



# Patient questionnaire into variations in end of life care for patients with a devastating brain injury

## General questions

1. Patient code.....

2. Unit/Ward where death was confirmed.

- Adult Intensive Care     Specialised Neurosurgical Intensive Care  
 Paediatric Intensive Care     Emergency Department  
 Medical ward     Stroke Unit  
 Other: please specify.....

3. Age.....

4. Gender     Male     Female

5.a Main general cause of death.....

5.b Main specific cause of death.....

Other: please specify.....

Trauma	S02 S061 S062 S063 S064 S067  S068 S069	Fracture of skull and facial bones Traumatic cerebral oedema Diffuse brain injury Focal brain injury Extradural haemorrhage Intracranial haemorrhage with prolonged coma Other intracranial injuries Intracranial injury unspecified
	I60 I61 I62	Subarachnoid haemorrhage Intracranial haemorrhage Other non traumatic intracranial

Cerebrovascular Accidents	I63	haemorrhage
	I64	Cerebral infarction
	I65	Stroke not specified as stroke or infarction
	I66	Occlusion and stenosis of precerebral arteries Occlusion and stenosis of cerebral arteries
Cerebral Damage	G931	Anoxic brain damage
	G935	Compression of brain
	G936	Cerebral oedema
Cerebral Neoplasm	C71	Malignant neoplasm of the brain
	D33	Benign neoplasm of the brain
Infections	G00 – G03	Meningitis

**6. Number of days from admission to brain injury.....**

**7. Number of days from date of brain injury to date of death.....**

**Q 1. Which statement best describes the care of the patient during his/her final illness? Please tick one box only.**

- Full Active treatment on Critical Care until the diagnosis of brain death. ***If you tick this option, please proceed straight to question 2.***
- Full Active treatment until unexpected cardiac arrest from which the patient could not be resuscitated. ***If you tick this option, please proceed straight to question 2.***
- Admitted to Critical Care in order to incorporate organ donation into end-of-life care. ***If you tick this option, please proceed straight to question 2***
- Full active treatment on Critical Care until the decision of withdrawal or limiting life sustaining therapy was made, with an expected final cardiac arrest without Cardio Pulmonary Resuscitation. ***If you tick this option, please proceed to question 1.1.***
- Not admitted, or admitted to Critical Care but subsequently discharged. ***If you tick this option, please proceed to question 1.1..***

**Q 1.1. Was it likely that the diagnosis of brain death could have been made, either at the time of the decision to withdraw/limit life sustaining treatment or to not admit/discharge, or within the next 48 hours, had active treatment continued?**

- Yes: please answer questions 1.2 and 1.3 and then proceed to question 2.
- No: please answer questions 1.2 and 1.3 and then proceed to question 2.

**Q 1.2. What was the Glasgow Coma Scale (GCS) at the time the decision to limit/withdraw treatment or to not admit/discharge was made?.....**

**Q 1.3. Why was full active treatment not continued or the patient not admitted/discharged? Please select one primary reason for not continuing full active treatment, and one secondary reason, if needed.**

**Primary reason**

**Secondary reason**

Legal and/or ethical concerns

- |                          |                          |   |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Clinical decision that further treatment was not appropriate or not effective |
| <input type="checkbox"/> | <input type="checkbox"/> | Not able to undertake brain death testing                                     |
| <input type="checkbox"/> | <input type="checkbox"/> | No critical care bed available  |
| <input type="checkbox"/> | <input type="checkbox"/> | Family reasons  |
| <input type="checkbox"/> | <input type="checkbox"/> | Other: please specify.....  |

**Q 2. Was the patient referred to Neurosurgery?**

- Yes: please answer **questions 2.1 and 2.2** and then proceed to **question 3.**
- No: please proceed to **question 3.**
- Don't Know: please proceed to **question 3.**

**Q2.1. Was the patient transferred to another hospital for neurosurgical treatment?**

- Yes  No  Neurosurgical facilities on site

**Q2.2. Did the patient receive any neurosurgical or neuroradiological treatment?**

- Yes  No  Don't Know

**Q 3. Was the patient intubated and receiving mechanical ventilation via an endotracheal or tracheostomy tube at the time of death or at the time of the decision to withdraw or limit life sustaining treatment?**

- Yes: please answer **questions 3.2, to 3.5** and then proceed to **question 4.**
- No: please answer **questions 3.1, to 3.5** and then proceed to **question 7.**



**Q 3.1 What was the reason for the patient not being intubated and receiving mechanical ventilation at that moment. Please tick only one option**

- Not needed
- Not appropriate
- Not of overall benefit to the patient due to the severity of the acute event
- Other: please specify.....

**Q 3.2. Speciality of primary professional making decisions about intubation and ventilation. Tick one option only.**

- Intensive Care     Emergency Medicine
- Neurosurgery/Neurology     General medicine
- General Surgery     Palliative Care
- Anaesthesia     Paramedic
- Out of hospital Dr     Other: please specify.....

**Q 3.3 Seniority of primary professional making the decision:**

- Trained professional     Professional in training

**Q 3.4. Was there a second professional involved in the decision about intubation and ventilation?**

- Yes     No     Don't know

**If yes:**

**Q 3.4a Speciality of second professional making the decision**

**Q 3.4b Seniority of second professional making the decision:**

- Trained professional     Professional in training

**Q 3.5 What was the patient's GCS score at the time of the decision about intubation and ventilation.....**



**Q 4. Was the patient's clinical condition consistent with brain death at any time during his/her present illness?**

- Yes: please proceed to **question 5**.
- No: please proceed to **question 7**.

**Q 5. Did the patient undergo brain death testing?**

- Yes: please answer **questions 5.2 5.4** and then proceed to **question 6**.
- No: please tick the appropriate boxes below, answer **questions 5.1 to 5.4** and then proceed to **question 7**.

**Q 5.1 Please select one primary reason for the patient not undergoing brain death testing, and one secondary reason, if needed.**

<b>Primary reason</b>	<b>Secondary reason</b>
<input type="checkbox"/>	<input type="checkbox"/> Not identified as potentially brain dead
<input type="checkbox"/>	<input type="checkbox"/> Family declined organ donation
<input type="checkbox"/>	<input type="checkbox"/> Family reasons not to test
<input type="checkbox"/>	<input type="checkbox"/> Cardiac arrest before testing could be performed
<input type="checkbox"/>	<input type="checkbox"/> Cardiorespiratory instability
<input type="checkbox"/>	<input type="checkbox"/> Reversible causes of coma and / or apnoea could not be satisfactorily excluded
<input type="checkbox"/>	<input type="checkbox"/> Unable to examine all brain stem reflexes or undertake ancillary tests
<input type="checkbox"/>	<input type="checkbox"/> Absolute or relative medical contraindication to organ donation. Please specify contraindication.....
<input type="checkbox"/>	<input type="checkbox"/> Other: please specify.....



**Q 5.2 Speciality of primary Dr making decision concerning brain death tests. Tick one option only.**

- Intensive Care     Emergency Medicine
- Neurosurgery/Neurology     General Medicine
- General Surgery     Palliative Care     Anaesthesia
- Other please specify.....

**Q 5.3 Seniority of primary Dr making the decision concerning brain death tests**

- Trained professional     Professional in training

**Q 5.4 Was there a second Dr involved in the decision about performing brain death tests?**

- Yes     No     Don't know

**If yes:**

**Q 5.4a Speciality of second Dr making the decision concerning brain death tests.....**

**Q5.4b Seniority of second Dr making the decision concerning brain death tests**

- Trained professional     Professional in training

**Q 6. Was the patient confirmed dead following brain death testing according to the criteria in your country?**

- Yes: please answer **questions 6.2, to 6.7** and then proceed to **question 8.**
- No: please answer **questions 6.1 to 6.7** and then proceed to **question 7.**



**Q6.1 What were the reasons for the patient not being confirmed brain dead following testing.**

- Positive brain stem reflex
- Not apnoeic
- Ancillary tests failed to confirm brain death
- Other: please specify.....

**Q 6.2 Speciality of first Dr performing brain death tests. Tick one option only.**

- Intensive Care       Emergency Medicine
- Neurosurgery/Neurology       General Medicine
- General Surgery       Palliative Care       Anaesthesia
- Other please specify.....

**Q 6.3 Seniority of first Dr performing brain death tests**

- Trained professional       Professional in training

**Q 6.4 Speciality of second Dr performing brain death tests (if applicable) tick one option only.**

- Intensive Care       Emergency Medicine
- Neurosurgery/Neurology       General Medicine
- General Surgery       Palliative Care       Anaesthesia
- Other: please specify.....

**Q 6.5 Seniority of second Dr performing brain death tests (if applicable)**

- Trained professional       Professional in training

**Q 6.6 Speciality of third Dr performing brain death tests (if applicable) tick one option only**

- Intensive Care       Emergency Medicine





- Neurosurgery/Neurology     General Medicine
- General Surgery     Palliative Care     Anaesthesia
- Other please specify.....

**Q 6.7 Seniority of third Dr performing brain death tests (if applicable)**

- Trained professional     Professional in training

**Q 7. If DBD was not a possibility and the patient's death followed planned withdrawal or limitation of life sustaining treatment, is there evidence that DCD was considered?**

- Yes: please proceed to **question 8**.
- No: please answer 7.1 and proceed to **question 8**.

**Q7.1 Please select one primary reason for DCD not being considered, and one secondary reason, if needed..**

<b>Primary Reason</b>	<b>Secondary Reason</b>
<input type="checkbox"/>	<input type="checkbox"/> DCD not lawful in this country.
<input type="checkbox"/>	<input type="checkbox"/> No DCD programme in this country.
<input type="checkbox"/>	<input type="checkbox"/> No DCD programme in this hospital.
<input type="checkbox"/>	<input type="checkbox"/> Not identified as a potential organ donor.
<input type="checkbox"/>	<input type="checkbox"/> Patient had an absolute or relative contraindication for organ donation. Please specify contraindication
<input type="checkbox"/>	<input type="checkbox"/> The nature of the withdrawal or limitation of treatment was not compatible with DCD.
<input type="checkbox"/>	<input type="checkbox"/> Due to the patient's clinical condition, it was predicted that circulatory arrest would not occur within a timeframe that would allow DCD to occur.



Other: please specify.....

**Q 8. Was the patient referred to a Key Donation Person?**

- Yes: please answer **question 8.2 to 8.4** and proceed to **question 9.**
- No: please answer **question 8.1 to 8.4** and proceed to **question 9.**
- Don't Know **please proceed to question 9**

**Q 8.1 What were the reasons for not referring to the Key Donation Person.**

**Primary reason**

**Secondary reason**

- |                          |   |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Not identified as a potential organ donor.   |
| <input type="checkbox"/> | <input type="checkbox"/> Coroner/prosecutor/judicial reason/Judge.  |
| <input type="checkbox"/> | <input type="checkbox"/> Known patient wish not to be a donor.  |
| <input type="checkbox"/> | <input type="checkbox"/> Family declined donation.  |
| <input type="checkbox"/> | <input type="checkbox"/> Patient inappropriately thought to be unsuitable for organ donation.   |
| <input type="checkbox"/> | <input type="checkbox"/> Patient deemed unsuitable for organ donation because of absolute or relative medical contraindications-.Please specify contraindication..... |
| <input type="checkbox"/> | <input type="checkbox"/> Other: please specify.....   |

**Q8.2 Speciality of primary professional making decision about notification/referral to key donation person. Tick one option only**

- Intensive Care     Emergency Medicine
- Neurosurgeon/Neurologist     General Medicine
- General Surgeon     Palliative Care     Anaesthetist
- Nurse     Other please specify.....

**Q 8.3 Seniority of primary professional making decision about notification/referral to key donation person**

- Trained professional       Professional in training

**Q 8.4 Was there a second professional involved in the decision about notification/referral to a key organ donation person**

- Yes       No       Don't know

**If yes:**

**Q 8.4a Speciality of second professional making decision about notification/referral to key donation person**

**Q 8.4b Seniority of second professional making decision about notification/referral to key donation person**

- Trained professional       Professional in training

**Q 9. Were the family approached or informed about the possibility of organ donation?**

- Yes: please proceed to **question 9.2**.
- No: please answer **question 9.1 and proceed to question 10**.
- Don't know please tick the appropriate box below and **proceed to question 10**

**Q 9.1 What were the reasons for not approaching or informing the family about organ donation.**

**Primary reason**

**Secondary reason**

- |                          |  |
|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> Unable to contact the family.                             |
| <input type="checkbox"/> | <input type="checkbox"/> Family had already declined the option of organ donation. |
| <input type="checkbox"/> | <input type="checkbox"/> Coroner/prosecutor/judicial reason.                       |
| <input type="checkbox"/> | <input type="checkbox"/> No critical care bed available.                           |



- Agreed medical contraindication to organ donation.  
Please specify medical contraindication
- Other: please specify.....

**Q 9.2. If the family were approached or informed about the possibility of organ donation, what was the speciality of the persons making the approach?**

Please tick all boxes that apply, answer **question 9.3** and then proceed to **question 10**.

- Intensive Care     Emergency Medicine
- Neurosurgery/Neurology     General Medicine
- General Surgery     Palliative Care     Anaesthesia
- Nurse     Key organ donation person
- Family initiated the donation conversation
- Other: please specify.....

**Q 9.3. Had at least one of the above professionals who had approached or informed the family about the possibility of organ donation received any formal training in how to approach a family about organ donation?**

- Yes     No     Don't know

**Q9.4. When were the family approached or informed about the possibility of organ donation?**

- Before referral to the Key Donation Person.
- Family approached clinical staff about organ donation.
- After referral to the Key Donation Person.
- Other pleas specify.

**Q 9.5. In the case of DBD when were the family approached or informed about the possibility of organ donation with regards to brain death testing**

- Before brain death tests.
- After brain death tests have started, but before they have been completed and death has been confirmed.
- After brain death tests have been completed and death has been confirmed.

**Q 9.6. In the case of DCD when were the family approached or informed about the possibility of organ donation with regards to withdrawal or limitation of life sustaining treatment**

- Before a formal decision to withdraw or limit life sustaining treatment.
- After a decision has been made to limit or withdraw life sustaining treatment.

**Q10. Did organ donation occur?**

- Yes, DBD     Yes, DCD

**you have completed the questionnaire**

- No: please answer **question 10.1**:

**Q 10.1 Please select one primary reason for donation not occurring and one secondary reason, if needed.**

<b>Primary reason</b>	<b>Secondary reason</b>
<input type="checkbox"/>	<input type="checkbox"/> Patient not intubated/receiving mechanical ventilation
<input type="checkbox"/>	<input type="checkbox"/> Clinical condition not consistent with brain death
<input type="checkbox"/>	<input type="checkbox"/> BD testing not undertaken despite clinical condition consistent with brain death
<input type="checkbox"/>	<input type="checkbox"/> Brain death diagnosis not confirmed after undertaking brain death testing
<input type="checkbox"/>	<input type="checkbox"/> DCD not considered



- |                          |                            |   |
|--------------------------|----------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/>   | Family refusal  |
| <input type="checkbox"/> | <input type="checkbox"/>   | Coroner/prosecutor/judicial reason  |
| <input type="checkbox"/> | <input type="checkbox"/>   | Patient referred as a potential donor but all organs deemed medically unsuitable by the transplant centres  |
| <input type="checkbox"/> | <input type="checkbox"/>   | Cardiac arrest before organ recovery could occur.   |
| <input type="checkbox"/> | <input type="checkbox"/>   | Maastricht Category 3 DCD where the donation process was stopped as the patient did not die following withdrawal or limitation of treatment within a suitable timeframe that would allow organ donation to occur. |
| <input type="checkbox"/> | <input type="checkbox"/>   | No suitable recipients for organs.  |
| <input type="checkbox"/> | <input type="checkbox"/>   | Logistical reasons  |
| <input type="checkbox"/> | Other: please specify..... |   |

**\*Categories of medical contraindications to organ donation:**

- Prior or present history of malignancy
- Prion disease
- HIV infection or disease
- HCV, HBV or HDV positive serology
- HTLV
- Sepsis/untreated/untreatable infectious disease
- Risk behaviour
- Haematological disease other than malignancy
- Autoimmune disease/connective tissue disorders
- Age criteria
- Unknown cause of death
- Unknown identity
- Other: please specify