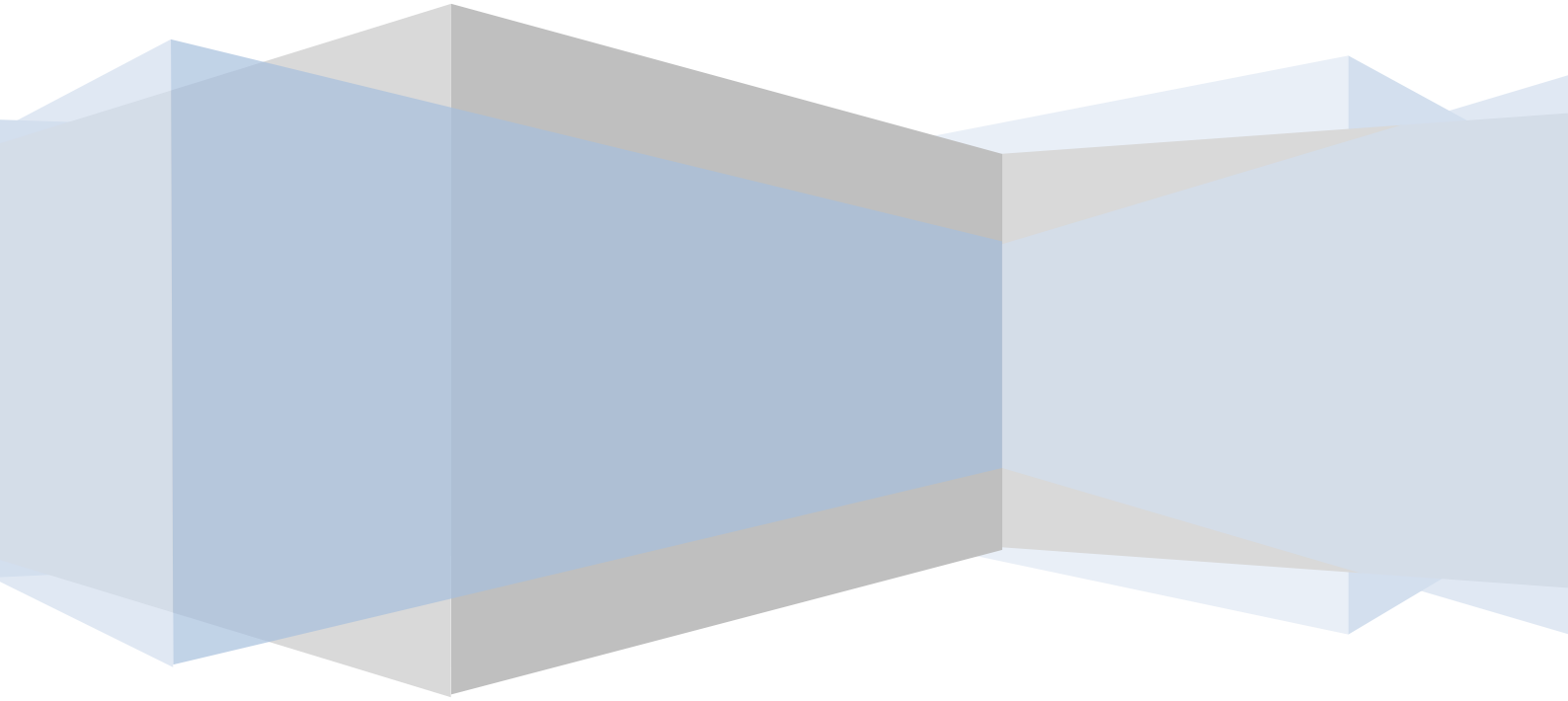
DRAFT PICANet ECMO Dataset Definitions Manual

Version 1.0 October 2023



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INTRODUCTION

BACKGROUND

PICANet collects an 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 associated ECMO admission information, providing evidence on standards of service across specialist paediatric intensive care.

The dataset forms an integral part of **PICANet Web**; a secure, centralised database application accessed using a web browser. PICANet Web permits Paediatric Intensive Care Units (PICUs) and Specialised Paediatric Transport Services (SPTS) to submit and interrogate referral, transport, admission and customised data collection details for their own patients regardless of their physical location.

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, 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, ECMO referral, transport or admission.

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.

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/or that conventional transport or mobile ECMO transport is required.
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 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.) permits epidemiological analysis of service organisation and geographical variation.

ECMO Admission

The typical ECMO admission data collection process is as follows:

1. If the patient is admitted as an ECMO assessment, or is 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

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.

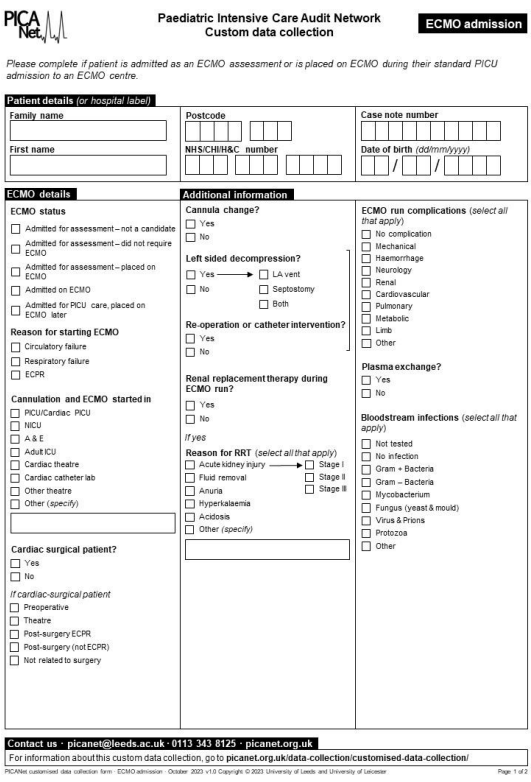
2. The ECMO centre **enters or uploads to PICANet Web** the completed ECMO admission event data.

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 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 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 compete the ECMO Admission form.

ECMO Admission form



Paediatric Intensive Care Audit Network
Custom data collection

ECMO admission

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

Patient details *(or hospital label)*

Family name
First name
Postcode
NHS/CHI/H&C number
Case note number
Date of birth *(dd/mm/yyyy)*

ECMO details

ECMO status
- 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

Reason for starting ECMO
- Circulatory failure
- Respiratory failure
- ECPR

Cannulation and ECMO started in
- PICU/Cardiac PICU
- NICU
- A & E
- Adult ICU
- Cardiac theatre
- Cardiac catheter lab
- Other theatre
- Other (*specify*)

Cardiac surgical patient?
- Yes
- No

If cardiac-surgical patient
- Preoperative
- Theatre
- Post-surgery ECPR
- Post-surgery (not ECPR)
- Not related to surgery

Additional information

Cannula change?
- Yes
- No

Left sided decompression?
- Yes → LA vent / Septostomy / Both
- No

Re-operation or catheter intervention?
- Yes
- No

Renal replacement therapy during ECMO run?
- Yes
- No

If yes

Reason for RRT (*select all that apply*)
- Acute kidney injury → Stage I / Stage II / Stage III
- Fluid removal
- Anuria
- Hyperkalaemia
- Acidosis
- Other (*specify*)

ECMO run complications (*select all that apply*)
- No complication
- Mechanical
- Haemorrhage
- Neurology
- Renal
- Cardiovascular
- Pulmonary
- Metabolic
- Limb
- Other

Plasma exchange?
- Yes
- No

Bloodstream infections (*select all that apply*)
- Not tested
- No infection
- Gram + Bacteria
- Gram – Bacteria
- Mycobacterium
- Fungus (yeast & mould)
- Virus & Prions
- Protozoa
- Other

Contact us · picanet@leeds.ac.uk · 0113 343 8125 · picanet.org.uk

For information about this custom data collection, go to **picanet.org.uk/data-collection/customised-data-collection/**

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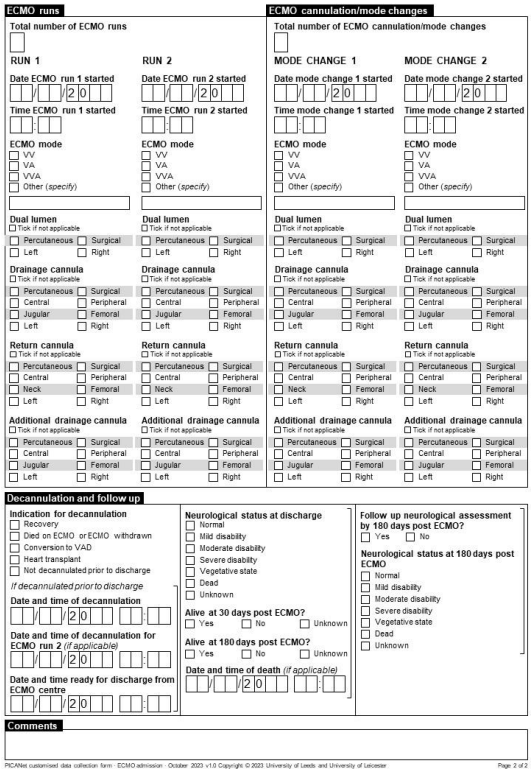

ECMO runs

Total number of ECMO runs

RUN 1	RUN 2
Date ECMO run 1 started	Date ECMO run 2 started
Time ECMO run 1 started	Time ECMO run 2 started
ECMO mode: VV / VA / VVA / Other (*specify*)	ECMO mode: VV / VA / VVA / Other (*specify*)
Dual lumen (Tick if not applicable): Percutaneous / Surgical; Left / Right	Dual lumen (Tick if not applicable): Percutaneous / Surgical; Left / Right
Drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right	Drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right
Return cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Neck / Femoral; Left / Right	Return cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Neck / Femoral; Left / Right
Additional drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right	Additional drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right

ECMO cannulation/mode changes

Total number of ECMO cannulation/mode changes

MODE CHANGE 1	MODE CHANGE 2
Date mode change 1 started	Date mode change 2 started
Time mode change 1 started	Time mode change 2 started
ECMO mode: VV / VA / VVA / Other (*specify*)	ECMO mode: VV / VA / VVA / Other (*specify*)
Dual lumen (Tick if not applicable): Percutaneous / Surgical; Left / Right	Dual lumen (Tick if not applicable): Percutaneous / Surgical; Left / Right
Drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right	Drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right
Return cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Neck / Femoral; Left / Right	Return cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Neck / Femoral; Left / Right
Additional drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right	Additional drainage cannula (Tick if not applicable): Percutaneous / Surgical; Central / Peripheral; Jugular / Femoral; Left / Right

Decannulation and follow up

Indication for decannulation
- Recovery
- Died on ECMO or ECMO withdrawn
- Conversion to VAD
- Heart transplant
- Not decannulated prior to discharge

If decannulated prior to discharge

Date and time of decannulation

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

Date and time ready for discharge from ECMO centre

Neurological status at discharge
- Normal
- Mild disability
- Moderate disability
- Severe disability
- Vegetative state
- Dead
- Unknown

Alive at 30 days post ECMO? Yes / No / Unknown

Alive at 180 days post ECMO? Yes / No / Unknown

Date and time of death *(if applicable)*

Follow up neurological assessment by 180 days post ECMO? Yes / No

Neurological status at 180 days post ECMO
- Normal
- Mild disability
- Moderate disability
- Severe disability
- Vegetative state
- Dead
- Unknown

Comments

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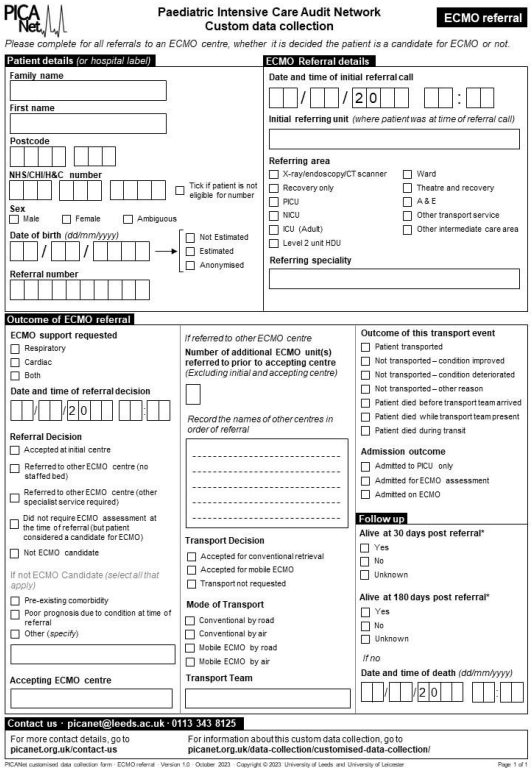
ECMO referral form



Paediatric Intensive Care Audit Network
Custom data collection

ECMO referral

Please complete for all referrals to an ECMO centre, whether it is decided the patient is a candidate for ECMO or not.

Patient details *(or hospital label)*

Family name
First name
Postcode
NHS/CHI/H&C number — Tick if patient is not eligible for number
Sex: Male / Female / Ambiguous
Date of birth *(dd/mm/yyyy)* — Not Estimated / Estimated / Anonymised
Referral number

ECMO Referral details

Date and time of initial referral call

Initial referring unit *(where patient was at time of referral call)*

Referring area
- X-ray/endoscopy/CT scanner
- Recovery only
- PICU
- NICU
- ICU (Adult)
- Level 2 unit HDU
- Ward
- Theatre and recovery
- A & E
- Other transport service
- Other intermediate care area

Referring speciality

Outcome of ECMO referral

ECMO support requested
- Respiratory
- Cardiac
- Both

Date and time of referral decision

Referral Decision
- Accepted at initial centre
- Referred to other ECMO centre (no staffed bed)
- Referred to other ECMO centre (other specialist service required)
- Did not require ECMO assessment at the time of referral (but patient considered a candidate for ECMO)
- Not ECMO candidate

If not ECMO Candidate (select all that apply)
- Pre-existing comorbidity
- Poor prognosis due to condition at time of referral
- Other (*specify*)

Accepting ECMO centre

If referred to other ECMO centre

Number of additional ECMO unit(s) referred to prior to accepting centre *(Excluding initial and accepting centre)*

Record the names of other centres in order of referral

Transport Decision
- Accepted for conventional retrieval
- Accepted for mobile ECMO
- Transport not requested

Mode of Transport
- Conventional by road
- Conventional by air
- Mobile ECMO by road
- Mobile ECMO by air

Transport Team

Outcome of this transport event
- Patient transported
- Not transported – condition improved
- Not transported – condition deteriorated
- Not transported – other reason
- Patient died before transport team arrived
- Patient died while transport team present
- Patient died during transit

Admission outcome
- Admitted to PICU only
- Admitted for ECMO assessment
- Admitted on ECMO

Follow up

Alive at 30 days post referral*
- Yes
- No
- Unknown

Alive at 180 days post referral*
- Yes
- No
- Unknown

If no

Date and time of death *(dd/mm/yyyy)*

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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 admission 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 burden 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	Family name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs or transport services.
Format	Free text (e.g. Brown). If no family name available record as UNKNOWN and indicate why not available in the comments section.

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	First name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. Can help identify individuals who may have had multiple referrals and /or admissions to one or more PICUs or transport services.
Format	Free text (e.g. John). If no first name available record as UNKNOWN and indicate why not available in the comments section.

Postcode

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

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 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	NHS, CHI or H&C number gives a unique, identifiable variable that will allow other identifiable data items to be removed from the database. Can identify individuals who may have had multiple admissions to one or more PICUs or paediatric intensive care transport services.
Format	Free text (e.g. 1463788990) Validation check that NHS, CHI or H&C number is a valid number

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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

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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: Male Female Ambiguous

Date of birth

Definition	The child's date of birth as recorded on the child's birth certificate or other appropriate document.
Reason	Date of birth and Date of admission are used to calculate age at admission to this paediatric intensive care service. Date of birth provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs and/or transport services.
Format	Date; dd/mm/yyyy. Date of birth should be between 01/01/1980 and Date of admission. 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). 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'. 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. Validation check if patient is aged 18 years or older

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	Choose from one of the following: Not estimated Estimated Anonymised

Referral number

Definition	Unique identifier assigned to each consecutive referral event. As recorded within your organisation to identify each referral episode.
Reason	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. Required for effective audit and assessment of geographical distribution of referring population to individual transport services/units.
Format	Free text (e.g. 2017 07)

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	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. 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. To enable effective audit and assessment of health services delivery.
Format	Date: dd/mm/yyyy Time: hh:mm (24-hour clock)

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	Record the name of hospital / DGH and specialist unit Free text e.g. Pilgrim Hospital A&E At data entry to PICANet Web select the select the organisation type – PICU or DGH from the organisation coder 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 If the name of the organisation is not known select 'Unknown organisation'

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 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

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
A&E
Other transport service
Other intermediate care area

Referring speciality

Definition

Specialty from which this request for ECMO admission is made.

Record the parent specialty of the doctor who made the ECMO referral.

Examples:

- 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
- The transport team call the ECMO centre to request a bed and arrange admission – referring speciality Paediatric Intensive Care Transport Service

Reason

Describes the background from which children are admitted for effective audit and assessment of health services delivery.

Format

Choose from one of the following:

General paediatrics
Sub-specialty paediatrics
Neonates
PICU
Anaesthetics
General ITU
Neurosurgery
General surgery
Accident and Emergency
Burns and plastics
ENT
Paediatric Intensive Care Transport Service
Other
Unknown

OUTCOME OF ECMO REFERRAL

ECMO support requested

Definition	Defines the Support type of ECMO that is likely to be required **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 **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 **Both** – Mixture of both respiratory and cardiac definitions above.
Reason	To enable effective audit and assessment of health services delivery and NHSE service specification.
Format	Choose **one** of the below Respiratory Cardiac Both

Date and time of referral decision

Definition	The actual date and time when clinicians agreed that the child is an appropriate candidate to receive ECMO if required. This is based on the patient's eligibility for ECMO (not the availability of a team or a bed). 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.
Reason	Date and time of the referral decision will be used to calculate the total time the referral decision takes for each individual patient. 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. To enable effective audit and assessment of health services delivery.
Format	Date: dd/mm/yyyy Time: hh:mm (24-hour clock)

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

First select referral decision, and then specify reason if not a candidate.

ECMO candidate

- Accepted at initial centre – (including if patient was already a PICU in 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
- Did not require ECMO assessment at time of referral (but patient considered a candidate for ECMO)
- Not ECMO candidate

If - *Not ECMO candidate* (*select all that apply*)

- Pre-existing comorbidity
- Poor prognosis due to condition at time of referral
- Other (*specify*)

If 'Other (*specify*)' selected give reason in free text box.

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

Record the name of the ECMO Centre
E.g. Evelina Children's Hospital

At data entry to PICANet Web select the select the organisation type – PICU 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

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

Definition	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. 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. Example – Unit A receives ECMO referral, and starts PICANet Referral form Unit is at capacity so refers to units B and C, who also cannot accommodate. Unit D accepts patient for ECMO assessment. Here there are 2 additional ECMO units the patient was referred to, B and C. Unit A is the owner organisation, and Unit D is the accepting centre as this information is collected elsewhere. Record the names of up to 5 other centres in the order of referral.
Reason	To enable effective audit and assessment of health services delivery. Required for geographic information to be linked to assessment of health services delivery.
Format	Record the ECMO centre refusing the ECMO admission At data entry to PICANet Web select the organisation type 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 If the name of the organisation is not known select 'Unknown organisation'

Transport decision

Definition	This intends to identify the decision that was made during the referral process, the outcome of the referral may be different. **Accepted for conventional retrieval –** the referral for ECMO was accepted, and the decision made for the child to be transported by conventional retrieval. **Accepted for mobile ECMO –** The referral for ECMO was accepted, and the decision made to transport the patient using mobile ECMO. **Transport not requested –** Patient was already at the referring centre so no transport required.
Reason	To enable effective audit and assessment of health services delivery.
Format	Choose **one** of the below - Accepted for conventional retrieval - Accepted for mobile ECMO - Transport not requested

Mode of transport

Definition	Identifies the main mode of transport used by the transport team at any time during the journey with the child. This may differ from the original decision made as part of the referral call. **Conventional by road** – The child was transported without ECMO by road transport **Conventional by air**– The child was transported without ECMO by air (helicopter/airplane) **Mobile ECMO by road** – The child was transported on ECMO by road transport **Mobile ECMO by air –**The child was transported on ECMO by air (helicopter/airplane)
Reason	To enable effective audit and assessment of health services delivery.
Format	Choose **one** of the below - 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 Centralised Transport Service (CTS), undertaking this episode of transport.
Reason	To enable effective audit and assessment of health services delivery.
Format	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. At data entry to PICANet Web select the organisation type - PICU, CTS 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 If the name of the organisation is not known select 'Unknown organisation'

Outcome of this transport event

Definition

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.

Patient transported - The child has been transported to the destination specified

Not transported - condition improved - The transport team arrived at the collection unit, the child's condition improved and PIC transport was no longer required

Not transported - condition deteriorated - The transport team arrived at the collection unit, the child's condition deteriorated and PIC transport was no longer appropriate

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

Patient died before transport team arrived - The child died after the transport team was mobilised but prior to arrival at the collection unit

Patient died while transport team present - The child died whilst the transport team were providing care at the collection unit

Patient died during transit - The child died during the return journey from the collection unit

Reason

To enable effective audit and assessment of health services delivery.

Format

Choose one of the following

Patient transported
Not transported- condition improved
Not transported - condition deteriorated
Not transported - other reason
Patient died before transport team arrived
Patient died while transport team present
Patient died during transit
Unknown

Admission Outcome

Definition	Identifies the admission outcome once the transport journey has been completed. **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 - Admitted to PICU only - Admitted for ECMO assessment - Admitted on ECMO

FOLLOW UP

Alive at 30 days post referral

Description Identifies the status (alive or dead) of the child on 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:

- Yes
- No
- Unknown

Alive at 180 days post referral

Description Identifies the status (alive or dead) of the child on 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:

- Yes
- No
- Unknown

Date of death post-referral

Description Identifies the date of death if this occurs following the ECMO referral and is identified at 30 or 180 day follow-up

Reason 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.

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

Format	Date: dd/mm/yyyy	Time: hh:mm (24-hour clock)

Comments

Definition	Any additional information considered relevant to the admission. 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. No identifiers (patient, nurse, doctor, ICU, hospital) should be included in text data entered into this field. 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.
Reason	No dataset specification covers all eventualities: to deal with this a text field has been included for comments/additional information.
Format	Free text

Form completed by

Definition	Name of person completing form
Reason	For local use only to assist with following up queries relating to completion of this form.

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	Family name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs or transport services.
Format	Free text (e.g. Brown). If no family name available record as UNKNOWN and indicate why not available in the comments section.

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	First name provides an additional identifier that can aid patient tracking throughout the hospital and PICANet Web. Can help identify individuals who may have had multiple referrals and /or admissions to one or more PICUs or transport services.
Format	Free text (e.g. John). If no first name available record as UNKNOWN and indicate why not available in the comments section.

Postcode

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

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 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	NHS, CHI or H&C number gives a unique, identifiable variable that will allow other identifiable data items to be removed from the database. Can identify individuals who may have had multiple admissions to one or more PICUs or paediatric intensive care transport services.
Format	Free text (e.g. 1463788990) Validation check that NHS, CHI or H&C number is a valid number

Case note number

Definition	Unique identifying number for an individual's hospital records at the treating unit. Allocated on first admission to hospital
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	Date of birth and Date of admission are used to calculate age at admission to this paediatric intensive care service Date of birth provides an additional identifier that can aid patient tracking throughout the paediatric intensive care service, hospital and PICANet Web Can help identify individuals who may have had multiple referrals and/or admissions to one or more PICUs
Format	Date; dd/mm/yyyy Date of birth should be on or prior to the date of admission If the child's date of birth is unobtainable, but the child is still on your unit, use your judgement to estimate year of birth and record as 1 January of estimated year (e.g. 01/01/YYYY). Then tick 'Estimated' in the section 'Indicate if date of birth is' Estimated/Anonymised/Unknown section below 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' 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 Validation check: if patient is aged 18 years or older at admission

ECMO DETAILS

ECMO status

Definition

Identifies the child's ECMO status on admission to the ECMO centre with one of the following:

- **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

Reason

To enable effective audit and assessment of health services delivery.

Format

Choose from one of the following:

- 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

Reason for starting ECMO

Definition	Identifies the underlying pathophysiology for requiring ECMO: **Respiratory failure–** The use of extracorporeal membrane oxygenation with a primary indication for support of respiratory failure **Circulatory failure–** The use of extracorporeal membrane oxygenation with a primary indication to support the circulation **ECPR –** Extracorporeal cardiopulmonary resuscitation is the initiation of ECMO after cardiac arrest while CPR is ongoing or just after CPR has been delivered (within 20minutes of return of circulation)
Reason	To enable effective audit and assessment of health services delivery.
Format	Choose from one of the following: • 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

Identifies timing of ECMO commencement in patients who receive cardiac surgery.

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)

Theatre - placed on ECMO immediately after cardiac surgery/ bypass

Post-surgery – ECPR- Placed on ECMO after surgery, outside of cardiac theatre and was ECPR

Post-surgery - Not ECPR- Placed on ECMO after surgery, outside of cardiac theatre and was not ECPR

Not related to surgery- Patient underwent cardiac surgery on this PICU admission but it was unrelated to receiving ECMO (eg patient underwent cardiac surgery successfully and while admitted to PICU developed influenza and received ECMO for respiratory failure).

Reason

To enable effective audit and assessment of health services delivery.

Format

Choose from one of the following:

- 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 whist 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 'Both'

Type of left sided decompression

Definition	If yes (*specify)* selected for 'Left sided decompression', did this involve an Left atrial (LA) vent and/or a septostomy
Reason	To enable effective audit and assessment of health services delivery

Format Choose from one of the following:

- LA vent
- Septostomy
- Both
- 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:

- 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: • Yes • No • Unknown

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If yes – Reason for RRT

Definition	Identifies the reason for 'Renal replacement therapy (RRT) during ECMO run, this includes continuous renal replacement therapy (Continuous Veno-Veno Haemofiltration (CVVH), Continuous Veno-Veno Heamodialysis (CVVHD), and Continuous Veno-Veno Haemodiafiltration (CVVHDF)), and peritoneal dialysis Acute Kidney Injury - also known as acute renal failure Fluid removal Anuria – lack of urine production Hyperkalaemia – potassium levels high in serum Acidosis – too much acid in the blood Other – use free text to specify
Reason	To enable effective audit and assessment of health services delivery.
Format	Choose from one of the following: • Acute kidney injury (*specify stage*) • Fluid removal • Anuria • Hyperkalaemia • Acidosis • Other (*specify*) *If* 'Acute kidney injury' specify – 'Stage I', 'Stage II' or 'Stage III' *If* 'Other (*specify*)' selected please use free text description to identify other reason.

Stage of acute kidney injury

Definition

If 'Acute kidney injury' selected for 'Reason for RRT':

Acute Kidney Injury - also known as acute renal failure has 3 stages:

Stage 1 – where serum creatinine 1.5 – 1.9 times higher than the baseline or ≥0.3 mg/dl(≥26.5mmol) increase or urine output <0.5 ml/kg for 6- 12 hours

Stage 2- Serum creatinine 2.0 – 2.9 times higher than baseline or urine output <0.5 ml/kg for ≥12 hours

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 <35ml/min per 1.73 m_2 or urine output <0.3 ml/kg for ≥24 hours or anuria for ≥12 hours.

Reason

To enable effective audit and assessment of health services delivery.

Format

Choose from one of the following:

- Stage I
- Stage II
- Stage III
- Unknown

ECMO complications?

Definition

Identifies complications that arise during the ECMO run

No complication – occurred during the ECMO run

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

- No complication
- Mechanical
- Haemorrhage
- Neurology
- Renal
- Cardiovascular
- Pulmonary
- Metabolic
- Limb
- Other
- Unknown

Plasma exchange?

Definition Identifies whether plasma exchange was undertaken during the child's ECMO run(s)

Plasma exchange is a procedure involving the separation and removal of the plasma from the blood in order to removal abnormal substances circulating in the plasma

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

Format Choose from one of the following:

- Yes
- No
- Unknown

Bloodstream infections?

Definition	Identifies the infections associated with the child on ECMO Include infections that occur during the ECMO Run **Not tested** – the patient was not tested for evidence of infection whilst on ECMO **No Infection** – the patient was tested for infection whilst on ECMO but no infection was detected **Gram positive bacteria** – such as staphylococcus, streptococcus, and clostridium **Gram negative bacteria** – such as Escherichia coli, pseudomonas, klebsiella and Acinetobacter **Mycobacterium** – such as tuberculosis and leprosy **Fungus** (yeast and mould) - such as aspergillus, candida, histoplasmosis and pneumocystis pneumonia (PCP) **Virus and Prions** – Viruses such as influenza (A, B & C), measles, mumps, chickenpox, prions such as neurodegenerative disorders **Protozoa** – such as malaria, giarda and toxoplasmosis **Other** – use free text to specify
Reason	To enable effective audit and assessment of health services delivery and NHSE service specification
Format	Select all that apply • 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 available for data entry if the number of 'ECMO runs' is over 1. And the 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 2nd 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	Identifies the date and time that the first and second ECMO run started This refers to the time that the extracorporeal blood flow was established through cannulas attached to an ECMO circuit. 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.
Reason	To enable effective audit and assessment of health services delivery.
Format	Date: dd/mm/yyyy Time: (24 hour clock); hh:mm

ECMO Mode : Run 1 & 2

Definition

Identifies the mode of drainage and return of blood in the extracorporeal system

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: Venovenoarterial 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 : Run 1 & 2

Definition	Specifies whether or not a dual lumen cannula was inserted during the relevant ECMO run Tick if not applicable - Tick if no dual lumen cannula was inserted Please 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) **Left** – Select if a Dual Lumen cannula was inserted into the Left Internal Jugular **Right**- Select if a Dual Lumen cannula was inserted in the Right Internal Jugular
Reason	To enable effective audit and assessment of health services delivery.
Format	Select one of the following • Not applicable • Percutaneous OR Surgical • Left OR Right

Drainage cannula: Run 1 & 2

Definition	Specifies whether or not a 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 drainage cannula was inserted Please 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

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

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

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

Format Please select **one** from each pair

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

Return Cannula: Run 1 & 2

Definition Specifies whether or not a Return cannula was inserted during the relevant ECMO run and specifies the location and type of insertion

Tick if not applicable - Tick if no single return cannula was inserted

Please 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

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 pair

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

Additional drainage cannula: Run 1 & 2

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

Please 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

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 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 mode change started

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: Venovenoarterial 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

Definition	Specifies whether or not a Dual Lumen cannula was inserted during the relevant ECMO cannulation/mode change Tick if not applicable - Tick if no dual lumen cannula was inserted **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) **Left** – Select if a Dual Lumen cannula was inserted into the Left Internal Jugular **Right**- Select if a Dual Lumen cannula was inserted in the Right Internal Cannula
Reason	To enable effective audit and assessment of health services delivery.
Format	Select one of the following • Not applicable • Left • Right

Drainage Cannula: ECMO cannulation/mode change 1 & 2

Definition	Specifies whether or not a 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 drainage cannula was inserted Please 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 **Peripheral** -records if the ECMO drainage cannula was not directly inserted into the heart **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
Reason	To enable effective audit and assessment of health services delivery.
Format	Please select **one** from each pair • Percutaneous OR Surgical • Central OR Peripheral • Jugular OR Femoral • Left OR Right

Return Cannula: ECMO cannulation/mode change 1 & 2

Definition

Specifies whether or not a Return 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 return cannula was inserted

Please 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

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 pair

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

Additional drainage cannula: ECMO cannulation/mode change 1 & 2

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

Please 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

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 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

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

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

Accurate recording of date and time of decannulation will allow analysis of ECMO service e.g. Capacity across the country or year.

Format

Choose one of the following:

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

Date and Time of decannulation (ECMO Run 1)

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 (*if applicable)*. 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)

Time ready for discharge from ECMO centre

Definition	The date and time that clinicians agreed that the child was ready for discharge from the ECMO centre to an appropriate destination. 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.
Reason	Date and time when ready for discharge and date and time of actual discharge will be used to calculate delayed discharge. Accurate recording of timings relating to discharge will allow analysis of ECMO service and delivery 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)

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

Alive at 30 days post ECMO

Definition	Identifies the status (alive or dead) of the child on 30 days post decannulation
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: • Alive • Dead • Unknown

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Status at 180 days post ECMO

Definition	Identifies the status (alive or dead) of the child on 180 days post decannulation
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: • Alive • Dead • Unknown

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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.
Reason	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 Accurate recording of date and time 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)

Follow up neurological assessment by 180 days post ECMO?

Definition	Identifies whether the child had a follow up neurological assessment by 180 days post decannulation
Reason	To enable effective audit and assessment of health services delivery
Format	Choose from one of the following: • Yes • No

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

Definition

To identify the child's neurological status at 180 days post decannulation 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 dayspost ECMO decannulation.

Format

Choose from one of the following:

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

Comments

Definition	Any additional information considered relevant to the admission. 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. No identifiers (patient, nurse, doctor, ICU, hospital) should be included in text data entered into this field. 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.
Reason	No dataset specification covers all eventualities: to deal with this a text field has been included for comments/additional information.
Format	Free text