PICANet Dataset Changes Over Time

Introduction

This document contains details on data availability and limitations which should be considered when submitting a data or information access request for PICANet data. Details on COVID data collection can be found in Appendix 2.

Contents

Data collection dates

The PICANet Admission collected data from all NHS PICUs in England and Wales from March 2003. Data collection subsequently rolled out to other countries and private PICUs in England as follows:

- Scotland – Edinburgh December 2004, Glasgow in April 2007
- Northern Ireland - April 2008
- Republic of Ireland – Crumlin January 2009, Temple Street March 2010
- England private – Harley Street September 2010, Portland June 2013.

PICU Name	Data available from	Data available until
Cambridge Addenbrooke's Hospital	Mar-02	
Leeds General Infirmary	Sep-02	
Sheffield Children's Hospital (NICU)	Nov-02	Dec-11
Hull Royal Infirmary	Nov-02	Sep-17
Birmingham Children's Hospital	Nov-02	
Bristol Royal Hospital for Children	Nov-02	
Cardiff Noah's Ark children's Hospital for Wales	Nov-02	
Leicester Glenfield Hospital	Nov-02	
Leicester Royal Infirmary	Nov-02	
Liverpool Alder Hey	Nov-02	
Manchester Royal Children's Hospital	Nov-02	
Middlesbrough James Cook Hospital	Nov-02	
Newcastle Freeman Hospital	Nov-02	
Newcastle Great North Childrens Hospital	Nov-02	
Nottingham Queen's Medical Centre	Nov-02	
Oxford John Radcliffe Hospital	Nov-02	
Sheffield Children's Hospital (PICU)	Nov-02	
Southampton Children's Hospital	Nov-02	
Stoke on Trent - Royal Stoke University Hospital.	Nov-02	
Brighton Royal Alexandra Hospital	Jan-03	Aug-15
London Evelina Children's Hospital	Jan-03	
London University Hospital Lewisham	Mar-03	Aug-10
London Great Ormond Street Hospital - CCCU	Mar-03	
London Great Ormond Street Hospital – PICU/NICU	Mar-03	
London Kings College Hospital	Mar-03	
London Royal Brompton Hospital	Mar-03	
London St George's Hospital	Mar-03	
London St Mary's Hospital	Jun-03	
Edinburgh Royal Hospital for Sick Children	Dec-04	
London The Royal London Hospital	Feb-07	
Glasgow Royal Hospital for Children	Apr-07	
Belfast Royal Belfast Hospital for Sick Children	Apr-08	
Dublin Our Lady's Children's Hospital Crumlin	Jan-09	
Dublin Children's University Hospital Temple Street	Mar-10	
London Harley Street Clinic	Sep-10	Mar-20
ADMEM	Jan-12	Dec-12
London The Portland Hospital	Jun-13	

PICANet Referral & Transport dataset data collection started June 2011.

Initially, referrals and transport information was recorded by the admitting PICU. From January 1st 2018, PICUs are only required to complete referral information for any patient referred to their PICU directly from the referring hospital (i.e. any children not referred via a PIC centralised transport service).

Anonymised records

Data for admissions / transports / referrals in Northern Ireland and Republic of Ireland are submitted in a pseudonymised format. This could limit identification of repeat admissions for individual children in some cases, if this will impact your request please discuss further with PICANet.

Records for patients aged over 18 and who haven't been admitted to PICU in the past 5 years are anonymised as per PICANet's anonymised records, method and policy.

Admissions dataset

Admission details

In 2014 PICANet changed how referral information was recorded on the admission form to align with the variables used in the referral and transport dataset.
Collection unit added to dataset with effect from 01/01/2018.

Paediatric Index of Mortality (PIM)

PICANet switched from collecting PIM2 variables to PIM3 variables in 2014. Where applicable, some of these variables can be calculated using the new / deprecated data fields. The change from the first PIM to PIM2 was made in 2012. Appendix 1 shows the variables collected for each version of PIM.

Blood gas measurement has been collected for all iterations of PIM. In 2014 base excess and lactate fields were added to this, along with source of sample (arterial/capillary/venous).

SpO2 and FiO2 at the time of SpO2 were introduced 01/01/2021.

Daily interventions

PCCMDS (daily interventions) data collection was introduced in August 2007, however this information is not complete for all hospitals prior to 2015.

With effect from 2014 the following additional variables were added to the daily interventions:
- High flow nasal cannula therapy *(record maximum flow in l/min)*
- Unplanned extubation *(record the number of unplanned extubations)*

With effect from Dec 2016 the following additional variables were added to the daily interventions:
- Arrhythmia requiring intravenous anti-arrhythmic therapy
- Status epilepticus requiring treatment with continuous infusion of anti-epileptic drugs
- Reduced consciousness level (GCS ≤ 12 AND hourly (or more frequent) GCS monitoring
- Epidural catheter in situ
- Continuous intravenous infusion of a sedative agent

Growth measurements

Weight became a mandatory data field from 01/01/2021, prior to this completion rates vary.
Height is not mandatory as this is often difficult to ascertain, therefore completion rates vary.
Abdominal circumference is not mandatory and is often not recorded.

Discharge information

Collection of mode of death information and transplant donor details were introduced 01/01/2021.

Follow-up 30 days post-discharge

30 day follow-up status is expected to be provided by all PICUs with the exceptions of: Brighton, Cambridge, The Royal London, Glasgow, Harley Street and the Portland; however completion rates vary.
From the 1st November 2019, completion of location of 30 day follow-up data was no longer required.

Referral dataset

Referral details

With effect from 01/01/2018, the date and time of referral was amended to be the date and time when clinicians agreed that the patient required PIC transport and/or a PICU bed, based on the patient's clinical condition as opposed to the availability of a team or a bed.

With effect from 01/01/2018 following fields were added:
- Referring area
- Referral number

With effect from 2014, "Transport Outcome" and "Admission Outcome" were reported separately (replacing "Decision of this referral call")
- Transport Outcome:
    o Accepted for transport
    o Refused – no transport team available
    o Refused – time critical transfer
    o Refused – out of scope of care
    o Transport not requested
- Admission Outcome:
    o Accepted for admission
    o Refused – no staffed bed available
    o Refused – out of scope of care
    o Admission not requested

Transport dataset

Transport details
"Transport classification" was added 01/01/2018 with response options being "Planned" or "Unplanned". Under "Type of Transport Team", the option of "Non-Specialist Team" was added.

Critical Incidents
In the 2014 PICANet transport form the number of boxes for critical incidents was reduced from 21 to 10, with a comment box added so that further detailed could be specified if the "other critical incident" option was ticked.

Transport times
Sections on "Base to collection unit", "Patient journey" & "Destination unit to base" were added to the Transport Times section in 2014.
An "Incident impacting on patient care" question was added to the Transport Times Section in 2014 with the following possible answers: "None", "Vehicle Accident", "Vehicle Breakdown".

Interventions (retrievals only)
With effect from 01/01/2018, high flow nasal cannula therapy information was added to both "Interventions by a local team prior to arrival of transport team" and "Interventions whilst transport team in attendance". These data are incomplete prior to 01/01/2020 (with the exception of transport teams which imported data, e.g. SORT and CATS).

In 2014 data collection began on "Other airway" interventions and "Non-invasive ventilation".

Paediatric Index of Mortality (PIM) (retrievals only)
PICANet switched from collecting PIM2 variables to PIM3 variables in 2014, where applicable some of these variables can be calculated using the new / deprecated data fields (see Appendix 1 for variables for each version of PIM).

Blood gas measurement, including base excess and lactate fields, were recorded from 2011. The source of blood gas measurement (arterial/capillary/venous) was added in 2014.

SpO_2 and FiO_2 at the time of SpO_2 were introduced 01/01/2021.

Appendix 1 - Variables included in each version of the Paediatric Index of Mortality (PIM)

Variables	PIM	PIM2	PIM3
Elective admission	Y	Y	Y
Underlying conditions	Y	Y	Y
None	Y	Y	Y
Cardiac arrest pre-hospital	Y	Y	Y
Severe combined immune deficiency	Y	Y	Y
Leukaemia or lymphoma	Y	Y	Y
Cerebral haemorrhage	Y	Y	Y
Cardiomyopathy/myocarditis	Y	Y	Y
Hypoplastic left heart	Y	Y	Y
HIV	Y	Y	
IQ <35	Y		
Neurodegenerative disorder	Y	Y	Y
Liver failure		Y	Y
Asthma		Y	Y
Bronchiolitis		Y	Y
Croup		Y	Y
Sleep apnoea		Y	Y
Diabetic ketoacidosis		Y	Y
Seizure disorder			Y
Bone marrow transplant			Y
Necrotising enterocolitis			Y
Pupil reaction	Y	Y	Y
Base excess	Y	Y	Y
PaO2	Y	Y	Y
FiO2	Y	Y	Y
Systolic blood pressure	Y	Y	Y
Mechanical ventilation	Y	Y	Y
Recovery from surgery		Y	Y
*Cardiac bypass**		Y	Y
Cardiac non-bypass			Y
Non cardiac			Y

*Cardiac Bypass was collected in the 'medical history' section for PIM2

Appendix 2 – COVID-19 Data Collection

A PICANet customised audit was established at the start of the COVID-19 pandemic to facilitate the collection of additional information concerning: 1) All children who tested positive for COVID-19 either prior to or during their PICU admission, and; 2) Children who remained COVID-19 suspected or probable after repeated COVID-19 negative laboratory test results and in the presence of no other positive virology and bacteriology results. These data are available from 01/03/2020.

From the 7th December 2020, this was extended to collect data on those children clinically diagnosed with PIMS-TS, confirmed by the absence of another cause, who may also have a positive COVID-19 PCR test. Additional data items included testing for COVID-19, symptoms, co-infection, echocardiogram findings, medication used, COVID-19 status on admission, up to three rounds of testing, reason for testing, types of samples taken, results of each test, laboratory markers at admission and co-infections.

A second revised version, COVID-19 II Customised Data Collection v1.0, was devised in December 2021 with input from clinicians (implemented from 13th December 2021). The COVID-19 II data collection differs from the first version in that the section on testing and sampling for COVID-19 is removed, and an additional collection of data items regarding PIMS-TS and potential COVID-19 vaccine related complications have been added.

COVID-19 II collects information about only **one** of the following:
1. Children aged less than 18 years clinically diagnosed with PIMS-TS (who may also have a positive COVID-19 PCR test or a positive antibody test) *or*
2. Children aged less than 18 years for whom a diagnosis of COVID-19 is confirmed by laboratory diagnosis during or immediately prior to admission to a paediatric intensive care unit (PICU) *or*
3. A child aged less than 18 years with suspected or potential COIVID-19 vaccine- related complications (e.g. myocarditis/pericarditis) (not PIMS-TS or COVID-19 confirmed by PCR).

The following updates were effective for all new admissions from 12 Feb 2022 and available for all COVID-19 II Custom Data Collection records to date[1]:

The *All admissions* section of the data collection form collects the following data items for all PICU admissions meeting the criteria for inclusion in the COVID-19 II Custom Data Collection:
- Number of doses of COVID-19 vaccine received
- Date of most recent COVID-19 vaccine
- Type of most recent COVID-19 vaccine

These fields were previously only collected in the Potential COVID 19 vaccine related complications section/ cohort which have now been removed to avoid duplication.

Other updates:

- *PIMS-TS* section: amended the "COVID-19 PCR test result" question title to "COVID-19 PCR test result during this admission".

---

[1] For the following changes PICUs are not expected to complete the fields retrospectively for earlier admissions

- *COVID-19 confirmed by PCR* section: amended the option title "No symptoms – asymptomatic throughout PICU stay" to "No symptoms attributed to COVID-19 throughout PICU stay / asymptomatic".