

## **Except from Potential Donor Audit Pilot Data Dictionary**

Table I: Data dictionary

PDA Question	Codes and Values	Data definitions
Subject to Data Governance, please confirm that the patient is deceased	Tick box response option	Self-explanatory
Hospital and Unit in which the patient died?	Beaumont Hospital Dublin  Beaumont Hospital General ICU  Richmond (Neurosurgical) ICU  CHI at Crumlin PCCU  Cork University Hospital  Cork University Hospital General ICU  Cork University Hospital Cardiothoracic ICU  St James' Hospital Dublin  St James's Hospital General ICU  St James's Hospital Cardiothoracic ICU  St James's Hospital Cardiothoracic ICU  St James's Hospital Burns ICU  Mater Misericordiae University Hospital Dublin  University Hospital Galway  University Hospital Limerick	Self-explanatory
MRN	Hospital Medical Record Number	Self-explanatory
Date of patient death	YYYY-MM-DD	Self-explanatory
Time of patient death	HH:MM	<ul> <li>Time of asystole</li> <li>Time of second set of brainstem tests</li> </ul>

PDA Question	Codes and Values	Data definitions
Was the patient invasively ventilated immediately prior to Withdrawal of Life Sustaining Therapy, neurological death testing or death?	Yes No	Invasive ventilation is positive pressure delivered to the patient's lungs via an endotracheal tube or a tracheostomy tube
Cause of Death	Neurological cause of death Non-neurological cause of death	Self-explanatory
Neurological Cause of Death	Haemorrhagic stroke (including non-traumatic SAH) Ischaemic stroke Anoxic brain injury Infective disease of the CNS - non-abscess Brain Abscess Space occupying lesion of brain - non abscess Traumatic Brain Injury Other Unknown	Self-explanatory
Was this patient an actual DCD donor or did they have the potential to become a DCD donor	Yes No	See Absolute Medical Contraindications
Date of birth /Age	YYYY-MM-DD Unknown	Self-explanatory
Sex	Male Female Unknown	The patient's sex assigned at birth

PDA Question	Codes and Values	Data definitions
Religion	Dropdown response options:  No religion Roman Catholic Church of Ireland Islam Orthodox Christian Presbyterian Jehovah's Witness Other, write in religion	A personal set or institutionalised system of religious attitudes, beliefs, and practices
Country of birth	Dropdown response option of all countries in the world	Self-explanatory
Ethnicity	Dropdown response options: White - Irish  • White - Irish traveller  • White - Roma  • White - Any other White background  • Black or Black Irish - African  • • Black or Back Irish - Any other Black background  Asian or Asian Irish - Chinese  Asian or Asian Irish - Indian / Pakistani / Bangladeshi  Asian or Asian Irish - Any other Asian background  Arabic  Mixed, write in description  Other, write in description  Unknown	Self-explanatory

PDA Question	Codes and Values	Data definitions
Did the patient meet the criteria for brainstem testing	Yes No	Each of the criteria for brainstem testing (ICSI, 2020) must be met in order to answer a "yes response":  o establish that coma is due to a condition which can cause irreversible brain damage,
		o exclude reversible factors, o demonstrate the loss of all cranial nerve and brainstem responses which can be tested in coma (i.e. pupils unreactive, no cough, no apparent respiratory effort).
Did brainstem and / or ancillary testing occur	Yes No	For brainstem testing to be complete, two sets of brainstem tests must be performed according to the ICSI (2020) guidelines.
Please select reasons why brainstem and / or ancillary testing did not occur?	<ul> <li>Not identified as a potential organ donor</li> <li>Absolute medical contraindication(s)</li> <li>Locally-determined medical contraindication(s)</li> <li>Patient did not wish to become an organ donor</li> <li>ICU resource issue</li> <li>Cardiac arrest before brainstem testing</li> <li>Patient thought to be outside age criteria for organ donation</li> <li>Reluctance to approach family</li> <li>Family had already expressed a wish not to donate</li> <li>Cardiorespiratory instability</li> <li>Not identified as potentially brainstem dead</li> <li>Reversible causes of coma could not be excluded</li> <li>Unable to examine all brain stem reflexes</li> <li>Unable to undertake ancillary tests</li> <li>One or more brainstem reflexes remained intact</li> <li>Family reasons not to brainstem test</li> <li>Other, please specify</li> </ul>	See Appendix 2: Additional guidance for PDA audit coordinators and clinical leads

PDA Question	Codes and Values	Data definitions
Was death by neurological criteria confirmed?	Yes No	For brainstem testing to be complete, two sets of brainstem tests must be performed according to the ICSI (2020) guidelines.
Was there Withdrawal of Life Sustaining Therapy?	Yes No	Withdrawal of Life Sustaining Therapies are processes by which medical interventions are discontinued or not further escalated, often with the understanding that the patient will most probably experience natural death from the underlying disease or related complications
What was the method of Withdrawal of Life Sustaining Therapy?	<ul> <li>Extubation</li> <li>Reduction or withdrawal of supports but not extubated</li> <li>Decision to remain on current level of intervention with no further escalation</li> </ul>	Self-explanatory
Date of Withdrawal of Life Sustaining Therapy?	YYYY-MM-DD	Please note the date of commencement of Withdrawal of Life Sustaining Therapy
Time of Withdrawal of Life Sustaining Therapy?	HH:MM	Please note the time of commencement of Withdrawal of Life Sustaining Therapy
Derive time to death from 'date-time of death' minus 'date-time of Withdrawal of Life Sustaining Therapy'	Hours and Minutes	No data entry required – automatically derived

PDA Question	Codes and Values	Data definitions
Was the patient referred to organ donation personnel?	Yes No	NHSBT Definition: A referral is the provision of information to ODP to determine organ donation suitability. NICE CG135 (England). Any form of contact is acceptable for a referral - conversation, phonecall or written information. It must be documented in the ODNM call log / medical notes patient healthcare record / identified through conversations with relevant personnel involved. ODP includes: Clinical Lead in Organ Donation, Organ Donation Nurse Manager or to the National Organ Procurement Service
When was the patient first referred to ODP?	<ul> <li>Prior to brainstem testing</li> <li>Between the first and second sets of brainstem tests After brainstem tests have been completed and death has been confirmed</li> <li>Between a decision to Withdraw Life Sustaining Therapy and Withdrawal of Life Sustaining Therapy</li> <li>Following Withdrawal of Life Sustaining Therapy</li> </ul>	Self-explanatory

PDA Question	Codes and Values	Data definitions
Please identify reason(s) for not referring to organ donation personnel	<ul> <li>Not identified as a potential organ donor (i.e. not considered)</li> <li>Patient thought to be medically unsuitable for organ donation, please specify</li></ul>	Explanation for why referral did not occur to either Clinical Lead in Organ Donation, Organ Donation Nurse Manager or to the National Organ Procurement Service  See Appendix 2: Additional guidance for PDA audit coordinators and clinical leads
Was the family approached regarding organ donation	Yes	Family approach relates the formal, planned, family discussion between family and ICU MDT about organ donation

PDA Question	Codes and Values	Data definitions
Please identify reason(s) for not formally approaching the family about organ donation?	<ul> <li>Patient was not expected to die within the timeframe compatible with organ donation</li> <li>Unable to contact the family</li> <li>Family had already expressed wish not to donate</li> <li>Coroner refusal</li> <li>Ward of court patient</li> <li>ICU resource issue</li> <li>Medical contraindication(s) to organ donation</li> <li>Patient not identified as a potential donor</li> <li>Patient thought to be medically unsuitable</li> <li>Patient thought to be outside age criteria</li> <li>Family deemed too upset to approach</li> <li>Cardiac arrest before approach made</li> <li>Other: please specify</li> </ul>	See Appendix 2: Additional guidance for PDA audit coordinators and clinical leads
When was the family formally approached?	<ul> <li>During prognosis conversation</li> <li>Separate to the prognosis conversation but before brainstem testing</li> <li>After the first set of brainstem tests and before the second set of brainstem tests</li> <li>Within the second brainstem tests results conversation</li> <li>Following brainstem tests or Withdrawal of Life Sustaining Therapy conversation</li> </ul>	Self-explanatory
Who was present for the formal approach?	Response options:  • Hospital group organ donation personnel • ICU Consultant  • Primary Team Consultant  • ICU NCHD  • Primary Team NCHD  • Bed-side nurse  • Nurse-in-charge  • Faith representative  • Professional interpreter	Self-explanatory

PDA Question	Codes and Values	Data definitions
Who was the lead person for the formal approach?	Response options:  • Hospital group organ donation personnel • ICU Consultant  • Primary Team Consultant  • ICU NCHD  • Primary Team NCHD  • Bed-side nurse  • Nurse-in-charge	Who was driving the conversation? Lead person from auditors perspective from the start (not necessarily the person who got the form signed)?
Were there any informal discussions held	Yes No	Was the topic of organ donation raised prior to the family approach?
Who raised the idea of organ donation prior to a family approach	Hospital personnel (ICU) Hospital personnel (ED) Family	This question only relates to an informal discussion.
Did the family assent to organ donation	Yes No	Did the family verbally agree to organ donation

PDA Question	Codes and Values	Data definitions
Please select reason(s) why the family did not assent	<ul> <li>Family unsure about patient's wishes</li> <li>Patient did not wish to become an organ donor</li> <li>Family concerned that organ donation would delay post-mortem or funeral</li> <li>Cultural / Religious reasons</li> <li>Family not prepared to wait the time required for organ donation</li> <li>Family uncomfortable with the organ donation process(including who receives the organs)</li> <li>Family did not accept death by neurological criteria or that death was imminent</li> <li>Family dissatisfied with patient care</li> <li>Family felt that the patient has "suffered" or been through enough</li> <li>Family divided over the decision</li> <li>Family wanted to stay with patient after patient death</li> <li>Family felt that the body should be buried whole (unrelated to religious / cultural reasons)</li> <li>Strong refusal, probing not appropriate</li> <li>Other: Please specify</li> </ul>	See Appendix 2: Additional guidance for PDA audit coordinators and clinical leads
Did organ donation occur?	Yes No	The occurrence of organ donation is measured as knife-to-skin
What type of organ donation occurred?	Donation after death by neurological criteria  Donation after death by circulatory criteria	Self-explanatory
Please select reason(s) for non-that organ donation outcome did not proceed	<ul> <li>Cardiac arrest</li> <li>Did not die in the timeframe required for organ donation</li> <li>Family withdrew consent after initial assent, please specify reason</li> <li>Patient referred as a potential donor but all organs deemed medically unsuitable by the transplant centres</li> <li>Other non-medical reasons</li> </ul>	See Appendix 2: Additional guidance for PDA audit coordinators and clinical leads

PDA Question	Codes and Values	Data definitions
Free text field that hospitals view themselves to inform training and improvement.		Do not record personal or identifiable information relating to patients, their relatives or staff within this audit teaching notes box.

## **Additional Guidance for PDA Audit Coordinators and Clinical Leads**

Table 2: Guidance for audit coordinators on response options for commonly occurring reasons for non-donation outcome

These response options relate to the audit questions:	Further explanation
Reasons for not brainstem testing /	
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<ul> <li>Reasons for not approaching the family</li> </ul>	
Not identified as a potential organ donor	Self-explanatory
Absolute medical contraindication(s)	Absolute list of contraindications: Defined list for the
7 booldte medicar contramalcation(3)	purpose of the audit. Calculating the number of eligible
	donors will exclude these patients.
	Locally-determined contraindication: This should only be
Locally-determined medical	selected when a contraindication for Organ Donation is
contraindication(s)	selected as reason for not brainstem testing, referring or
	approaching a patient but that contraindication is not on
	the accepted defined list. There has been no consultation
	with ODP or the transplant centre.
Transplant centre determined	Transplant centre - determined contraindication: This
contraindication	should only be selected when a transplant centre has
	been consulted following an informal expression of
	interest and the transplant centre have made the decision
	regarding donor eligibility at some point in the patient
	journey. Calculating the number of eligible donors will exclude these patients.
Patient did not wish to become an organ	Self-explanatory
donor	Sch-explanatory
ICU resource issue	Any resource that is unavailable to the ICU team,
	including personnel or bed availability
Cardiac arrest before brainstem testing /	This option should only be selected if the patient
referral / approach mad	experiences cardiac arrest before neurological testing /
	referral / approach made as appropriate.
Patient thought to be outside age criteria for	Should only be selected when hospital personnel
organ donation	excluding ODP thought the patient was outside the age
	criteria for organ donation
Reluctance to approach family	Examples may include family distress, or that the family
	did not demonstrate an understanding of death or
Equally had alwaydy assumption of a suite mass to	imminence of death
Family had already expressed a wish not to donate	Self-explanatory
donate	

Table A.2.2: Guidance for audit coordinators on response options for reasons why brainstem and / or ancillary testing did not occur

These response options relate to the audit question:  • Reasons why brainstem and / or ancillary testing did not occur?	Further Explanation
Cardiorespiratory instability	Unstable Heart Rate, Respiratory rate (including apnea including oxygen saturation) and / or Blood Pressure and / or high respiratory support (High Peep/High FiO2)
Not identified as potentially brainstem dead	Self-explanatory
Reversible causes of coma could not be excluded	Exclusion of reversible cause of coma- sedative drugs; Poisoning and drug overdose; Hypothermia; Metabolic or endocrine causes and severe hypotension
Unable to examine all brain stem reflexes	Examples may include situations where it is not possible to examine all brain stem reflexes due to severe facial / head injuries or for neonatal patients
Unable to undertake ancillary tests	Example may include a situation where the personnel or equipment for ancillary tests is unavailable e.g. not in the hospital or unavailable due to weekend hours
One or more brainstem reflexes remained intact	Brainstem reflexes detected during brainstem testing e.g., cough, eye movement
Family reasons not to brainstem test	This may relate to reasons whereby brainstem testing is not acceptable

Table 3: Guidance for audit coordinators on additional response options for a) reasons for not referring and reasons for not approaching the family

These response options specifically relate to the audit questions:  Reasons for not referring Reasons for not approaching the family	Further Explanation
Coroner refusal	Self-explanatory
Ward of court	Self-explanatory
No family/next of kin	Self-explanatory
Unable to contact the family	Self-explanatory
Patient was not expected to die within	Timeframe specified by ICSI DCD Guidelines.
the timeframe compatible with organ	Currently 90 minutes
donation	
Patient unidentified	Self-explanatory
Clinician chose not to refer	Self-explanatory
The nature of the withdrawal or	E.g. weaning of inotrope or ventilatory support rather than
limitation of treatment was not compatible with DCD	extubation

Table 4: Guidance for audit coordinators on additional response options for reasons why the family did not assent

These response options specifically	Further Explanation
relates to the to the audit question:	Turtici Explanation
Reasons why the family did	
not assent	
Family unsure about patient's wishes	Self-explanatory
Patient did not wish to become an	Self-explanatory
	Self-explanatory
organ donor	
Family concerned that organ donation	Self-explanatory
would delay post-mortem or funeral	
Cultural / Religious reasons	This option can should be selected if these reasons are verbally
	expressed
Family not prepared to wait the time	Self-explanatory
required for organ donation	
Family uncomfortable with the organ	This is any aspect of the organ donation process including
donation process (including who	surgery, e.g., virology testing or tissue typing
receives the organs)	
Family did not accept death by	Self-explanatory
neurological criteria or that death was	
imminent (broader than UK version	
which covers only neurological death)	
Family dissatisfied with patient care	This could be any aspect of patient care and family verbalises
	specific issue(s)
Family felt that the patient has	Self-explanatory
"suffered" or been through enough	. ,
Family divided over the decision	Self-explanatory
Family wanted to stay with patient	Self-explanatory
after patient death	. ,
Family felt that the body should be	Self-explanatory
buried whole (unrelated to religious /	, ,
cultural reasons)	
Strong refusal, probing not	Self-explanatory
appropriate	· · · · · · · · · · · · · · · · · · ·

Table 5: Guidance for audit coordinators on additional response options for reasons organ donation did not proceed after family assent

Specific reasons organ donation did not proceed after family assent	Further Explanation
Didn't die in the timeframe required	Timeframe specified by ICSI DCD Guidelines.
for organ donation	Currently 90 minutes
Family withdrew consent after initial	Self-explanatory
assent	
Other non-medical reasons	This relates to any non-medical issue for example logistical issues, an appropriate surgical team not being available, transport or no suitable transplant recipient