consent for organ donation: from survey to bedside. *Transplantation Proceedings* 2000; **32:** 1563.

Title: Factors influencing families' consent for donation of solid organs for transplantation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 387 Author: Siminoff et al (2001) Study type: Retrospective study (chart review and interviews)	<u>Study group:</u> 420 cases 238 donors 182 non-donors <u>Control group:</u> N/A <u>Study period:</u> Jan 1994 to Dec 1999 <u>Setting:</u> 9 trauma hospitals, Southwestern Pennsylvania and Northeastern Ohio	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> There were no differences between participants and non participants by age, sex, or ethnicity.	The goals were to assess the determinants of families' willingness to donate solid organs, to describe the process and content of the conversations surrounding the donation request, and to evaluate the correlation between these factors and the consent rate. Data collection was done via chart reviews, telephone interviews with health care practitioners (HCPs) or organ procurement organization (OPO) staff, and interviews with family for all donor-eligible deaths.	N/A	**Associations of factors predating the donation decision.** Families of white patients (61.4% vs. 38.6%, p- <0.001), younger patients (p- 0.001), and male patients (62.2% vs. 37.8%, p- 0.007) were more likely to consent to organ donation. Consent was also associated with deaths due to trauma compared with non-trauma related deaths (65.1% vs. 34.9%, p- 0.002). No associations were found between consent rates and families' educational attainment or income. Families who reported positive beliefs about organ donation and had prior knowledge of the patients' wishes regarding organ donation were significantly more likely to donate. Knowing the patient had a donor card (p- <0.001), having had an explicit discussion about donation with the patient (p- 0.02), and a belief that patient would have wanted to donate (p- <0.001) were strongly associated with consent to organ donation. HCPs' comfort with answering families' questions about donation was significantly associated with organ

						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 or 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 9p- <0.001).

Additional comments:

Reference: Siminoff, LA, Gordon, N, Hewlett, J, Arnold, RM Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001; **286:** 71-77.

Title: Donor Families' Attitude Toward Organ Donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1558 Author: La Spina et. al (1993) Study type: Retrospective study	Study group: 20 families Control group: N/A Study period: Not mentioned Setting: Italy	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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 1CU medical staff at the end of the clinical event, either in case of a consent to donation or refusal.	N/A	Beyond the generally defined "humanitarian" 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.
Additional comments:						

Reference: La, SF, Sedda, L, Pizzi, C, Verlato, R, Boselli, L, Candiani, A, Chiaranda, M, Frova, G, Gorgerino, F, Gravame, V, Mapelli, A, Martini, C, Pappalettera, M, Seveso, M, Sironi, PG Donor families' attitude toward organ donation. *Transplantation Proceedings* 1993; **25:** 1699-701.

Title: Demographic factors influencing consent for cadaver organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 686 Author: Pike et. al (1990) Study type: Retrospective study (audit)	<u>Study group:</u> 566 potential donors referred <u>Control group:</u> N/A <u>Study period:</u> Jan 1984 to Jun 1989 <u>Setting:</u> Groote Schuur Hospital, Cape Town.	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> 424 males 137 females Mean age- 28 years <u>Baseline Measurements:</u> Not mentioned	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.	N/A	**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**

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

Reference: Pike, RE, Kahn, D, Jacobson, JE Demographic factors influencing consent for cadaver organ donation. *South African Medical Journal* 1991; Suid-Afrikaanse**:** 264-67.

Title: Information on Relatives of Organ and Tissue Donors. A Multicenter Regional Study: Factors for Consent or Refusal.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 554 Author: Noury et. al (1996) Study type: Retrospective study	Study group: 300 interviews Control group: N/A Study period: Eastern France-Jan 1991 to Sept. 1992 Western France-Jul 1992 to Apr 1993 Setting: Eastern (8 hospitals) and Western (9 Hospitals) France	N/A	Inclusion /Exclusion(study group): Brain dead patients. Characteristics of cases: 200 males 100 females Baseline Measurements: Not mentioned	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.	N/A	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.
Additional comments:						

Reference: Noury, D, Jacob, F, Pottecher, T, Boulvard, A, Pain, L Information on relatives of organ and tissue donors. A multicenter regional study: factors for consent or refusal. *Transplantation Proceedings* 1996; **28:** 135-36.

Title: Barriers to Obtaining Family Consent for Potential Organ Donors.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1143 Author: Brown et. al (2010) Study type: Retrospective study	Study group: 827 potential organ donor referrals Control group: N/A Study period: 2004 to 2007 Setting: USA	N/A	Inclusion /Exclusion(study group): All potential organ donor referrals to TOSA (Texas organ sharing alliance) during the 4-year period from January 1, 2004, through December 31, 2007, were included in the analysis. Characteristics of cases: Average age- 39±18 yrs 467 males Baseline Measurements: Not mentioned	The purpose of this study was to compare families who declined organ donation to those Who granted consent, specifically to identify barriers to family consent for successful organ donation. Information was collected from a database of all potential organ donors maintained by TOSA. Once contacted by the healthcare team about a potential organ donor, TOSA responds immediately with a standard structure of approach. The approach of TOSA for potential organ donors includes (1) an assessment of the family; (2) collaboration with the healthcare team regarding: family visitation with their loved one, timing of approach, a private setting for discussion, assistance for the family, and introduction of TOSA staff to the family; (3) verifying family understanding of their loved one's condition; (4) offering the opportunity for organ donation; (5) providing information and answering questions regarding organ donation; (6) allowing time for the family to make a decision; and (7). The family then decides whether to consent or decline organ donation.	N/A	The average time from declaration of brain death to approach by TOSA was 213 minutes ± 958 minutes. 471 families consented to donation 356 declined donation Consent rates were lower in the Hispanic (46%) and African American (33%) populations, than among Caucasian (75%) potential donors ($p < 0.001$). The decline group more often had an approach initiated independently by a healthcare provider (15% vs. 8%, p - 0.001). Families approached at the time of or within 1 hour of brain death consented to organ donation in 61% of cases, but if approached >3 hours after brain death consent rates dropped to 51% ($p < 0.001$). Consent rates were significantly lower for medical (51%) patients than for trauma (67%>) patients ($p < 0.001$). Similarly, older patients (aged 50 years or older) had a lower consent rate than younger

						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:						

Reference: 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.

Title: The process of organ donation and its effect on consent.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 397 Author: Siminoff et. al (2000) Study type: Prospective study	Study group: 827 potential organ donor referrals 1207 individual HCPs Control group: N/A Study period: 1991 to 1995 Setting: 23 Hospitals in the Pittsburgh and Min-neapolis/St Paul	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	N/A	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 ($p > 0.001$). 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 unfavor-able 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 ($OR = 2.71$, $p < 0.002$). 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.

						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:						

Reference: Siminoff, LA, Arnold, RM, Hewlett, J The process of organ donation and its effect on consent. *Clinical Transplantation* 2001; **15:** 39-47.

Title: Knowing Patients' Preferences about Organ Donation: Does it Make a Difference?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 530 Author: Siminoff et. al (2002) Study type: Retrospective study (survey)	Study group: 420 individuals Control group: N/A Study period: 1994 to 1998 Setting: 9 trauma hospitals in southwest Pennsylvania and northeast Ohio	N/A	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	N/A	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 transplan-tation (33.3%); Not liking the HCPs/OPOs or the hospital (33.3%); The family made their own assessment about eligi-bility 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

						(16.7%); and the absence of a donor card (8.3%). 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:						

Reference: Siminoff, LA, Lawrence, RH Knowing patients' preferences about organ donation: does it make a difference? *Journal of Trauma-Injury Infection & Critical Care* 2002; **53:** 754-60.

Title: A Survey of Families of Brain Dead Patients: Their Experiences, Attitudes to Organ Donation and Transplantation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1527 Author: Pearson et. al (1995) Study type: Retrospective study (survey)	<u>Study group:</u> 211 brain dead patients 163 questionnaires sent out 69 replied 32 donor families 21 non-donor families <u>Control group:</u> N/A <u>Study period:</u> Jan 1987 to Oct 1990 <u>Setting:</u> Westmead Hospital ICU, Australia	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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.	N/A	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:						

Reference: Pearson, IY, Bazeley, P, Spencer-Plane, T, Chapman, JR, Robertson, P A survey of families of brain dead patients: Their experiences, attitudes to organ donation and transplantation. *Anaesthesia and Intensive Care* 1995; **23:** 88-95.

Title: Organ donation and family decision-making within the Spanish donation system.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 577 Author: Martinez et. al (2001) Study type: Retrospective study	Study group: 68 cases 18 refused to donate 50 donated Control group: N/A Study period: May 1994 to May 1995 Setting: 13 Spanish hospitals	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	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 lo 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.
Additional comments:						

Reference: Martinez, JM, Lopez, JS, Martin, A, Martin, MJ, Scandroglio, B, Martin, JM Organ donation and family decision-making within the Spanish donation system. *Social Science & Medicine* 2001; **53:** 405-21.

Title: Family Refusal in Organ Donation: Analysis of Three Patterns.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1398 Author: Frutos et. al (2002) Study type: Retrospective study	Study group: 269 interviews 248 valid reports 21 incomplete interviews Control group: N/A Study period: Jan 1995 to Dec 2000 Setting: Spain	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	To evaluate the guidelines followed by the transplant coordinators during family interviews. The participants were divided into the following groups: Group A- acceptance of donation Group B- refusal of donation Group C- indecision. The interviews with the families of potential donors were always performed after confirmation of brain death by neurological examination and an instrument test (usually an EEG). Two members of the transplant coordination team (a doctor and a nurse), as well as a doctor from the intensive care unit, participated in the interview. The most common place was in a room near the ICU; we always tried to ensure the presence of the immediate family of the deceased, having the power of decision, with no restriction as to the number of persons. If the family initially refused or were unsure, subsequent meetings were held if there was no objection.	N/A	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. 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.
Additional comments:						

Reference: Frutos, MA, Ruiz, P, Requena, MV, Daga, D Family refusal in organ donation: Analysis of three patterns. *Transplantation Proceedings* 2002; **34:** 2513-14.

Title: Factors affecting cadaveric organ donation: A national survey of organ procurement coordinators.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 1725 Author: Douglas (1994) Study type: Retrospective study	<u>Study group:</u> 210 questionnaires mailed 202 returned <u>Control group:</u> N/A <u>Study period:</u> Not mentioned. <u>Setting:</u> USA	N/A	<u>Inclusion /Exclusion(study group):</u> 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. <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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.	N/A	**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:						

Reference: Douglas, S Factors affecting cadaveric organ donation: a national survey of organ procurement coordinators. *Journal of Transplant Coordination* 1994; **4:** 96-103.

Title: Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 345 Author: Cleiren et. al (2002) Study type: Cross sectional survey	<u>Study group:</u> 183 families approached 100 consented to participate 5 families excluded 95 study sample 36 donated 23 refused donation 36 not asked for donation <u>Control group:</u> N/A <u>Study period:</u> Not mentioned. <u>Setting:</u> 27 hospitals, Netherlands	N/A	<u>Inclusion /Exclusion(study group):</u> Inclusion criteria were that the deceased had to be less than 65 years of age, and died of primary brain tumor, cerebral hemorrhage, or cerebral anoxia. A further criterion was that the bereaved had to be next of kin in the first degree, that is, loss of a spouse, (adult) child, parent, or sibling. <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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. The instrument used was an elaborate structured interview containing precoded answering categories as well as open questions. 3 groups were identified: ODC- organ donation consent ODR-organ donation refusal NDR-no donation request	N/A	**Information** 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.
Additional comments:						

Reference: Cleiren, MP, Van Zoelen, AA Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. *Death Studies* 2002; **26:** 837-49.

Title: Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 115 Author: Sque et. al (2007) Study type: Retrospective cross sectional qualitative study	<u>Study group:</u> 26 relatives who declined donation <u>Control group:</u> N/A <u>Study period:</u> 2005 <u>Setting:</u> 4 ICUs, UK	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Age-26-75 years <u>Baseline Measurements:</u> 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 1. **Protecting the dead body**- participants did not wish to relinquish their guardianship of the body and they wished to keep it intact; for it not to be cut up. 2. **Circumstances at the time of the death**- participants had usually experienced a sudden, unexpected change in the health status of their relative and therefore needed time to recognize: what had happened to their relative, the seriousness of the critical injury, that despite technological progress in medicine their relative would not survive, and finally, that their relative was dead based on neurological criteria even though the deceased body appeared viable and unscathed. 3. **A lack of knowledge**- some participants lacked information about the process of organ donation actually involved. 4. **The donation discussion**- concerned the timelines and sensitivity of the discussion 5. **Witnessing the observable ending of life** (represented by cessation of the heartbeat)- some participants needed to witness the observable ending of life 6. **The expressed views towards donation of participants** and the reported views of their deceased relatives, at the time of decision-making.
<u>Additional comments:</u>						

Reference: Sque, M, Long, T, Payne, S, Allardyce, D Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? *Journal of Advanced Nursing* 2008; **61:** 134-44.

Title: Identification of variables that influence brain-dead donors' family groups regarding refusal.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 20 Author: Sotillo et. al (2009) Study type: Retrospective descriptive study	Study group: 186 family interviews Control group: N/A Study period: 2007 Setting: Venezuela	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Average age-27 years 71.11% male Baseline Measurements: Not mentioned	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.	N/A	**Strategies used by transplant coordinators were:** • 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 **Reasons for denials from families include**: • 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:						

Reference: Sotillo, E, Montoya, E, Martinez, V, Paz, G, Armas, A, Liscano, C, Hernandez, G, Perez, M, Andrade, A, Villasmil, N, Mollegas, L, Hernandez, E, Milanes, CL, Rivas, P Identification of variables that influence brain-dead donors' family groups regarding refusal. *Transplantation Proceedings* 2009; **41:** 3466-70.

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

Reference: Chapman, JR, Hibberd, AD, McCosker, C, Thompson, JF, Ross, W, Mahony, J, Byth, P, Macdonald, GJ Obtaining consent for organ donation in nine NSW metropolitan hospitals. *Anaesthesia & Intensive Care* 1995; **23:** 81-87.

<table>
<tr><th colspan="7">Title: The timing factor in the consent process.</th></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>ID:
526

Author:
Niles
et. al (1996)

Study type:
Retrospective study</td><td><u>Study group:</u>
203 referrals
127 cases were suitable for family approach for consent

<u>Control group:</u>
N/A

<u>Study period:</u>
Jan 1994 to Nov 1995

<u>Setting:</u>
Dayton Regional Office, Ohio</td><td>N/A</td><td><u>Inclusion /Exclusion(study group):</u>

Not mentioned

<u>Characteristics of cases:</u>

Not mentioned

<u>Baseline Measurements:</u>
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.

A data collection questionnaire, developed by OPO coordinators, was completed by one of three OPO coordinators receiving referral.</td><td>N/A</td><td>Table: Consent by request or role

<table><tr><th>Requestor</th><th>Requests</th><th>Consent obtained</th><th>Consent rate (%)</th></tr><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>Total</td><td>127</td><td>71</td><td>56</td></tr></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.</td></tr>
<tr><td colspan="7"><u>Additional comments:</u></td></tr>
</table>

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

Title: Decoupling: What is it and does it really help increase consent to organ donation?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 97 Author: Siminoff et. al (2002) Study type: Retrospective study	Study group: 11 560 medical records of deceased Control group: N/A Study period: Jan 1994 to Dec 1999 Setting: 9 trauma hospitals, Southwest Pennsylvania and Northeast Ohio.	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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. In-depth interviews were conducted with family members, healthcare professional and OPO staff involved in the process.	N/A	There was a greater likelihood of the family donating if the patient was younger ($p \leq 0.05$) The family has stronger pro-donation attitudes ($p \leq 0.0001$), and The family felt they had enough information about the patient's wishes ($p \leq 0.0001$). Donation was also associated with agreement between the healthcare professional and the family about the initial reaction regarding donation ($p \leq 0.01$) 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.
Additional comments:						

Reference: 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.

Title: Donor families' experience of organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 97 Author: Douglass et. al (1995) Study type: Retrospective study	<u>Study group:</u> 108 consenting families 12 not contactable 44 indicated willingness to participate 42 returned questionnaires <u>Control group:</u> N/A <u>Study period:</u> Jan 1991 to Dec 1992 <u>Setting:</u> Queensland, Australia	N/A	<u>Inclusion /Exclusion(study group):</u> 12 paediatric donors under the age of 12 years were excluded <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	The purpose of this study was to survey the donor families in the state of Queensland, to evaluate their experience of the donation process.	N/A	86% (n-36) felt they were given enough information to prepare themselves for the fact that their loved one would not survive. 90% were able to understand the explanation of brain death that was provided to them. 86% found that the request regarding organ donation was made in a sensitive manner. 83% were given the opportunity to ask questions. 86% felt they were given enough time to discuss the issue of organ donation and to make their decision. 81% felt that the timing of the request for organ donation (at completion of brain death tests) was appropriate. 93% felt they were given enough time to say their final goodbye. 60% indicated that they were offered some form of follow-up from either Social Worker or Transplant Coordinator and 83% found the contact helpful.
<u>Additional comments:</u>						

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

<table>
<tr><th colspan="6">Title: Parental consent for pediatric cadaveric organ donation.</th></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>ID:
506

Author:
Weiss et. al (1997)

Study type:
Retrospective study (survey)</td>
<td><u>Study group:</u>
152 households
97-donors
55-non donors
78 completed questionnaires
64-donors
14- non donors

<u>Control group:</u>
N/A

<u>Study period:</u>
Jan 1990 to Jun 1992

<u>Setting:</u>
USA</td>
<td>N/A</td>
<td><u>Inclusion /Exclusion(study group):</u>

Entry criteria for parents were:
1. Their child has been declared dead by whole brain criteria
2. Their child ranged in age from birth to 18 years
3. They spoke English or Spanish.

<u>Characteristics of cases:</u>
Not mentioned

<u>Baseline Measurements:</u>
Not applicable.</td>
<td>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.</td>
<td>N/A</td>
<td>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>
<tr><td>Parents agreeing with statement</td><td>Donors (n-64) No. (%)</td><td>Non-Donors (n-14) No. (%)</td><td>p-value</td></tr>
<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>
</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</td>
</tr>
</table>

						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 (95%) 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 o donate.
Additional comments:						

Reference: Weiss, AH, Fortinsky, RH, Laughlin, J, Lo, B, Adler, NE, Mudge, C, Dimand, RJ Parental consent for pediatric cadaveric organ donation. *Transplantation Proceedings* 1997; **29:** 1896-901.

Title: Pediatric organ transplantation and the Hispanic population: approaching families and obtaining their consent.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 288 Author: Pietz et . al (2004) Study type: Retrospective study	Study group: 250 deaths 63 declared brain dead Control group: N/A Study period: 1990 to 1999 Setting: 3 hospitals in San Antonia, Texas	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not applicable.	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.	N/A	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)
Additional comments:						

Reference: Pietz, CA, Mayes, T, Naclerio, A, Taylor, R Pediatric organ transplantation and the hispanic population: approaching families and obtaining their consent. *Transplantation Proceedings* 2004; **36:** 1237-40.

<table>
<tr><th colspan="7">Title: Parental Willingness To Donate the Organs of a Child.</th></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>ID:
776

Author:
Frauman et. al (1987)

Study type:
Retrospective study (survey)</td>
<td><u>Study group:</u>
585 individuals

<u>Control group:</u>
N/A

<u>Study period:</u>
1986

<u>Setting:</u>
University of North Carolina</td>
<td>N/A</td>
<td><u>Inclusion /Exclusion(study group):</u>

Not mentioned

<u>Characteristics of cases:</u>

Mean age- 47 years(19-91)
81%-white
18%-minority groups (blacks and native Americans)

<u>Baseline Measurements:</u>
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

<table>
<tr><td></td><td>Agreed with reason
n-143
n (%)</td></tr>
<tr><td>Idea bothers me</td><td>106 (74)</td></tr>
<tr><td>Body mutilation</td><td>87 (61)</td></tr>
<tr><td>Might interfere with survival</td><td>46 (32)</td></tr>
<tr><td>Don’t understand the procedure</td><td>46 (32)</td></tr>
<tr><td>Against religion</td><td>33 (23)</td></tr>
</table>

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).</td>
</tr>
<tr><td colspan="7"><u>Additional comments:</u></td></tr>
</table>

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.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 959 Author: Bellali et. al (2006) Study type: Qualitative study	<u>Study group:</u> 29 Families of children 22 consented (11 consents and 11 refusals) 9 declined participation <u>Control group:</u> N/A <u>Study period:</u> 1995 to 2002. <u>Setting:</u> Pediatric intensive care units (PICUs), Greece.	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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.	N/A	**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.
Additional comments:						

Reference: Bellali, T, Papadatou, D The decision-making process of parents regarding organ donation of their brain dead child: A Greek study. *Social Science and Medicine* 2007; **64:** 439-50.

Title: Empirically based recommendations to support parents facing the dilemma of pediatric cadaver organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 138 Author: Bellali et. al (2007) Study type: Qualitative study	Study group: 22 families Control group: N/A Study period: 1995 to 2002. Setting: Pediatric intensive care units (PICUs), Greece.	N/A	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). Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	N/A	**The pre-donation period** **Personal challenges** 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 appear-ance 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. 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.
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?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 174 Author: Bellali et. al (2007) Study type: Qualitative study	Study group: 22 families Control group: N/A Study period: 1995 to 2002. Setting: Pediatric intensive care units (PICUs), Greece.	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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 dona-tion.	N/A	**MEANING ATTRIBUTED TO THE ACT OF ORGAN DONATION** 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:						

Reference: 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.

Title: Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 20 Author: Vane et. al (2001) Study type: Retrospective study	<u>Study group:</u> 43 deaths 33 suitable for donation <u>Control group:</u> N/A <u>Study period:</u> Jan 1993 to Aug 1999 <u>Setting:</u> USA	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Age of donors- 1month to 18 years 27 boys 6 girls <u>Baseline Measurements:</u> Not mentioned	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.	N/A	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.
<u>Additional comments:</u>						

Reference: Vane, DW, Sartorelli, KH, Reese, J Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims. *Journal of Trauma-Injury Infection & Critical Care* 2001; **51:** 329-31.

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.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 526 Author: Niles et. al (1996) Study type: Retrospective study	<u>Study group:</u> 203 referrals 127 cases were suitable for family approach for consent <u>Control group:</u> N/A <u>Study period:</u> Jan 1994 to Nov 1995 <u>Setting:</u> Dayton Regional Office, Ohio	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> NA	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. Families who were approached for donation were divided in to 3 subcategories: 1. Those who were approached for donation before death had occurred ('before'-n- 52). 2. Those who were asked for donation at the same time they were being told of the death ('same'-n-12). 3. Those families who were asked for donation after they had been told of the death ('after'-n- 63).	N/A	**Before group (n-52)** 32 (62%) families gave consent for donation. **Same group (n-12)** 3 (25%) families gave consent for donation. **After group (n-63)** 36 (57%) families gave consent for donation.
<u>Additional comments:</u>						

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

Title: Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 20 Author: Vane et. al (2001) Study type: Retrospective study	Study group: 43 deaths 33 suitable for donation Control group: N/A Study period: Jan 1993 to Aug 1999 Setting: USA	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Age of donors- 1month to 18 years 27 boys 6 girls Baseline Measurements: Not mentioned	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.	N/A	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-0.03)
Additional comments:						

Reference: Vane, DW, Sartorelli, KH, Reese, J Emotional considerations and attending involvement ameliorates organ donation in brain dead pediatric trauma victims. *Journal of Trauma-Injury Infection & Critical Care* 2001; **51:** 329-31.

Title: Decoupling: What is it and does it really help increase consent to organ donation?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 97 Author: Siminoff et. al (2002) Study type: Retrospective study	Study group: 11 560 medical records of deceased Control group: N/A Study period: Jan 1994 to Dec 1999 Setting: 9 trauma hospitals, Southwest Pennsylvania and Northeast Ohio.	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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. In-depth interviews were conducted with family members, healthcare professional and OPO staff involved in the process.	N/A	Families were most commonly asked about organ donation concurrent with their loved one's death (40.9%) and had donation rates of 51.2% Followed by before death (39.3%) with donation rates of 63% Followed by after death with donation rates of 56.6%
Additional comments:						

Reference: 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.

Title: Increasing the availability of cadaveric organs for transplantation maximizing the consent rate.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 97 Author: Cutler et. al (1993) Study type: Retrospective study	<u>Study group:</u> 212 BSD patient's families <u>Control group:</u> N/A <u>Study period:</u> 1990 to 1991 <u>Setting:</u> USA	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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.	N/A	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.
<u>Additional comments:</u>						

Reference: Cutler, JA, David, SD, Kress, CJ, Stocks, LM, Lewino, DM, Fellows, GL, Messer, SS, Zavala, EY, Halasz, NA Increasing the availability of cadaveric organs for transplantation maximizing the consent rate. *Transplantation* 1993; **56:** 225-28.

Title: A qualitative examination of the needs of families faced with the option of organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 234 Author: Jacoby et al (2005) Study type: Qualitative study (interviews)	<u>Study group:</u> 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 <u>Control group:</u> N/A <u>Study period:</u> July 1998 to Dec. 2000 <u>Setting:</u> 3 sites in New York	N/A	<u>Inclusion /Exclusion(study group):</u> Eligible legal next of kin who consented or refused donation of their loved one's organs. <u>Characteristics of cases:</u> Age range- 31-65 years (mean-43 yrs) <u>Baseline Measurements:</u> Not mentioned	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?	N/A	**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.
<u>Additional comments:</u>						

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.

Title: Donor and non-donor families' accounts of communication and relations with healthcare professionals.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 290 Author: Haddow (2004) Study type: Qualitative retrospective study	Study group: Donor families-19 Non-donor families-4 Control group: N/A Study period: Not mentioned Setting: Scotland	N/A	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.	N/A	**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.						

Reference: Haddow, G Donor and nondonor families' accounts of communication and relations with healthcare professionals. *Progress in Transplantation* 2004; **14:** 41-48.

Title: Two perspectives on organ donation: experiences of potential donor families and intensive care physicians of the same event.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 199 Author: Sanner et. al (2007) Study type: Qualitative study	Study group: 20 relatives (donors and non-donors) 25 physicians Control group: N/A Study period: Not mentioned Setting: Sweden	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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. Relatives were mostly interviewed in their homes, but in some cases in our offices. Physicians were either interviewed by telephone or in their offices. An open interview method was chosen to allow informants to speak freely about their experiences, although predetermined issues were also covered.	N/A	**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 talk with other close kin.
Additional comments:						

Reference: 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.

Title: The decision-making process of parents regarding organ donation of their brain dead child: A Greek study.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 959 Author: Bellali et. al (2006) Study type: Qualitative study	<u>Study group:</u> 29 Families of children 22 consented (11 consents and 11 refusals) 9 declined participation <u>Control group:</u> N/A <u>Study period:</u> 1995 to 2002. <u>Setting:</u> Pediatric intensive care units (PICUs), Greece.	N/A	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> Not mentioned	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.	N/A	**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. **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.
<u>Additional comments:</u>						

Reference: Bellali, T, Papadatou, D The decision-making process of parents regarding organ donation of their brain dead child: A Greek study. *Social Science and Medicine* 2007; **64:** 439-50.

Title: Empirically based recommendations to support parents facing the dilemma of pediatric cadaver organ donation.						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 138 Author: Bellali et. al (2007) Study type: Qualitative study	Study group: 22 families Control group: N/A Study period: 1995 to 2002. Setting: Pediatric intensive care units (PICUs), Greece.	N/A	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). Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	N/A	**The pre-donation period** **Personal challenges** 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. **Conditions of organ request** 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** 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.
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?						
Study type	No. of people	Prevalence/ incidence	Patient characteristics	Methods	Reference standard	Results
ID: 174 Author: Bellali et. al (2007) Study type: Qualitative study	Study group: 22 families Control group: N/A Study period: 1995 to 2002. Setting: Pediatric intensive care units (PICUs), Greece.	N/A	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: Not mentioned	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.	N/A	**MEANING ATTRIBUTED TO THE ACT OF ORGAN DONATION** 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:						

Reference: 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.

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

<table>
<tr><th colspan="6">Title: Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals</th></tr>
<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>
<tr>
<td>ID: 226

Study type: Observational

Authors: Shafer et al (1998)</td>
<td><u>Setting:</u>
20 non-donor hospitals in US</td>
<td><u>Non-donor hospitals:</u>
• >100 beds,
• regional or community centres,
• had ICUs, operating rooms, staff neurologists and an 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
<table>
<tr><th>.</th><th>1991-3</th><th>1995-7</th><th>Increase (%)</th></tr>
<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>
</table>
</td>
</tr>
<tr><td colspan="6"><u>Additional comments</u>: 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.</td></tr>
</table>

Reference: T. J. Shafer, R. Durand, M. J. Hueneke, W. S. Wolff, K. D. Davis, R. N. Ehrle, C. T. Van Buren, J. P. Orlowski, D. H. Reyes, R. T. Gruenenfelder, and C. K. White. Texas non-donor-hospital project: a program to increase organ donation in community and rural hospitals. *Journal of Transplant Coordination* 8 (3):146-152, 1998.

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

Level of Evidence	Patient Population/ Characteristics	Selection/Inclusion criteria	Intervention	Comparison	Follow-up	Outcome and Results

ID: 284

Study type: Observational

Authors: Shafer et al (2004)

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

	Centres with in-house co-ordinators (n=8)	**Centres without in-house co-ordinators (n=6)**
Consent rate (%)	60	53
Conversion rate (%)	55	48

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.

Reference: T. J. Shafer, R. N. Ehrle, K. D. Davis, R. E. Durand, S. M. Holtzman, C. T. Van Buren, N. J. Crafts, and P. J. Decker. Increasing organ recovery from level I trauma centers: The in-house coordinator intervention. *Progress in Transplantation* 14 (3):250-263, 2004.

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

Study type	No. of people	Patient characteristics	Methods	Results
ID: 62 Author: Roth et. al (2003) Study type: Observational study	<u>Study group:</u> Not mentioned <u>Control group:</u> N/A <u>Study period:</u> 1996 to 2001 <u>Setting:</u> USA	<u>Inclusion /Exclusion(study group):</u> Not mentioned <u>Characteristics of cases:</u> Not mentioned <u>Baseline Measurements:</u> 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/program me 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 See table below 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.

Parameter	Statistic	1996-98	1999-01	% change	p-value
Patient referrals for organ donation	3 year total	256	373	+46%	0.0495
	Mean per year ± SD	85 ± 9	124 ± 30		
Suitable donor	3 year total	155	190	+23%	0.1046
	Mean per year ± SD	52 ± 1	63 ± 10		
Actual donor	3 year total	46	77	+67%	0.0495
	Mean per year ± SD	15 ± 2	26 ± 5		
Actual organs donated	3 year total	157	267	+70%	0.0495
	Mean per year ± SD	52 ± 7	89 ± 24		

			was in place Phase II- 1999 to 2001- after implementation of the new programme.	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:				

Reference: Roth, BJ, Sher, L, Murray, JA, Belzberg, H, Mateo, R, Heeran, A, Romero, J, Mone, T, Chan, L, Selby, R Cadaveric organ donor recruitment at Los Angeles County Hospital: improvement after formation of a structured clinical, educational and administrative service. *Clinical Transplantation* 2003; **17:** Suppl-7.

Title: Improving organ donation in Central Saudi Arabia.				
Study type	No. of people	Patient characteristics	Methods	Results
ID: 53 Author: Al-Sebayel et. al (2004) Study type: Observational study	Study group: Not mentioned Control group: N/A Study period: Jan 2003 to Dec 2003 Setting: 3 hospitals in Riyadh, Saudi Arabia	Inclusion /Exclusion(study group): Not mentioned Characteristics of cases: Not mentioned Baseline Measurements: NA	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).	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 2003until 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.
Additional comments:				

Reference: Al-Sebayel, MI, Al-Enazi, AM, Al-Sofayan, MS, Al-Saghier, MI, Khalaf, HA, Kabbani, MA, Nafae, OM, Khuroo, SS Improving organ donation in Central Saudi Arabia. *Saudi Medical Journal* 2004; **25:** 1366-68.

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.