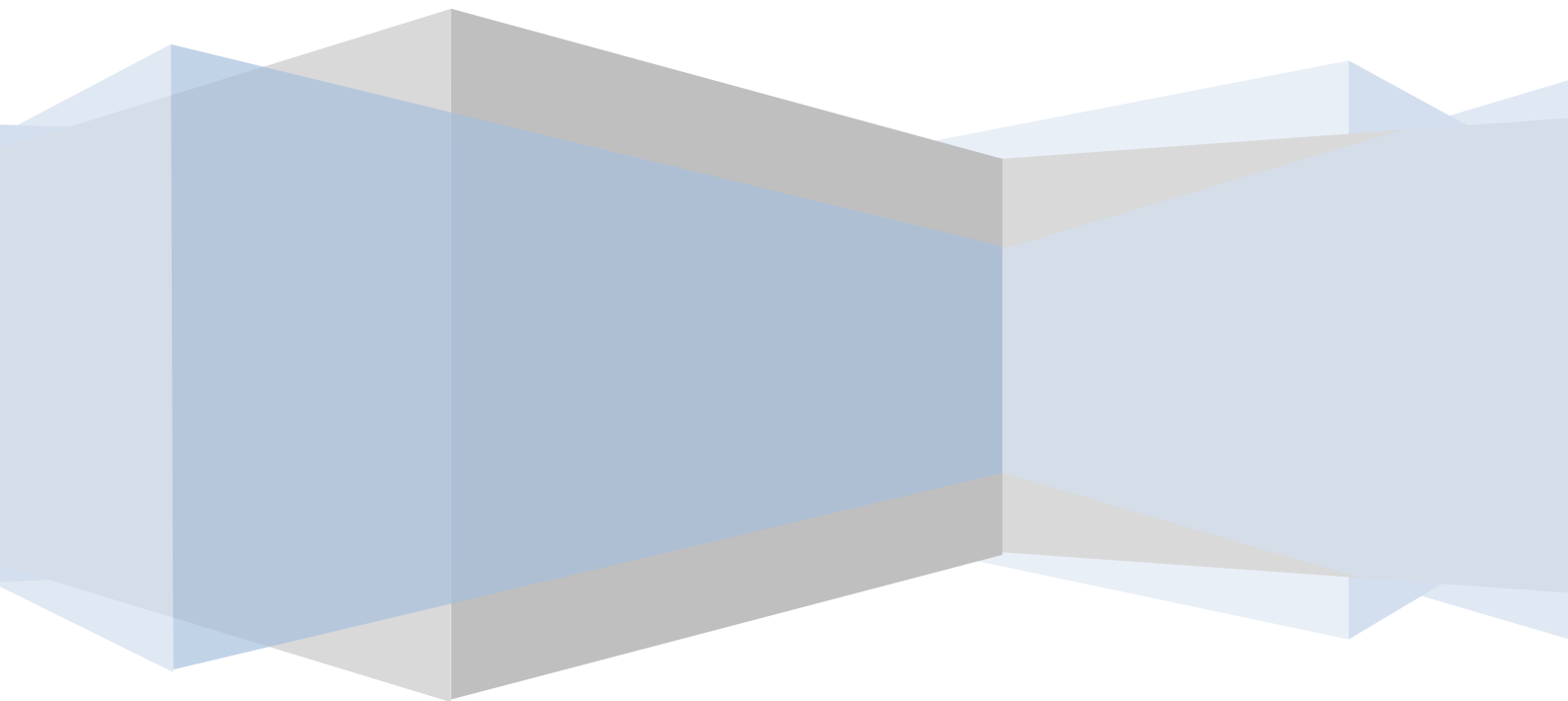


PICANet ECMO Dataset Definitions Manual

Version 2.1 March 2024



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INTRODUCTION

BACKGROUND

PICANet collects the Extracorporeal Membrane Oxygenation (ECMO) referral and admission dataset to supplement the clinical database of paediatric intensive care activity. The extended dataset includes information about ECMO referral calls and ECMO admission information; providing evidence on standards of service across specialist paediatric intensive care.

TERMINOLOGY

Extracorporeal Life Support (ECLS) is a collective term for extracorporeal therapies used for the support of various presentations of cardiac and/or pulmonary conditions through the use of an extracorporeal circuit.

ECMO is the provision of oxygen and carbon dioxide exchange through the use of an extracorporeal circuit consisting minimally of a blood pump, artificial lung, and vascular access cannulae, and using blood flows sufficient to support oxygenation and enhance carbon dioxide removal. ECMO is a type of ECLS.

Extracorporeal cardiopulmonary resuscitation (ECPR) is the initiation of ECMO after cardiac arrest while CPR is ongoing or just after CPR has been delivered. It is used as an adjunct to CPR to support the circulation and allow clinicians to assess the potential reversal of the underlying pathology. The aim of this is to improve long-term survival and neurological outcomes from cardiac arrest.

EVENTS

PICANet uses the term ‘*event*’ to describe a single instance of paediatric intensive care activity, such as a referral, transport, admission or ECMO referral. A patient referred and subsequently admitted following the referral would have both a PICANet referral ‘*event*’ and a PICANet admission ‘*event*’. They may also have a transport ‘*event*’. These may or may not be submitted by the same organisation.

ORGANISATIONS

We use the term *organisation* to represent any unit or service involved in the provision of paediatric intensive care (PIC). The key organisation types are **Paediatric Intensive Care Unit (PICU)**, **Centralised Transport service (CTS)** and **District General Hospital (DGH)**, although the term also includes other locations from or to which PIC patients are retrieved or transferred, such as an **airport** or **hospice**.

Note that for PICANet purposes;

- CTS is a Specialised Paediatric Critical Care Centralised Transport Service
- DGH refers to any hospital without a PICU, as well as any non-PIC hospital ward or department where there is a co-located PICU. PICU sites will therefore have both a DGH and PICU code.

DATA COLLECTION

ECMO Referral

The typical ECMO Referral data collection process is as follows:

1. A **referral call is made** to an ECMO centre requesting consideration of ECMO.
2. The clinicians then consider whether or not the patient is an ECMO candidate and if the child requires conventional transport or mobile ECMO.
3. A **Referral form is completed** by the ECMO centre taking the referral call.
Details are required for **all referrals to** an ECMO centre, whether it is decided the patient is a candidate for ECMO or not.
Once the referral call is made to the ECMO centre, the ECMO centre assumes ownership of this referral, and of the PICANet ECMO Referral Data Collection. They need to record all of the relevant information regardless of whether the child was admitted to their unit or referred onto another unit (e.g., if they had no staffed bed available).
4. A **Transport form will be completed** by the CTS/specialised ECMO transport service providing the transport where appropriate.

ECMO Referral data items include patient demographic information, basic details about the referring unit, details of the ECMO support requested, the decision of the referral call, basic details of the transport if appropriate, and any subsequent follow-up post referral.

Please note: There is only **one** referral form to be completed even if the child is refused and subsequently referred to another ECMO centre. Unlike an ordinary PICANet PICU referral, details of any refusing ECMO centres are included within the same form. This includes the unit that accepted, any refusing units and details of the transport undertaken. There is also a section related to the admission outcome and follow up post-referral.

Certain information on the referral form will be required to be completed retrospectively, when transport, admission and/or follow-up has taken place.

Data on admissions refused for organisational reasons (lack of beds, staff etc.) helps to identify the difficulties and challenges faced by ECMO services and the geographical variation.

ECMO Admission

The typical ECMO admission data collection process is as follows:

1. If the patient is admitted for an ECMO assessment, admitted on ECMO or placed on ECMO during their standard PICU admission to an ECMO centre the **ECMO admission custom audit is completed as part of the PICANet Admission record** by the admitting Centre.

There are a few circumstances that could surround this;

- a) The patient is admitted for assessment only – an ECMO Admission form is required to be completed even if the patient is deemed not to be a candidate
 - b) The patient is admitted for assessment and then goes onto ECMO – an ECMO Admission Form is required to be completed.
 - c) The patient is admitted on ECMO – an ECMO Admission Form is required to be completed.
 - d) A patient is admitted to PICU within the ECMO centre for standard PICU treatment and then subsequently requires ECMO.
2. The ECMO centre **enters or uploads to PICANet Web** the completed ECMO admission event data.

Admission data items include patient demographic details, ECMO mode and configurations, brief details of up to two ECMO runs, and/or ECMO cannulation/mode changes, renal replacement therapy, complications, decannulation, neurological status pre admission, at discharge and post discharge, and any subsequent follow up status.

If the child has been referred and admitted to the same ECMO centre then **both** a Referral and Admission form will need to be completed alongside a PICANet PICU admission form.

If a child has been referred to an ECMO centre, but subsequently transferred and admitted to an alternative ECMO centre then the original referring centre complete the Referral, and the ECMO centre the child was admitted to complete the ECMO Admission form.

DATA COLLECTION FORMS

ECMO referral form



Paediatric Intensive Care Audit Network - Data collection form **ECMO referral**

Please complete for all referrals for ECMO support, whether or not clinicians decide the patient is a candidate for ECMO.

| | |
|---|--|
| Patient details (or hospital label) | |
| Family name | NHSCHINAC number |
| First name | Date of birth (dd/mm/yyyy) |
| Postcode | Sex |
| | <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Ambiguous |
| ECMO referral details | |
| Date and time of initial referral call | Referring area |
| Referral number | Referring speciality |
| Initial referring unit (where patient was at time of referral call) | |
| ECMO referral outcome | |
| ECMO support requested | Accepting ECMO centre |
| Date and time of referral decision | Referral decision |
| Reason not ECMO candidate (select all that apply) | Transport decision |
| Second opinion sought? | ECMO centre providing second opinion |
| Comments | Form completed by |

ECMO Admission form



Paediatric Intensive Care Audit Network - Data collection form **ECMO admission**

Please complete if patient is admitted as an ECMO assessment, admitted on ECMO, or is placed on ECMO during their standard PICU admission to an ECMO centre.

| | |
|---|--|
| Patient details (or hospital label) | |
| Family name | Postcode |
| First name | NHSCHINAC number |
| | Case note number |
| | Date of birth (dd/mm/yyyy) |
| Admission details | |
| ECMO status | Neurological status on admission |
| Admitted for assessment – not a candidate | Left sided decompression? |
| Admitted for assessment – did not require ECMO | Reason for RRT (select all that apply) |
| Admitted for assessment – placed on ECMO | Re-operation or catheter intervention? |
| Admitted on ECMO | Renal replacement therapy during ECMO run? |
| Admitted for PICU care, placed on ECMO later | Cardiac surgical patient? |
| If patient was admitted for assessment but ultimately did not receive ECMO, follow up information is still required to be completed | |
| ECMO details | |
| Reason for starting ECMO | Additional information |
| Canalisation and ECMO started in | ECMO run complications (select all that apply) |
| Cardiac surgical patient? | Plasma exchange? |
| | Bloodstream infections (select all that apply) |
| | |

| | |
|---|--|
| ECMO runs | |
| Total number of ECMO runs | ECMO mode |
| Run 1 | Run 2 |
| Date and time run started | Date and time run started |
| ECMO mode | ECMO mode |
| Canal type | Canal type |
| Dual lumen (if applicable) | Dual lumen (if applicable) |
| Drainage cannula (if single lumen) | Drainage cannula (if single lumen) |
| Return cannula (if single lumen) | Return cannula (if single lumen) |
| Additional drainage cannula | Additional drainage cannula |
| Decannulation | ECMO follow up |
| Indication for decannulation | Neurological status at discharge |
| Date and time of decannulation for ECMO run 1 (if applicable) | Status at 30 days post ECMO assessment? |
| Date and time of decannulation for ECMO run 2 (if applicable) | Status at 180 days post ECMO assessment? |
| Date and time ready for discharge from ECMO centre | Date and time of death (if available) |
| Comments | Form completed by |

RESPONSIBILITY FOR DATA COLLECTION

For any child receiving ECMO, an ECMO Admission and ECMO referral form is required. The responsibility for the 'ECMO Admission' form will always be the PICU they are receiving ECMO in.

If the child has been referred and subsequently admitted to the same ECMO centre then **both** the 'ECMO Referral' and 'ECMO Admission' form will need to be completed alongside a standard PICANet PICU admission form by the admitting centre.

If a child has been referred to an ECMO centre, but then transferred and admitted to an alternative ECMO centre then the original centre the child was referred to complete the 'ECMO Referral', and the ECMO centre the child was subsequently admitted to will complete the 'ECMO Admission'.

For an ECMO referral, the unit the child is initially referred to takes on the onus of the 'ECMO referral' data entry. This remains the case wherever the child is admitted to. This centre will collect all of the information required for the 'ECMO Referral' data collection form.

Referral dataset

PATIENT DETAILS

Family name or Surname

| | |
|-------------------|--|
| Definition | The last or family name or surname given to the child as it would appear on the child's birth certificate or other appropriate document. |
| Reason | <p>Family name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs or transport services.</p> |
| Format | <p>Free text (e.g., Brown).</p> <p>If no family name available record as UNKNOWN and indicate why not available in the comments section.</p> |

First name

| | |
|-------------------|--|
| Definition | The first name given to the child as it would appear on the child's birth certificate or other appropriate document. |
| Reason | <p>First name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple referrals and /or admissions to one or more PICUs or transport services.</p> |
| Format | <p>Free text (e.g., John).</p> <p>If no first name available record as UNKNOWN and indicate why not available in the comments section.</p> |

Postcode

| | |
|-------------------|--|
| Definition | The postcode for the child's normal place of residence. |
| Reason | <p>Postcode provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple admissions to one or more PICUs or transport services.</p> <p>Postcode provides a means of linkage to geographic and demographic information for effective audit and assessment of health services delivery.</p> |
| Format | <p>Text (e.g., S10 8NN).</p> <p>Foreign postcodes will be accepted by PICANet Web.</p> <p>If postcode is unobtainable, record as UNOBTAINABLE.</p> <p>A list of postcodes for overseas countries is available on request.</p> |

NHS, CHI or H&C number

| | |
|-------------------|---|
| Definition | Unique identifying number enabling tracing of a patient through the NHS system in the United Kingdom. For English and Welsh patients use the NHS number, for Scottish patients the CHI number and for Northern Ireland the H&C number is used as a unique numeric identifier. |
| Reason | <p>NHS, CHI or H&C number gives a unique, identifiable variable that will allow other identifiable data items to be removed from the database.</p> <p>Can identify individuals who may have had multiple admissions to one or more PICUs or paediatric intensive care transport services.</p> |
| Format | <p>Free text (e.g., 1463788990)</p> <p>Validation check that NHS, CHI or H&C number is a valid number</p> |

NHS, CHI or H&C number eligibility

| | |
|-------------------|---|
| Definition | The patient is not eligible for NHS, CHI or H&C number, he or she is an overseas national who is not ordinarily a resident in the UK and therefore does not have an allocated NHS, CHI or H&C number. |
| Reason | To enable effective audit of availability of NHS, CHI or H&C number and assessment of health services delivery. |
| Format | Tick box if patient is not eligible for an NHS, CHI or H&C number |

Date of birth

| | |
|-------------------|--|
| Definition | The child's date of birth as recorded on the child's birth certificate or other appropriate document. |
| Reason | <p>Date of birth and Date of admission are used to calculate age at admission to this paediatric intensive care service.</p> <p>Date of birth provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs and/or transport services.</p> |
| Format | <p>Date; dd/mm/yyyy.</p> <p>Date of birth should be on or prior to the date of admission</p> <p>If the child's date of birth is unobtainable, but the child is under your care, use your judgement to estimate year of birth and record as 1 January of estimated year (e.g., 01/01/YYYY).</p> <p>If information is being extracted from notes and the child's date of birth is not recorded, or recorded as unavailable, leave the field blank and in the 'Indicate if date of birth is' field below tick 'Unknown'.</p> <p>If it is necessary for Date of birth to be partly anonymised, enter the correct month and year and record 01 for the day (e.g., 01/MM/YYYY). Then tick 'Anonymised' below.</p> <p>Validation check if patient is aged 18 years or older</p> |

Indicate if date of birth is...

| | |
|-------------------|---|
| Definition | Specifies whether the date of birth is Not estimated, estimated or anonymised. |
| Reason | Date of birth and Date of admission to your unit are used to calculate age at admission to your unit. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">Not estimatedEstimatedAnonymised |

Sex

| | |
|-------------------|---|
| Definition | Identifies the genotypical sex of the child at referral or admission to this paediatric intensive care service. |
| Reason | Sex is important for reporting demographic statistics for admissions to your unit. Sex provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. |
| Format | Choose from one of the following: <ul style="list-style-type: none">MaleFemaleAmbiguous |

ECMO REFERRAL DETAILS

Date and time of initial referral call

| | |
|-------------------|---|
| Definition | The actual date and time when the initial referral call for ECMO consideration was made to the ECMO centre. |
| Reason | <p>Date and time of the initial referral call will be used to calculate the total time it takes for an ECMO referral decision to be made.</p> <p>Accurate recording of date and time will allow analysis of organisational delays e.g. due to lack of availability of staffed beds or transport teams and is required for NHSE service specifications.</p> <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy</p> <p>Time: hh:mm (24-hour clock)</p> |

Referral number

| | |
|-------------------|---|
| Definition | <p>Unique identifier assigned to each consecutive ECMO referral event.</p> <p>As recorded within your organisation to identify each ECMO referral episode.</p> |
| Reason | <p>Referral number provides a unique identifier for each referral episode to an organisation participating in PICANet and thus allows identification of a series of one or more referral events from another.</p> <p>Required for effective audit and assessment of geographical distribution of referring population to individual transport services/units.</p> |
| Format | Free text (e.g., 2017 07) |

Initial referring unit

| | |
|-------------------|---|
| Definition | Identifies the referring hospital, DGH or PICU where the child is located at the time of the referral call. |
| Reason | Required for effective audit and assessment of geographical distribution of referring population to individual units/transport services. |
| Format | <p>Record the name of hospital / DGH and specialist unit</p> <p>Free text e.g., Pilgrim Hospital A&E</p> <p>At data entry to PICANet Web select the select the organisation type – PICU or DGH from the organisation coder</p> <p>Search for the name of the organisation. If this is not available in the given list, but known select 'Other organisation' and enter the name in the 'Other' box, using free text</p> <p>If the name of the organisation is not known select 'Unknown organisation'</p> |

Referring area

Definition

Identifies the care area where the child is located at the time of the referral call.

X-ray, endoscopy, CT scanner or similar - identifies that the child came from an area where diagnostic procedures may have been carried out at the time of collection from the referring hospital

Recovery only - means the child was receiving care in the recovery area at the time of collection from the referring hospital

PICU - means the child was receiving care within PICU at the time of collection from the referring hospital

NICU - means the child was receiving care within NICU at the time of collection from the referring hospital

ICU (Adult) - means the child was receiving care within an adult or other specialist ICU, which is not designated as a PICU, at the time of collection from the referring hospital

Level 2 unit (HDU) - means the child was receiving care in a Level 2 critical care/high dependency area at the time of collection from the referring hospital

Ward - means the child was receiving care in a ward at the time of collection from the referring hospital

Theatre and recovery - means the child has undergone all or part of a surgical procedure or has received an anaesthetic for a procedure and was receiving care within the theatre and recovery area at the time of collection from the referring hospital

Emergency department (A&E) - means the child was receiving care within an Accident and Emergency Department at the time of collection from the referring hospital

Other transport service - the patient is received from a different transport service i.e., at an airport or port for international transfer.

Other intermediate care area - is an area where the level of care is greater than that of the normal wards, but not an ICU/PICU/NICU or HDU

Reason

To enable effective audit and assessment of health services delivery.

Format

Choose from one of the following

X-ray, endoscopy, CT scanner or similar

Recovery only

PICU

NICU

ICU (Adult)

Level 2 unit (HDU)

Ward

Theatre and recovery

Emergency department (A&E)

Other transport service

Other intermediate care area

Referring speciality

| | |
|-------------------|---|
| Definition | <p>Specialty from which this request for ECMO admission is made.</p> <p>Record the parent specialty of the doctor who made the ECMO referral.</p> <p>Examples:</p> <ul style="list-style-type: none">▪ A patient is admitted to A & E with respiratory failure, an PICU consultant attends and decides to refer for ECMO – referring speciality PICU▪ A patient has deteriorated in neonatal intensive care, the consultant calls the ECMO centre for consideration of ECMO and the decision is taken to admit the patient – referring speciality NICU▪ |
| Reason | <p>Describes the background from which children are admitted for effective audit and assessment of health services delivery.</p> |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">General paediatricsSub-specialty paediatricsNeonatesPICUAnaestheticsGeneral ITUNeurosurgeryGeneral surgeryAccident and EmergencyBurns and plasticsENTPaediatric Intensive Care Transport ServiceOtherUnknown |

ECMO Referral Outcome

ECMO support requested

| | |
|-------------------|---|
| Definition | <p>Defines the ECMO support type that has been requested</p> <p>Respiratory – The use of extracorporeal membrane oxygenation with a primary indication for support of respiratory failure by providing gas exchange support. Does not imply ECLS mode or cannula configuration</p> <p>Cardiac – The use of extracorporeal membrane oxygenation with a primary indication for support of left and/or right ventricle failure by providing cardiac and gas exchange support. Does not imply any specific ECLS mode or cannulation configuration</p> <p>Both – Mixture of both respiratory and cardiac definitions above.</p> |
| Reason | <p>To enable effective audit and assessment of health services delivery and NHSE service specification.</p> |
| Format | <p>Choose one of the below</p> <p>Respiratory Cardiac Both</p> |

Date and time of referral decision

| | |
|-------------------|--|
| Definition | <p>The actual date and time when clinicians agreed on the outcome of the ECMO referral call. This is based on the patient's eligibility for ECMO (not the availability of a team or a bed).</p> <p>This may not be the date of the first telephone call to the PICU or transport service as this may have been for advice or discussion only.</p> |
| Reason | <p>Date and time of the referral decision will be used to calculate the total time the referral decision takes for each individual patient.</p> <p>Accurate recording of date and time will allow analysis of organisational delays e.g., due to lack of availability of staffed beds or transport teams.</p> <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy Time: hh:mm (24-hour clock)</p> |

Referral decision

| | |
|-------------------|--|
| Definition | Specifies patients' status as an ECMO candidate and outcome of referral decision. |
| Reason | To enable effective audit and assessment of health services delivery, including NHSE service specification compliance |
| Format | <p>First select referral decision, and then specify reason if not a candidate.</p> <p>ECMO candidate</p> <ul style="list-style-type: none">- Accepted at initial centre – including if patient was already a patient in the initial centre- Referred to other ECMO centre (no staffed bed)- Referred to other ECMO centre (specialist service required) - such as heart transplant/Berlin Heart- Did not require ECMO assessment at time of referral (but patient considered a candidate for ECMO)- Not ECMO candidate <p><i>If 'Not ECMO candidate' - Reason Not ECMO candidate (select all that apply)</i></p> <ul style="list-style-type: none">- Pre-existing comorbidity- Poor prognosis due to condition at time of referral- Other (<i>specify</i>) <p>If 'Other (<i>specify</i>)' selected give reason in free text box.</p> |

Second opinion sought?

| | |
|-------------------|---|
| Definition | Specifies whether the referring centre sought a second opinion |
| Reason | To enable effective audit and assessment of health services delivery, including NHSE service specification compliance |
| Format | <p>Choose one of the following</p> <p>Yes</p> <p>No</p> <p>Unknown</p> |

ECMO centre providing second opinion

| | |
|-------------------|--|
| Definition | Specifies the ECMO centre that was contacted for further advice regarding the referral |
| Reason | To enable effective audit and assessment of health services delivery, including NHSE service specification compliance |
| Format | <p>Record the name of the ECMO Centre that was contacted for advice e.g., Leicester Royal Infirmary CPICU</p> <p>At data entry to PICANet Web select organisation from one of the ECMO centres in the pre-defined list</p> |

Accepting ECMO centre

| | |
|-------------------|--|
| Definition | The accepting ECMO centre identifies the exact destination where the child was accepted for admission/transfer |
| Reason | Required for geographic information to be linked to assessment of health services delivery. |
| Format | <p>Record the name of the ECMO Centre e.g., Evelina Children's Hospital</p> <p>At data entry to PICANet Web select organisation from one of the ECMO centres in the pre-defined list</p> |

If referred to other ECMO centre – Number of additional ECMO units referred to prior to accepting centre

| | |
|-------------------|--|
| Definition | <p>If 'Referred to other ECMO centre (no staffed bed)' or 'Referred to other ECMO centre (specialist service required)' specify the number of additional ECMO units that the patient was referred to prior to acceptance in chronological order.</p> <p>You do not need to include the owner centre or the accepting centre as additional units. This is intended to collect the number of refusals.</p> <p>Example – Unit A receives ECMO referral, and starts PICANet Referral form. Unit A is at capacity so refers to units B and C, who also cannot accommodate. Unit D accepts patient for ECMO assessment.</p> <p>Here there are 2 additional ECMO units the patient was referred to, B and C. Unit A is the owner organisation, Unit D is the accepting centre. Information on units A and D are not included as this information is collected elsewhere</p> <p>Record the names of up to 5 additional centres in the order of referral.</p> |
| Reason | <p>To enable effective audit and assessment of health services delivery.</p> <p>Required for geographic information to be linked to assessment of health services delivery.</p> |
| Format | <p>Record the ECMO centre refusing the ECMO admission</p> <p>At data entry to PICANet Web select organisation from one of the ECMO centres in the pre-defined list</p> |

Transport decision

| | |
|-------------------|---|
| Definition | <p>This intends to identify the decision that was made during the referral process, the outcome of the referral may be different.</p> <p>Accepted for conventional retrieval – the referral for ECMO was accepted, and the decision made for the child to be transported by conventional retrieval.</p> <p>Accepted for mobile ECMO – The referral for ECMO was accepted, and the decision made to transport the patient using mobile ECMO.</p> <p>Transport not requested – Patient was already at the referring centre so no transport required.</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose one of the below</p> <ul style="list-style-type: none">- Accepted for conventional retrieval- Accepted for mobile ECMO- Transport not requested |

Mode of transport

| | |
|-------------------|---|
| Definition | <p>Identifies the main mode of transport used by the transport team at any time during the journey with the child.</p> <p>This may differ from the original decision made as part of the referral call.</p> <p>Conventional by road – The child was transported without ECMO by road transport</p> <p>Conventional by air– The child was transported without ECMO by air (helicopter/airplane)</p> <p>Mobile ECMO by road – The child was transported on ECMO by road transport</p> <p>Mobile ECMO by air –The child was transported on ECMO by air (helicopter/airplane)</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose one of the below</p> <ul style="list-style-type: none">- Conventional by road- Conventional by air- Mobile ECMO by road- Mobile ECMO by air |

Transport team

| | |
|-------------------|--|
| Definition | The name of the mobile ECMO transport team, PICU or Specialised Paediatric Transport Service (CTS), undertaking this episode of transport. |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Record the full name or recognised abbreviation of the PICU, or CTS e.g., CATS or Heartlink in the text box – please note Heartlink is known as a CTS on PICANet Web.</p> <p>At data entry to PICANet Web select the organisation type - PICU, CTS</p> <p>Search for the name of the organisation, if this is not available in the given list, but known select 'Other organisation' and enter the name in the 'Other' box, using free text</p> <p>If the name of the organisation is not known select 'Unknown organisation'</p> |

Transport outcome

| | |
|-------------------|---|
| Definition | <p>The result of the transport episode once the decision to mobilise the transport team has been made and/or the transport journey has been completed.</p> <p>Patient transported - the child has been transported to the destination specified</p> <p>Not transported - condition improved - the transport team arrived at the collection unit, the child's condition improved and PIC/ECMO transport was no longer required</p> <p>Not transported - condition deteriorated - the transport team arrived at the collection unit, the child's condition deteriorated and PIC/ECMO transport was no longer appropriate</p> <p>Not transported - other reason - the transport was cancelled either after initial acceptance, when the transport team were en route to the collection unit or after the transport team arrived at the collection unit, the child was not transferred to another unit or location by the transport team. Enter reason in comments box</p> <p>Patient died before transport team arrived - the child died after the transport team was mobilised but prior to arrival at the collection unit</p> <p>Patient died while transport team present - the child died whilst the transport team were providing care at the collection unit</p> <p>Patient died during transit - the child died during the return journey from the collection unit</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Choose one of the following <ul style="list-style-type: none">Patient transportedNot transported- condition improvedNot transported - condition deterioratedNot transported - other reasonPatient died before transport team arrivedPatient died while transport team presentPatient died during transitUnknown |

Admission Outcome

| | |
|------------|--|
| Definition | Identifies the admission outcome Admitted to PICU only – admitted for PICU care only Admitted for ECMO assessment – admitted for assessment for ECMO on PICU Admitted on ECMO – Admitted already on ECMO |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Choose one of the below <ul style="list-style-type: none">- Admitted to PICU only- Admitted for ECMO assessment- Admitted on ECMO |

FOLLOW UP

Status at 30 days post referral

| | |
|--------------------|--|
| Description | Identifies the status (alive or dead) of the child at 30 days post referral |
| Reason | Required for epidemiological analysis, assessment of health services delivery and NHSE Service Specification. |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Alive• Dead• Unknown |

Status at 180 days post referral

| | |
|--------------------|--|
| Description | Identifies the status (alive or dead) of the child at 180 days post referral |
| Reason | Required for epidemiological analysis, assessment of health services delivery and NHSE Service specification |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Alive• Dead• Unknown |

Date and time of death

| | |
|-------------------|--|
| Definition | Identifies the date of death if this occurs following the ECMO referral and is identified at the 30- or 180-day follow-up |
| Reason | <p>Date of death and Time of death are identified as one of the principal outcomes of paediatric intensive care. Required for epidemiological analysis and assessment of health services delivery.</p> <p>The time of death is important for this purpose if it is during or immediately following the referral episode. If the death occurs after this period and the time of death is not known then the time of death may be left blank</p> |
| Format | <p>Date: dd/mm/yyyy</p> <p>Time: hh:mm (24-hour clock)</p> |

Comments

| | |
|-------------------|---|
| Definition | <p>Any additional information considered relevant to the admission.</p> <p>Text entered in this field may provide extra information about data entered elsewhere in a specific field in the dataset, or may provide extra information on the ECMO referral, which is not collected as part of the dataset.</p> <p>No identifiers (patient, nurse, doctor, ICU, hospital) should be included in text data entered into this field.</p> <p>As there is limited space in this field all text data should be kept to a minimum and be as concise as possible. Text data must not contain any punctuation except a period (full-stop) at the end of each data point.</p> |
| Reason | No dataset specification covers all eventualities: to deal with this a text field has been included for comments/additional information. |
| Format | Free text |

Admission dataset

PATIENT DETAILS

Family name or Surname

| | |
|-------------------|--|
| Definition | The last or family name or surname given to the child as it would appear on the child's birth certificate or other appropriate document. |
| Reason | <p>Family name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs or transport services.</p> |
| Format | <p>Free text (e.g. Brown).</p> <p>If no family name available record as UNKNOWN and indicate why not available in the comments section.</p> |

First name

| | |
|-------------------|--|
| Definition | The first name given to the child as it would appear on the child's birth certificate or other appropriate document. |
| Reason | <p>First name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple referrals and /or admissions to one or more PICUs or transport services.</p> |
| Format | <p>Free text (e.g. John).</p> <p>If no first name available record as UNKNOWN and indicate why not available in the comments section.</p> |

Postcode

| | |
|-------------------|---|
| Definition | The postcode for the child's normal place of residence. |
| Reason | <p>Postcode provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web.</p> <p>Can help identify individuals who may have had multiple admissions to one or more PICUs or transport services.</p> <p>Postcode provides a means of linkage to geographic and demographic information for effective audit and assessment of health services delivery</p> |
| Format | <p>Text (e.g. S10 8NN).</p> <p>Foreign postcodes will be accepted by PICANet Web.</p> <p>If postcode is unobtainable, record as UNOBTAINABLE.</p> <p>A list of postcodes for overseas countries is available on request.</p> |

NHS, CHI or H&C number

| | |
|-------------------|---|
| Definition | Unique identifying number enabling tracing of a patient through the NHS system in the United Kingdom. For English and Welsh patients use the NHS number, for Scottish patients the CHI number and for Northern Ireland the H&C number is used as a unique numeric identifier. |
| Reason | <p>NHS, CHI or H&C number gives a unique, identifiable variable that will allow other identifiable data items to be removed from the database.</p> <p>Can identify individuals who may have had multiple admissions to one or more PICUs or paediatric intensive care transport services.</p> |
| Format | <p>Free text (e.g. 1463788990)</p> <p>Validation check that NHS, CHI or H&C number is a valid number</p> |

Case note number

| | |
|-------------------|---|
| Definition | <p>Unique identifying number for an individual's hospital records at the treating unit.</p> <p>Allocated on first admission to hospital</p> |
| Reason | Case note number provides a unique identifier that can aid patient tracking throughout the hospital |
| Format | Free text (e.g. 1463788990) |

Date of birth

| | |
|-------------------|---|
| Definition | The child's date of birth as recorded on the child's birth certificate or other appropriate document |
| Reason | <p>Date of birth and Date of admission are used to calculate age at admission to this paediatric intensive care service</p> <p>Date of birth provides an additional identifier that can aid patient tracking throughout the paediatric intensive care service, hospital and PICANet Web</p> <p>Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs</p> |
| Format | <p>Date; dd/mm/yyyy</p> <p>Date of birth should be on or prior to the date of admission</p> <p>Validation check: if patient is aged 18 years or older at admission</p> |

ADMISSION DETAILS

ECMO status

| | |
|-------------------|--|
| Definition | <p>Identifies the child's ECMO status on admission to the ECMO centre with one of the following:</p> <ul style="list-style-type: none">• Admitted for assessment - not a candidate (the child was admitted for consideration of ECMO but after assessment the decision was taken that they were not a candidate for ECMO)• Admitted for assessment - did not require ECMO (the child was admitted for consideration of ECMO but did not require ECMO during this PICU admission)• Admitted for assessment - placed on ECMO• Admitted on ECMO - the child was admitted already on ECMO• Admitted for PICU care, placed on ECMO later - the child was a standard admission to PICU. They subsequently require ECMO during this PICU admission• Admitted for PICU care only – the child was admitted for PICU care, and was never referred for ECMO. <p>Note: 'Admitted for PICU care only' is available on PICANet Web to determine whether a patient is eligible for the ECMO data collection.</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">• Admitted for assessment -not a candidate• Admitted for assessment – did not require ECMO• Admitted for assessment -placed on ECMO• Admitted on ECMO• Admitted for PICU care, placed on ECMO later• Admitted for PICU care only |

Neurological status on admission

Definition Identifies the neurological status on admission using the Paediatric Cerebral Performance Category scale:

Normal (1): At age-appropriate level; school age child attends regular school

Mild Disability (2): Conscious, alert, able to interact at age-appropriate level; regular school but cognition perhaps not age appropriate, possibility of mild neurological deficit.

Moderate Disability (3): Conscious, age-appropriate independent activities of daily life, special education classroom and/or learning

Severe Disability (4): Conscious, dependent on others for daily support because of impaired brain function

Coma or vegetative state (5): Any degree of coma, unaware even if awake in appearance, without interaction with the environment, no evidence of cortex function, possibility for some reflexive response, spontaneous eye-opening, sleep-wake cycles

Dead (6)

Reason To enable effective audit and assessment of health care services and NHSE service specification on neurological follow up

Format Choose from one of the following:

- Normal
 - Mild disability
 - Moderate disability
 - Severe disability
 - Vegetative state
 - Dead
 - Unknown
-

Date of referral decision

| | |
|-------------------|---|
| Definition | <p>The actual date when clinicians agreed on the outcome of the ECMO referral call resulting in this ECMO admission</p> <p>This may not be the date of the first telephone call to the PICU or transport service as this may have been for advice or discussion only.</p> <p><i>For in house cannulation this may also be the date when the ECMO team were first made aware of the potential requirement for ECMO cannulation such as a high-risk procedure in catheter suite or theatre.</i></p> <p><i>For those children who were cannulated in theatre (e.g. after failure to come off bypass or low cardiac output), where the ECMO team had no prior notice, then the date of the referral decision would be the same as the date of the operation or procedure.</i></p> |
| Reason | <p>Date of the referral decision will be used to calculate the total time the referral process takes for each individual patient and assist in linking admission/referral events</p> <p>Accurate recording of date will allow analysis of resources involved e.g., due to lack of availability of staffed beds or transport teams.</p> <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy</p> |

ECMO DETAILS

Reason for starting ECMO

| | |
|------------|--|
| Definition | <p>Identifies the underlying pathophysiology for requiring ECMO:</p> <p>Respiratory failure – The use of extracorporeal membrane oxygenation with a primary indication for support of respiratory failure</p> <p>Circulatory failure – The use of extracorporeal membrane oxygenation with a primary indication to support the circulation</p> <p>ECPR – Extracorporeal cardiopulmonary resuscitation is the initiation of ECMO after cardiac arrest while CPR is ongoing or just after CPR has been delivered (within 20 minutes of return of circulation)</p> |
| Reason | <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">• Circulatory failure• Respiratory failure• ECPR |

Cannulation and ECMO started in

| | |
|-------------------|---|
| Definition | Identifies the location where the ECMO cannulas were place and ECMO initiated |
| Reason | To enable effective audit and assessment of health services delivery. |

Format Choose from one of the following:

- PICU/Cardiac PICU
- NICU
- A&E
- Adult ICU
- Cardiac theatre
- Cardiac catheter lab
- Other theatre
- Other (*specify*)
- Unknown

If 'Other (specify) selected please use free text description to identify other location.

Cardiac surgical patient?

Definition Identifies if patient is a cardiac surgical patient (includes planned or unplanned).
If yes - specify timing of ECMO.

Reason To enable effective audit and assessment of health services delivery.

Format Choose from one of the following:

- Yes
- No

If cardiac surgical patient

| | |
|-------------------|---|
| Definition | <p>Identifies timing of ECMO commencement in patients who receive cardiac surgery.</p> <p>Preoperative - patients are placed on ECMO prior to cardiac surgery. This includes patients who were initially placed on ECMO where it was not known that they would require cardiac surgery (e.g. undiagnosed TAPVD)</p> <p>Theatre - placed on ECMO immediately after cardiac surgery/bypass</p> <p>Post-surgery – ECPR - Placed on ECMO after surgery, outside of cardiac theatre and was ECPR</p> <p>Post-surgery - Not ECPR - Placed on ECMO after surgery, outside of cardiac theatre and was not ECPR</p> <p>Not related to surgery - Patient underwent cardiac surgery on this PICU admission but it was unrelated to receiving ECMO (e.g. patient underwent cardiac surgery successfully and while admitted to PICU developed influenza and received ECMO for respiratory failure).</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">• Preoperative• Theatre• Post-surgery - ECPR• Post-surgery - Not ECPR• Not related to surgery |

ADDITIONAL INFORMATION

This following section applies to the entirety of the ECMO process, including any second or subsequent runs, and cannulation or mode changes.

Cannula Change?

Definition Identifies whether at any point whilst the patient was on ECMO they required a change/replacement of cannula(s)

Reason To enable effective audit and assessment of health services delivery.

Format Choose from one of the following:

- Yes
- No
- Unknown

Left sided decompression?

Definition Identifies whether left side of heart needed decompression whilst on ECMO

Reason To enable effective audit and assessment of health services delivery

Format Choose from one of the following:

- Yes (*specify*)
- No
- Unknown

If yes specify – ‘LA Vent’, ‘Septostomy’ or ‘Impella/Balloon Device’

Type of left sided decompression

| | |
|-------------------|---|
| Definition | If yes (<i>specify</i>) selected for 'Left sided decompression', did this involve a Left atrial (LA) vent and/or a septostomy and/or an Impella/Balloon Device |
| Reason | To enable effective audit and assessment of health services delivery |
| Format | Tick any of the following that apply: <ul style="list-style-type: none">• LA vent• Septostomy• Impella/Balloon Device• Unknown |

Re-operation or catheter intervention

| | |
|-------------------|--|
| Definition | Identifies whether the patient required a surgical or catheter intervention whilst on ECMO. |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Yes• No• Unknown |

Renal replacement therapy (RRT) during ECMO run?

| | |
|-------------------|--|
| Definition | Identifies whether renal replacement support was required whilst the child was on ECMO |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Yes• No• Unknown |

If yes – Reason for RRT

| | |
|-------------------|---|
| Definition | <p>Identifies the clinical indication that was the reason for 'Renal replacement therapy (RRT) during ECMO run, this includes continuous renal replacement therapy (Continuous Veno-Veno Haemofiltration (CVVH)), Continuous Veno-Veno Haemodialysis (CVVHD)), Continuous Veno-Veno Haemodiafiltration (CVVHDF)), and peritoneal dialysis.</p> <p>Acute Kidney Injury - also known as acute renal failure and specify which stage of AKI: Stage 1, Stage 2, or Stage 3.</p> <p>Fluid removal</p> <p>Anuria – absence of urine output</p> <p>Hyperkalaemia – potassium levels high in serum</p> <p>Acidosis – too much acid in the blood</p> <p>Other – use free text to specify</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">• Acute kidney injury (<i>specify stage</i>)• Fluid removal• Anuria• Hyperkalaemia• Acidosis• Other (<i>specify</i>) <p><i>If 'Acute kidney injury' specify – 'Stage 1', 'Stage 2' or 'Stage 3'</i></p> <p><i>If 'Other (specify)' selected please use free text description to identify other reason.</i></p> |

Stage of acute kidney injury

| | |
|-------------------|--|
| Definition | <p>If 'Acute kidney injury' selected for 'Reason for RRT':</p> <p>Acute Kidney Injury - also known as acute renal failure has 3 stages:</p> <p>Stage 1 – Serum creatinine 1.5 – 1.9 times higher than the baseline or ≥ 0.3 mg/dl (≥ 26.5 mmol) increase or urine output < 0.5 ml/kg for 6- 12 hours</p> <p>Stage 2 Serum creatinine 2.0 – 2.9 times higher than baseline or urine output < 0.5 ml/kg for ≥ 12 hours</p> <p>Stage 3 – Serum creatinine 3.0 times higher than baseline or increase in serum creatinine to ≥ 4.0 mg/dl (≥ 353.6 mmol/l) or in patients < 18 years decrease in eGFR to < 35 ml/min per $1.73 m_2$ or urine output < 0.3 ml/kg for ≥ 24 hours or anuria for ≥ 12 hours.</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none">• Stage 1• Stage 2• Stage 3• Unknown |

ECMO run complications?

Definition

Identifies complications that arise during ECMO run(s)

No complication – occurred during ECMO

Mechanical – such as membrane lung failure, blood pump failure, raceway rupture, other tubing rupture, circuit change, cannula problems, temperature regulation device malfunction, clots and air emboli, clots in the haemofilter affecting flow, and air in circuit

Haemorrhage – such as GI haemorrhage, Peripheral cannula site bleeding, mediastinal cannulation site bleeding, surgical site bleeding.

Neurology – such as brain death, seizures clinically determined, seizures confirmed by EEG, CNS diffuse ischaemia (confirmed by CT/MRI), CNS infarction (confirmed by CT/MRI), Intra/extra parenchymal CNS haemorrhage (confirmed by US, CT/MRI), neurological intervention performed (ICP monitor, external ventricular drain, craniotomy).

Renal – Creatinine 1.5 – 3.0, creatinine > 3.0 and renal replacement therapy required

Cardiovascular – such as CPR required, Cardiac arrhythmia requiring antiarrhythmic medication infusion, overdrive pacing, cardioversion or defibrillation, tamponade (not blood) requiring pericardial drain or mediastinal washout, and tamponade (blood) requiring pericardial drain or mediastinal washout

Pulmonary – such as pneumothorax or pulmonary haemorrhage (requiring pRBC transfusion - > 20ml/kg/24 hours of pRBCs or >3U PRBCs/24hours in neonates and paediatrics).

Metabolic – such as

- hyperbilirubinemia – neonatal – conjugated bilirubin >20umol/L (>1.2 mg/dl, paediatric- total bilirubin >170umol/L (>10mg/dL or conjugated bilirubin >51umol(>3mg/dL), or need for extracorporeal purification for elevated bilirubin
- moderate haemolysis – peak plasma haemoglobin 50-100 mg/dL or 500 -1000 mg/dL occurring at least once during the ECMO run and sustained for at least 2 days
- severe haemolysis - peak plasma haemoglobin >100 mg/dL or >1000 mg/dL occurring at least once during the ECMO run and sustained for at least 2 consecutive days OR if the level of haemolysis leads to a major component change namely the membrane lung, blood pump, or entire circuit.

Limb – such as limb compartment syndrome, fasciotomy, limb amputation, limb ischaemia requiring limb reperfusion canulae.

Other – any other complications not shown here

Reason

To enable effective audit and assessment of health services delivery.

| | |
|---------------|--|
| Format | Select all that apply |
| | <ul style="list-style-type: none"> • No complication • Mechanical • Haemorrhage • Neurology • Renal • Cardiovascular • Pulmonary • Metabolic • Limb • Other • Unknown |

Plasma exchange?

| | |
|-------------------|--|
| Definition | <p>Identifies whether plasma exchange was undertaken during the child's ECMO run(s)</p> <p>Plasma exchange is a procedure involving the separation and removal of the plasma from the blood in order to remove abnormal substances circulating in the plasma</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Choose from one of the following:</p> <ul style="list-style-type: none"> • Yes • No • Unknown |

Bloodstream infections?

| | |
|-------------------|--|
| Definition | <p>Identifies the infections associated with the child on ECMO</p> <p>Include infections that occur during the ECMO Run</p> <p>Not tested – the patient was not tested for evidence of infection whilst on ECMO</p> <p>No Infection – the patient was tested for infection whilst on ECMO but no infection was detected</p> <p>Gram positive bacteria – such as staphylococcus, streptococcus, and clostridium</p> <p>Gram negative bacteria – such as Escherichia coli, pseudomonas, klebsiella and Acinetobacter</p> <p>Mycobacterium – such as tuberculosis and leprosy</p> <p>Fungus (yeast and mould) - such as aspergillus, candida, histoplasmosis and pneumocystis pneumonia (PCP)</p> <p>Virus and Prions – Viruses such as influenza (A, B & C), measles, mumps, chickenpox, prions such as neurodegenerative disorders</p> <p>Protozoa – such as malaria, giarda and toxoplasmosis</p> <p>Other – use free text to specify</p> |
| Reason | <p>To enable effective audit and assessment of health services delivery and NHSE service specification</p> |
| Format | <p>Select all that apply</p> <ul style="list-style-type: none">• Not tested• No infection• Gram + Bacteria• Gram - Bacteria• Mycobacterium• Fungus (yeast & mould)• Virus & Prions• Protozoa• Other infection• Unknown |

ECMO Runs and Changes

The following data items are a suite of variables to complete as a set for up to 2 ECMO runs and/or changes as specified by the 'Total number of ECMO runs' and 'Total number of ECMO cannulation/mode changes' questions.

On PICANet Web the second suite of variables for ECMO Run 2 will be available for data entry if the number of 'ECMO runs' is over 1. The relevant suites of variables will be available for 'ECMO cannulation/mode change 1 or 2' will be available if the number is equal to or over 1.

Total number of ECMO runs?

| | |
|-------------------|--|
| Definition | Identifies the number of ECMO runs for this admission The first time a patient is placed on ECMO prior to or during this admission is classed as Run 1 Temporary transition of ECLS support to cardiopulmonary bypass (CPB) for cardiac surgery would not be categorised as an additional run Changes to ECMO mode such as from VA to VV do not constitute a new run in isolation, but are recorded in 'ECMO cannulation/mode changes' section Provide details of 2 nd ECMO run (if applicable) in 'ECMO run 2' section. Further ECMO runs are not required to be entered |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Numerical value e.g. 1 Validation check if range exceeds 3 |

Date & Time ECMO run started: Run 1 & 2

| | |
|------------|---|
| Definition | <p>Identifies the date and time that the first and second ECMO run started</p> <p>This refers to the time that the extracorporeal blood flow was established through cannulas attached to an ECMO circuit.</p> <p>This date and time will be prior to the admission date and time in a child who was commenced on ECMO in another organisation prior to being admitted to your ECMO centre.</p> |
| Reason | <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy</p> <p>Time: (24 hour clock); hh:mm</p> |

ECMO Mode: Run 1 & 2

| | |
|-------------------|---|
| Definition | <p>Identifies the mode of drainage and return of blood in the extracorporeal system</p> <p>Select the primary cannulation configuration even if multiple cannulas are placed</p> <p>VV; Venovenous support is where the blood drains from the venous system and reinfuses into the venous system (or pre lung). VV ECMO operates in series with the heart and lungs and does not provide bypass of these organs.</p> <p>VA: Venoarterial support is where the extracorporeal circuit drains blood from the venous system and returns into the systemic arterial system. VA ECMO operates in parallel with and providing partial, or complete bypass of the heart and lungs</p> <p>VVA: Venovenarterial is a hybrid configuration of VA and VV where the blood is drained from the venous system and reinfuses both into the venous and systemic arterial systems. VVA ECMO provides both pulmonary and cardiac support in patients with combined cardiopulmonary failure</p> <p>Other: indicates a support not listed – indicate the primary cannulation configuration in free text</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Select the initial mode of ECMO prior to any configuration changes</p> <ul style="list-style-type: none">• VV• VA• VVA• Other – please specify |

Cannula Type

| | |
|-------------------|---|
| Definition | Specifies whether a single or dual lumen was used |
| Reason | To enable effective audit and assessment of health services delivery and to guide the completion of the following data items. |
| Format | Select one of the following <ul style="list-style-type: none">• Single lumen• Dual lumen• Unknown |

Dual Lumen: Run 1 & 2 (*if applicable*)

| | |
|-------------------|---|
| Definition | <p>For dual lumen, select one from each pair</p> <p>Percutaneous – records if the ECMO drainage cannula was inserted peripherally (without incision and dissection of the vessel)</p> <p>Surgical -records if the ECMO drainage cannula was inserted surgically (with incision and dissection of the vessel)</p> <p>Left – Select if a Dual Lumen cannula was inserted into the Left Internal Jugular</p> <p>Right- Select if a Dual Lumen cannula was inserted in the Right Internal Jugular</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Select one of the following <ul style="list-style-type: none">• Not applicable• Percutaneous OR Surgical• Left OR Right |

Drainage cannula: Run 1 & 2 (*if single lumen*)

Definition

For drainage cannula, select one from each pair

Percutaneous – records if the ECMO drainage cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical -records if the ECMO drainage cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO drainage cannula was inserted directly centrally into the heart e.g. via sternotomy. *If the child is cannulated centrally then you will not be required to complete the cannula site pair of Jugular OR Femoral, nor the cannula body side of left OR Right*

Peripheral -records if the ECMO drainage cannula was not directly inserted into the heart

If peripheral, select one from each pair

Jugular- records if the ECMO drainage cannula was inserted into the right or left internal jugular vein

Femoral – records if the ECMO drainage cannula was inserted into the right or left femoral vein

**This pair is not required if the selected site insertion of the cannulation is Central*

Left - indicates the ECMO drainage cannula was placed on the left side

Right - indicates the ECMO drainage cannula was placed on the right side

**This pair is not required if the selected site insertion of the cannulation is Central*

Reason

To enable effective audit and assessment of health services delivery.

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Jugular OR Femoral
- Left OR Right

Return Cannula: Run 1 & 2 (*if single lumen*)

Definition

For return cannula, select one from each pair

Percutaneous – records if the ECMO return cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical -records if the ECMO return cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO return cannula was inserted directly centrally into the heart e.g. via sternotomy

Peripheral -records if the ECMO return cannula was not directly inserted into the heart

If peripheral, select one from each pair

Neck - records if the ECMO return cannula was inserted into the right/left internal jugular vein or carotid artery

Femoral – records if the ECMO return cannula was inserted into the right or left femoral vein/artery

Left - indicates the ECMO return cannula was placed on the left side

Right - indicates the ECMO return cannula was placed on the right side

Reason

To enable effective audit and assessment of health services delivery.

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Neck OR Femoral
- Left OR Right

Additional drainage cannula: Run 1 & 2 (if applicable)

Definition

Specifies whether or not an additional drainage cannula was inserted during the relevant ECMO run and specifies the location and type of insertion

Tick if not applicable - Tick if no single additional drainage was inserted

Select one from each pair

Percutaneous – records if the ECMO additional drainage cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical - records if the ECMO additional drainage cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO additional drainage cannula was inserted directly centrally into the heart e.g. via sternotomy

Peripheral -records if the ECMO additional drainage cannula was not directly inserted into the heart

If peripheral, select one from each pair

Jugular- records if the ECMO additional drainage cannula was inserted into the right or left Internal jugular vein

Femoral – records if the ECMO additional drainage cannula was inserted into the right or left femoral vein

Left - indicates the ECMO additional drainage cannula was placed on the left side

Right - indicates the ECMO additional drainage cannula was placed on the right side

Reason

To enable effective audit and assessment of health services delivery.

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Jugular OR Femoral
- Left OR Right

Total number of ECMO cannulation/mode changes

| | |
|-------------------|--|
| Definition | Identifies the number of ECMO cannulation/mode changes for this admission This is recorded when there is a change of cannula or mode during an ECMO run |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Numerical value e.g. 1 Validation check if range exceeds 3 |

Date and Time of ECMO cannulation/mode change started: 1 & 2

| | |
|-------------------|--|
| Definition | Identifies the date and time that the first and/or second ECMO cannulation/mode changes were commenced. This specifically refers to the time that the extracorporeal blood flow was established through newly placed cannulas attached to a current ECMO circuit. Temporary transition of ECLS support to cardiopulmonary bypass (CPB) for cardiac surgery would not be recorded as an additional cannulation or mode change |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | Date: dd/mm/yyyy Time: (24 hour clock); hh:mm |

ECMO cannulation/mode changes: ECMO Mode 1 & 2

Definition Identifies the new configuration mode of drainage and return of blood in the extracorporeal system for the ECMO mode change/cannulation change 1 & 2.

Select the primary cannulation configuration even if multiple cannulas are placed

VV; Venovenous support is where the blood drains from the venous system and reinfuses into the venous system (or pre lung). VV ECMO operates in series with the heart and lungs and does not provide bypass of these organs.

VA: Venoarterial support is where the extracorporeal circuit drains blood from the venous system and returns into the systemic arterial system. VA ECMO operates in parallel with and providing partial, or complete bypass of the heart and lungs

VVA: Venovenarterial is a hybrid configuration of VA and VV where the blood is drained from the venous system and reinfuses both into the venous and systemic arterial systems. VVA ECMO provides both pulmonary and cardiac support in patients with combined cardiopulmonary failure

Other: indicates a support not listed – indicate the primary cannulation configuration in free text

Reason To enable effective audit and assessment of health services delivery.

Format Select the initial mode of ECMO prior to any configuration changes

- VV
- VA
- VVA
- Other – please specify

Dual Lumen: ECMO cannulation/mode change 1 & 2 *(if applicable)*

| | |
|-------------------|---|
| Definition | <p>For dual lumen, select one from each pair</p> <p>Percutaneous – records if the ECMO drainage cannula was inserted peripherally (without incision and dissection of the vessel)</p> <p>Surgical -records if the ECMO drainage cannula was inserted surgically (with incision and dissection of the vessel)</p> <p>Left – Select if a Dual Lumen cannula was inserted into the Left Internal Jugular</p> <p>Right- Select if a Dual Lumen cannula was inserted in the Right Internal Cannula</p> |
| Reason | To enable effective audit and assessment of health services delivery. |
| Format | <p>Select one of the following</p> <ul style="list-style-type: none">• Not applicable• Percutaneous OR Surgical• Left OR Right |

Drainage Cannula: ECMO cannulation/mode change 1 & 2 (*if single lumen*)

Definition

For drainage cannula, select one from each pair

Reason

Percutaneous – records if the ECMO drainage cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical -records if the ECMO drainage cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO drainage cannula was inserted directly centrally into the heart e.g. via sternotomy

Peripheral -records if the ECMO drainage cannula was not directly inserted into the heart

If peripheral, select one from each pair

Jugular- records if the ECMO drainage cannula was inserted into the right or left internal jugular vein

Femoral – records if the ECMO drainage cannula was inserted into the right or left femoral vein

Left - indicates the ECMO drainage cannula was placed on the left side

Right - indicates the ECMO drainage cannula was placed on the right side

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Jugular OR Femoral
- Left OR Right

Return Cannula: ECMO cannulation/mode change 1 & 2 (*if single lumen*)

Definition

For return cannula, select one from each pair

Percutaneous – records if the ECMO return cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical -records if the ECMO return cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO return cannula was inserted directly centrally into the heart e.g. via sternotomy

Peripheral -records if the ECMO return cannula was not directly inserted into the heart

If peripheral, select one from each pair

Neck - records if the ECMO return cannula was inserted into the right/left internal jugular vein or carotid artery

Femoral – records if the ECMO return cannula was inserted into the right or left femoral vein/artery

Left - indicates the ECMO return cannula was placed on the left side

Right - indicates the ECMO return cannula was placed on the right side

Reason

To enable effective audit and assessment of health services delivery.

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Neck OR Femoral
- Left OR Right

Additional drainage cannula: ECMO cannulation/mode change 1 & 2 (if applicable)

Definition

Specifies whether or not an additional drainage cannula was inserted during the relevant ECMO cannulation/mode change and specifies the location and type of insertion

Tick if not applicable - Tick if no single additional drainage was inserted

Select one from each pair

Percutaneous – records if the ECMO additional drainage cannula was inserted peripherally (without incision and dissection of the vessel)

Surgical -records if the ECMO additional drainage cannula was inserted surgically (with incision and dissection of the vessel)

Central – records if the ECMO additional drainage cannula was inserted directly centrally into the heart e.g. via sternotomy

Peripheral -records if the ECMO additional drainage cannula was not directly inserted into the heart

If peripheral, select one from each pair

Jugular- records if the ECMO additional drainage cannula was inserted into the right or left Internal jugular vein

Femoral – records if the ECMO additional drainage cannula was inserted into the right or left femoral vein

Left -indicates the ECMO additional drainage cannula was placed on the left side

Right - indicates the ECMO additional drainage cannula was placed on the right side

Reason

To enable effective audit and assessment of health services delivery.

Format

Please select **one** from each applicable pair

- Percutaneous OR Surgical
- Central OR Peripheral
- Jugular OR Femoral
- Left OR Right

DECANNULATION AND FOLLOW UP

Indication for decannulation

Definition Identifies the reason the child was decannulated from ECMO, if multiple runs select reason for final decannulation
Choose one reason for discontinuing ECMO support

Recovery - ECMO discontinued as patient improved and is expected to recover. If recovery was due to transplant do not choose recovery, select heart transplant instead

Died on ECMO or ECMO withdrawn - patient dies whilst on ECMO or ECMO discontinued due to poor prognosis or treatment limitations due to irrevocable disease, patient experienced organ failure, or a diagnosis incompatible with life, or family/patient requested discontinuation.

Conversion to Ventricular Assist Device (VAD) - in anticipation of continued need for extracorporeal support the patient was taken off ECMO to be transitioned to a LVAD, RVAD, BiVAD.

Heart Transplant - Patient was decannulated from ECMO due to resolved need after a new heart transplant

Other reason for decannulation - such as ECMO complications required withdrawal of ECMO or resource limitations

Not decannulated prior to discharge - Patient transferred to another ECMO centre for further specialist treatment whilst on ECMO

Reason Date and time of decannulation will be used to calculate the total time spent on ECMO

Format Choose one of the following:

- Recovery
- Died on ECMO or ECMO withdrawn
- Conversion to VAD
- Heart Transplant
- Other reason for decannulation
- Not decannulated prior to discharge

Date and Time of decannulation for ECMO Run 1 *(if applicable)*

| | |
|-------------------|--|
| Definition | The actual date and time when the child was decannulated from ECMO Run. This specifically refers to the date and time that the cannulas are removed |
| Reason | Date and time of decannulation will be used to calculate the total time spent on ECMO Accurate recording of date and time of decannulation will allow analysis of ECMO service e.g. Capacity across the country or year. To enable effective audit and assessment of health services delivery. |
| Format | Date: dd/mm/yyyy Time: hh:mm (24-hour clock) |

Date and Time of decannulation for ECMO run 2 *(if applicable)*

| | |
|-------------------|--|
| Definition | The actual date and time when the child was decannulated from the second ECMO run <i>(if applicable)</i> . This specifically refers to the date and time that the cannulas are removed |
| Reason | Date and time of decannulation will be used to calculate the total time spent on ECMO Accurate recording of date and time of decannulation will allow analysis of ECMO service e.g. Capacity across the country or year. To enable effective audit and assessment of health services delivery. |
| Format | Date: dd/mm/yyyy Time: hh:mm (24-hour clock) |

Date & Time ready for discharge from ECMO centre

| | |
|-------------------|---|
| Definition | <p>The date and time that clinicians agreed that the child was ready for discharge from the ECMO centre to an appropriate destination.</p> <p>The acuity of the patient will vary depending on discharge location for example if discharge is back to tertiary NICU, patient may still be ventilated but no longer at risk of requiring ECMO.</p> |
| Reason | <p>Date and time when ready for discharge and date and time of actual discharge will be used to calculate delayed discharge.</p> <p>Accurate recording of timings relating to discharge will allow analysis of ECMO service and delivery e.g. Capacity across the country or year.</p> <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy</p> <p>Time: hh:mm (24-hour clock)</p> |

Neurological status at discharge

Definition Identifies the neurological status at discharge using the Paediatric Cerebral Performance Category scale:

Normal (1): At age-appropriate level; school age child attends regular school

Mild Disability (2): Conscious, alert, able to interact at age-appropriate level; regular school but cognition perhaps not age appropriate, possibility of mild neurological deficit.

Moderate Disability (3): Conscious, age-appropriate independent activities of daily life, special education classroom and/or learning

Severe Disability (4): Conscious, dependent on others for daily support because of impaired brain function

Coma or vegetative state (5): Any degree of coma, unaware even if awake in appearance, without interaction with the environment, no evidence of cortex function, possibility for some reflexive response, spontaneous eye-opening, sleep-wake cycles

Dead (6)

Reason To enable effective audit and assessment of health care services and NHSE service specification on neurological follow up

Format Choose from one of the following:

- Normal
 - Mild disability
 - Moderate disability
 - Severe disability
 - Vegetative state
 - Dead
 - Unknown
-

Status at 30 days post ECMO/assessment

| | |
|-------------------|---|
| Definition | Identifies the status (alive or dead) of the child on 30 days post decannulation if patient received ECMO, or 30 days post ECMO assessment if the outcome of the assessment was 'Did not require ECMO' or 'Not a candidate' |
| Reason | To enable effective audit and assessment of healthcare services delivery and NHSE service specification of patient surviving >30 days post decannulation |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Alive• Dead• Unknown |

Status at 180 days post ECMO/assessment

| | |
|-------------------|---|
| Definition | Identifies the status (alive or dead) of the child on 180 days post decannulation if patient received ECMO, or 180 days post ECMO assessment if the outcome of the assessment was 'Did not require ECMO' or 'Not a candidate' |
| Reason | To enable effective audit and assessment of healthcare services delivery and NHSE service specification of patient surviving >180 days post decannulation |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Alive• Dead• Unknown |

If dead – Date and time of death

| | |
|-------------------|---|
| Definition | The actual date and time of death if this occurs post-discharge from your unit and is identified at follow-up. If death occurs later and time is unavailable then date is sufficient. |
| Reason | <p>Date of death and Time of death are identified as one of the principal outcomes of paediatric intensive care. Required for epidemiological analysis and assessment of health services delivery</p> <p>Accurate recording of date and time will allow analysis of ECMO service e.g. Capacity across the country or year.</p> <p>To enable effective audit and assessment of health services delivery.</p> |
| Format | <p>Date: dd/mm/yyyy</p> <p>Time: hh:mm (24-hour clock)</p> |

Follow up neurological assessment by 180 days post ECMO/assessment?

| | |
|------------|---|
| Definition | Identifies whether the child had a follow up neurological assessment by 180 days post decannulation if patient received ECMO, or 180 days post ECMO assessment if the outcome of the assessment was 'Did not require ECMO' or 'Not a candidate' |
| Reason | To enable effective audit and assessment of health services delivery |
| Format | Choose from one of the following: <ul style="list-style-type: none">• Yes• No |

If yes - Follow up neurological assessment by 180 days post ECMO/assessment?

Definition To identify the child's neurological status at 180 days post decannulation if patient received ECMO, or 180 days post ECMO assessment if the outcome of the assessment was 'Did not require ECMO' or 'Not a candidate' using the Paediatric Cerebral Performance categories:

Normal (1): At age-appropriate level; school age child attends regular school

Mild Disability (2): Conscious, alert, able to interact at age-appropriate level; regular school but cognition perhaps not age appropriate, possibility of mild neurological deficit.

Moderate Disability (3): Conscious, age-appropriate independent activities of daily life, special education classroom and/or learning

Severe Disability (4): Conscious, dependent on others for daily support because of impaired brain function

Coma or vegetative state (5): Any degree of coma, unaware even if awake in appearance, without interaction with the environment, no evidence of cortex function, possibility for some reflexive response, spontaneous eye-opening, sleep-wake cycles

Dead (6)

Reason To enable effective audit and assessment of health services delivery.
Comply with NHSE service specification of neurological follow up 180 days post ECMO decannulation.

Format Choose from one of the following:

- Normal
- Mild disability
- Moderate disability
- Severe disability
- Vegetative state
- Dead
- Unknown

Comments

| | |
|------------|--|
| Definition | <p>Any additional information considered relevant to the admission.</p> <p>Text entered in this field may provide extra information about data entered elsewhere in a specific field in the dataset, or may provide extra information on the referral, which is not collected as part of the dataset.</p> <p>No identifiers (patient, nurse, doctor, ICU, hospital) should be included in text data entered into this field.</p> <p>As there is limited space in this field all text data should be kept to a minimum and be as concise as possible. Text data must not contain any punctuation except a period (full-stop) at the end of each data point.</p> |
| Reason | <p>No dataset specification covers all eventualities: to deal with this a text field has been included for comments/additional information.</p> |
| Format | <p>Free text</p> |
