Paediatric Intensive Care Audit Network

National Paediatric Critical Care Audit

State of the Nation Report 2023

Appendices

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Acknowledgements

The Paediatric Intensive Care Audit Network (PICANet) gathers information on all patients admitted to paediatric intensive care units (PICUs) in the United Kingdom and Republic of Ireland, in conjunction with specialist paediatric transport services (SPTS).

We are indebted to the efforts of all of the administrative staff, nurses and doctors who support and contribute to PICANet from their PICUs and SPTS. We are particularly grateful for everyone's support and contributions over the past three years given the significant challenges of the COVID-19 pandemic.

PICANet continues to rely on the expertise and support from the Paediatric Critical Care Society (PCCS), the PICANet Steering Group and members of the Clinical Advisory Group who provide an essential link between PICANet and the clinical care teams. We would like to acknowledge this support, which enables the PICANet audit to continue to be a success.

The PICANet National Paediatric Critical Care Audit (NPCCA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), the Welsh Health Specialised Services Committee (WHSSC), NHS Lothian/NHS Greater Glasgow and Clyde, the Royal Belfast Hospital for Sick Children, the National Office of Clinical Audit (NOCA) for the Republic of Ireland and HCA Healthcare UK.

Glossary

CAG	Clinical Advisory Group
CHI	Community Health Index
GDPR	General Data Protection Regulation
CYP	Children and Young People
HD	High Dependency
HQIP	Healthcare Quality Improvement Partnership
HRA CAG	Health Research Authority Confidentiality Advisory Group
HRG	Healthcare Resource Group
IC	Intensive Care
ICB	Integrated Care Board
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NHS	National Health Service
NOCA	National Office of Clinical Audit
NPCCA	National Paediatric Critical Care Audit
PCCS	Paediatric Critical Care Society
PIC	Paediatric Intensive Care
PICANet	Paediatric Intensive Care Audit Network
PICS	Paediatric Intensive Care Society (now PCCS)
PICU	Paediatric Intensive Care Unit
PIM3	Paediatric Index of Mortality 3
RSPRT	Resetting Sequential Probability Ratio Test
ROI	Republic of Ireland
SG	Steering Group
SMR	Standardised Mortality Ratio
SPTS	Specialist Paediatric Transport Services
UK	United Kingdom
WHSSC	Welsh Health Specialised Service Committee

Organisation Key

A	Addenbrooke's Hospital, Cambridge
C	Noah's Ark Children's Hospital for Wales, Cardiff
D	Royal Manchester Children's Hospital
E1	Great Ormond Street Hospital, London (PICU/NICU)
E2	Great Ormond Street Hospital, London (CICU)
F	Evelina London Children's Hospital
H	King's College Hospital, London
I	Leeds Children's Hospital
K2	Freeman Hospital, Newcastle upon Tyne
K3	Great North Children's Hospital, Newcastle upon Tyne
L	Royal Stoke University Hospital
M	Nottingham Children's Hospital, Queens Medical Centre, Nottingham
N	John Radcliffe Hospital, Oxford
O	Royal Brompton Hospital, London
P	Alder Hey Children's Hospital, Liverpool
Q	Sheffield Children's Hospital
R	Southampton Children's Hospital
S	James Cook University Hospital, Middlesbrough *(not included in key metrics)*
T	St George's Hospital, London
U	St Mary's Hospital, London
V	Birmingham Children's Hospital
W	Bristol Royal Hospital for Children
X2	Leicester Royal Infirmary CICU
X3X1	Leicester Royal Infirmary CPICU (previously Glenfield Hospital, Leicester)
Y	Royal Hospital for Children and Young People, Edinburgh
Z	The Royal London Hospital
ZA	Royal Hospital for Children, Glasgow
ZB	Royal Belfast Hospital for Sick Children
ZC	Children's Health, Ireland, Crumlin formerly Our Lady's Children's Hospital, Crumlin, Dublin
ZD	Children's Health, Ireland, Temple Street, formerly Temple Street Children's University Hospital, Dublin
ZE	Harley Street Clinic, London *(not included in key metrics)*
ZF	The Portland Hospital, London
T001	Children's Acute Transport Service (CATS)
T002	Embrace: Yorkshire & Humber Infant & Children's Transport Service
T003	North West and North Wales Paediatric Transport Service (NWTS)
T004	South Thames Retrieval Service (STRS)
T005	KIDS Intensive Care and Decision Support
T008	Southampton Oxford Retrieval Team (SORT)
T010	Northern Ireland Specialist Transport and Retrieval (NISTAR) Paediatric
T020	Scotland Specialist Transport and Retrieval (ScotSTAR)
T022	Irish Paediatric Acute Transport Service (IPATS)
T024	Wales and West Acute Transport for Children (WATCh)
T026	North East Children's Transport and Retrieval Service (NECTAR)
T027	Children's Medical Emergency Transport Service (CoMET)
T028	*Heart Link ECMO Children's Service (included in Tables & Figures only)*
T032	Paediatric and Neonatal Decision Support and Retrieval Service (PaNDR)

Background and participating organisations

PICANet was established in 2002 with funding from the Department of Health and started collecting data from English and Welsh paediatric intensive care units in November 2002. The PICUs at the Royal Hospital for Sick Children, Edinburgh (now Royal Hospital for Children and Young People) and the Royal Hospital for Children, Glasgow started submitting data in December 2004 and April 2007 respectively. The Royal Belfast Hospital for Sick Children joined in April 2008 and Children's Health, Ireland, Crumlin and Children's Health, Ireland, Temple Street, both based in Dublin, have submitted anonymised data to PICANet since January 2009 and March 2010, respectively. The Harley Street Clinic PICU started contributing data in September 2010, and the PICU at the Portland Hospital from June 2013, allowing both these non-NHS units to compare their performance against the national benchmark provided by PICANet. The Harley Street Clinic PICU permanently closed in March 2020.

During the reporting period there were 32 PICUs and 13 specialist paediatric transport services (SPTS) submitting data to PICANet. The audit covers the whole of the UK and the Republic of Ireland. A full list of participating PICUs can be found in the Participating Organisation & Unit Characteristics 2022 section. Changes to participation are detailed in the Important notes section.

Governance

PICANet continues to receive support from the NHS Health Research Authority Confidentiality Advisory Group (HRA CAG) to collect personally identifiable data without consent on all patients accepted for referral, transported, or admitted to paediatric intensive care. Most patients are comprised of infants, children and young people although on occasion may include older adults. The HRA CAG references are: 21/CAG/0090 (non-research) and 21/CAG/0098 (research).

See the HRA CAG register of approvals here: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/

The Secretary of State for Health and Social Care, having considered the advice from the HRA CAG, has granted PICANet's clinical audit an exemption from the National Data Opt-Out (England).

Ethics approval for the PICANet research database has been granted by the East Midlands – Derby Research Ethics Committee, ref. 18/EM/0267.

PICANet have approval from NHS Scotland's Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) for NHS Scotland data for use by PICANet. The reference is 1819-0107 Feltbower.

PICANet supports transparency in its data processing and has patient information sheets and posters on display in PICUs and SPTS. A Privacy Notice and Fair Processing Statement on our website outlines the legal basis for processing of data under the General Data Protection Regulation (May 2018). Details can be found at https://www.picanet.org.uk/about/policies/.

PICANet receives support and advice from our dedicated Clinical Advisory Group (CAG) drawing on the expertise of doctors and nurses working within the speciality and a Steering Group (SG), whose membership includes health services researchers, representatives from the Royal Colleges of Paediatrics and Child Health, Nursing and Anaesthetics, parent/ carer representatives and commissioners. For a full list of CAG and SG members, see Clinical Advisory Group Membership 2020 – 2022 and Steering Group Membership 2020 - 2022. Additional support from the clinical community is provided through the UK Paediatric Critical Care Society.

Methods

Basic methodology

Most critically ill children who need complex clinical care and life support are treated in Paediatric Intensive Care Units (PICUs). These children may have had complex surgery, an accident or a severe infection and may arrive in the PICU from an operating theatre, emergency department or from a hospital ward. In some cases they may have been transferred from another hospital and, occasionally, admitted directly from home.

The NPCCA collects personal, organisational and clinical data on all children with a clinically determined need for paediatric intensive care in the UK and Ireland, to compare outcomes and activity between PICUs, SPTS, health regions and nations.

Data are stored on a secure database. Each organisation can view and download their own data, reports on their data quality and activity as well as comparative national data. The annual State of the Nation report includes a summary of what has happened to children admitted to PICU including why they were admitted, where they were admitted from, how long they stayed, what treatments they received and their outcome at the time of discharge. Comparisons between PICUs are made to assess how well they perform against established clinical standards and guidelines.

In addition to the annual report, PICANet provides technical and statistical support for the use of its data for local audit and research, regional and national commissioning, national and international research and to provide baseline information for clinical intervention trials.

Data collected

PICANet collects three core datasets:

Admission data contains demographic details of each child including their name*, date of birth**, NHS/CHI number, address* and ethnic group; it also records where children are admitted from, their date of admission and clinical diagnoses, some physiological parameters on admission including blood gases, blood pressure, medical history and ventilation status. Data on outcome and discharge details are included. The medical interventions received on each day by each child are recorded as part of the audit and to help NHS organisations in England to supply information on the cost of their activity.

Referral data for all children where clinicians agree a paediatric intensive care bed and/or paediatric intensive care transport is required includes details of the referring hospital, demographic details of the child, grade of the referring doctor or nurse, the outcome of the referral, the transport team involved and the destination PICU.

Transport data for all children transported to a PICU from their original admitting hospital or who are transported by a specialist PIC transport service but are not admitted to a PICU includes patient details as well as information about their presenting physiology. Details of the composition of the transport team, journey times, any interventions carried out and critical incidents are also recorded.

*   Not collected from Northern Ireland or the Republic of Ireland

** Limited to month and year for Northern Ireland

Data submission and storage

Data are submitted by individual PICUs prospectively, using our secure web-based data collection application called PICANet Web. Data submission can involve direct entry or an upload

of a data file from an existing clinical information system. PICANet provides full documentation on data definitions, which have been developed in collaboration with our Clinical Advisory Group, as well as technical specifications for IT and database professionals. In addition, standardised data collection forms are supplied to all organisations where there is no in-house provision for data collection.

All data submitted is stored in the Leeds Analytic Secure Environment for Research (LASER) system. All data at rest in the LASER system is encrypted to AES-256 Bit encryption.

Data quality, validation, and case ascertainment

Data validation is carried out at the point of data entry on the PICANet Web system and centrally on the database. Validation checks for logical inconsistencies, out of range values, missing and incorrect data are reported back to the individual participating organisations on demand via the web interface. PICANet Web also allows PICU staff to obtain reports on their own data to aid quality assurance, data validation checks and check case ascertainment.

The Modulus 11 algorithm is used to validate the NHS number based on a check digit – this is a standard method of ensuring the NHS number is a true NHS number and improves our ability to trace patients through the PICANet database and in linked healthcare data.

Validation reports are provided to participating organisations every 6 weeks and virtual validation visits are conducted by PICANet staff, aiming to have one visit every 12 – 18 months per participating organisation.

The six-weekly validation reports alert participating organisations to timeliness of data entry, validation queries for resolution for core data collection and any customised data collection audits. Twice a year, they also involve checking case ascertainment - a cross check of admission records with those recorded on PICANet Web.

Quarterly risk-adjusted Resetting Sequential Probability Ratio Test (RSPRT) plots are sent to each unit to address any immediate concerns if applicable and RSPRT guidance for units is available to support this process on the PICANet QI Resources webpage.

The virtual validation visits allow for an in-depth review of case ascertainment, data quality and validation and are a core element of our data quality assurance. These visits are vitally important to maintain contact with PCC staff, pick up on systematic errors that may appear in the data and assist in managing user access and identifying team changes not already reported to PICANet.

Case ascertainment is measured via units comparing the admission count in their admission book/electronic system over a two-month period and comparing these numbers to the number of admissions on PICANet Web database.

Collaborative working supporting policy, commissioning, research and clinical trials

PICANet has become established as the definitive source of data on paediatric intensive care activity in the UK and Ireland. The data have been used to plan PIC services, model demand, assess interventions and outcomes and provide data to underpin research to facilitate the development of new standards for critical care provision for children. PICANet has provided baseline data for the development of the IKID, SANDWICH and FEVER trials, all of which were funded and made use of the routinely collected PICANet data using the custom data download facility. This allows local control over the data. We also work closely with other funded studies, including DEPICT, FIRST-ABC, GIRFT, LAUNCHES-QI, NEURO-PACK, OCEANIC, Oxy-PICU, PERMIT, and PICnIC. PICANet have also supported the NHS response to the COVID-19 pandemic by providing key data to inform the modelling of bed occupancy rates.

Analytical techniques

The Statistical Analysis Plan for the State of the Nation Report 2023 is available on the PICANet website. Statistical techniques used include simple cross tabulations, the calculation of crude and risk-adjusted standardised mortality ratios (SMRs) and 95% confidence intervals; the construction of crude and risk-adjusted funnel plots of SMRs; and local provision of risk-adjusted RSPRT plots to assess real-time performance related to in-PICU mortality. Risk-adjusted SMRs were calculated using the latest version of the Paediatric Index of Mortality (PIM3)[1] recalibrated based on data within the current reporting period.

Small number policy

Publication of PICANet data is subject to scrutiny of small numbers. When small numbers of admissions are involved, other data items may become identifiable i.e. a living individual may be identified from the data. This can still be the case in aggregated data where small groups of individuals are presented. These are reviewed and categories are combined or cells anonymised where necessary.

Outlier policy

PICANet recalibrate the Paediatric Index of Mortality version 3 (PIM3) parameters for each year's report and use these to calculate an SMR for each unit. When the SMR shows that risk-adjusted mortality within a unit is higher or lower than expected, the unit will be subject to the formal process outlined in PICANet's Outlier policy (v3.0, 2023). The process within the policy allows PICANet and the unit to better understand the reason(s) behind their outlier status, and improves knowledge of good practice/areas for improvement which can be shared across providers.

How we present our results

Results are presented in tables and figures. This Report mainly focuses on children aged 0–15 years apart from tables capturing the workload of the PICU (e.g. what treatments were used, how many bed days the PICU provided, etc.) unless otherwise stated. Where we present data on 0-15 year olds or we present data by gender we exclude data relating to children who are recorded as having 'ambiguous' sex due to the increased risk of reidentification due to small numbers (i.e. to maintain statistical disclosure control).

We report on five key metrics: case ascertainment including timeliness of data submission, retrieval mobilisation times, emergency readmissions within 48 hours of discharge, unplanned extubation in PICU and mortality in PICU. The infographic highlights the main findings of the report.

Measures include the number of admissions, how many days patients are in PICU, the types of treatments patients receive and clinical outcomes such as death. We present data according to sex, age, ethnicity, deprivation, country of admission, treating PICU as well as country of residence and where the child is living.

Data are presented in more granular detail in the "Tables and Figures" available on the Reports webpage. In general, data are presented for children aged 0–15 years and do not include any

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[1] Straney, L., et al., *Paediatric Index of Mortality 3: An Updated Model for Predicting Mortality in Pediatric Intensive Care.* Pediatric Critical Care Medicine, 2013. **14**(7): p. 673-681.

admissions where the child's age is unknown, however, some tables also include data relating to all patients admitted to PICU (including those who are 16 years and older or where we don't know the patient's age); this will be made clear for relevant tables.

Rates

We present certain information in the form of rates, enabling comparisons to be made between countries even though the population size in each country is different. Rates are usually presented as the number per 1,000 or per 100,000 of the relevant population.

When we want to compare two rates we divide one rate by the other, to get a relative rate. For example, to compare the admission rate in Scotland to that in England we would divide the Scottish admission rate by the English admission rate. If the two rates were the same then the relative rate would be one. If the Scottish rate was higher than the English rate then the relative rate would be greater than one. If the Scottish rate was lower than the English rate then the relative rate would be less than one. This measure allows us to talk about the Scottish rate in comparison (or relative) to the English rate.

Deaths

We measure how poorly children were at the point when they were admitted to PICU usingPIM3[2]. This takes into account many factors (such as whether the child was admitted as an emergency and whether they needed help breathing) to estimate how likely each child is of dying.

When comparing deaths in PICU, we calculate the risk-adjusted standardised mortality ratio (SMR). This compares the number of deaths that have happened in a PICU and how many deaths we expected to happen given how poorly children were when they were admitted to PICU. We also use 'funnel plots' to compare individual PICUs in terms of mortality which enables us to display and compare the risk-adjusted SMR on the same graph. These plots tell us what range of values we might expect to see for the SMR in each PICU, given that we expect a certain amount of variation as these calculations are based on a very small number of deaths. This is the process used to identify outliers as described in the Outlier Policy section.

Important notes

PICANet database outage

In March 2022 the University of Leeds proactively dealt with a cyber-security issue and as a precaution there was a period of outage for the PICANet Web database. On 06 June 2022 the system became available to all participating organisations for manual data entry and validation and on 20 July 2022 the importing of data could resume. The outage affected both PICANet and the units, and so additional time was allowed in 2022 for units to ensure their 2021 data were up to date for the State of the Nation Report 2022. The outage had a substantial impact on the timely submission of the 2022 data (presented in Metric 1 of the State of the Nation Report 2023) and this is reflected in a lower than usual average case ascertainment and three month timeliness of data entry value of 75.8%[3] in 2022, compared to 87.7% in 2021.

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[2] Straney, L., et al., *Paediatric Index of Mortality 3: An Updated Model for Predicting Mortality in Pediatric Intensive Care.* Pediatric Critical Care Medicine, 2013. **14**(7): p. 673-681.

[3] This is the three month timeliness value and therefore does not correspond to Metric 1 in the Summary Report.

Compared with previous years, there was a noticeable reduction in the number of data access requests fulfilled in 2022 as a result of the database outage.

Data collection issues

The PICUs in the Republic of Ireland, Children's Health Ireland at Crumlin (ZC) and at Temple Street (ZD), had low levels of timely data completion and submission in 2021 due to the Health Service Executive (HSE) experiencing a major ransomware cyberattack on 14 May 2021. This caused all IT systems nationwide to be shut down and Children's Health Ireland were heavily impacted by the cyberattack.

The Freeman Hospital PICU (K2) experienced local IT issues from April 2022 which hindered their usual data submission and validation routine and contributed to low levels of timely data completion. To ensure that data for admissions in 2022 were included in the 2023 State of the Nation Report, the method of data entry was changed to ensure that the backlog of data were entered and validated.

Case ascertainment

The Portland Hospital (ZF) were identified as having low case ascertainment for admissions to PICU during 2021 due to a resourcing issue at the unit. Following identification of the issue, efforts were made to ensure that backlog of data entry was undertaken during Summer 2022. As such, the unit is included in the State of the Nation Reports covering this period.

COVID-19 data collection

UK units ceased the rapid reporting of the number of new admissions with SARS-CoV-2 and clinically diagnosed PIMS-TS to PICANet in June 2023. PICUs continue to complete the COVID-19 II custom audit data collection where appropriate. We are grateful to the PICU teams for the work put into the rapid reporting and for their continuation with the customised data collection.

Closure of ZE – Harley Street PICU

One non-NHS PICU (ZE) closed to paediatric admissions permanently in March 2020. Data presented for this unit does not cover the full reporting period and as such data from this unit is not included in key metrics. ZE will no longer be included in the State of the Nation report from 2024 onwards.

Redesignation of S – James Cook University Hospital (Middlesbrough)

One NHS PICU (S) was redesignated from a Level 3 paediatric intensive care unit to a Level 2 unit in 2019 and as such data from this unit is not included in key metrics from this report onwards.

Addition of T032 – PaNDR

The Paediatric and Neonatal Decision Support and Retrieval Service (PaNDR) provides critical care transports for children in the East of England. They have submitted data for paediatric critical care transports carried out from April 2021.

Changes to the units in Leicester

The cardiac paediatric intensive care unit (CPICU) in Leicester (X3) formerly known as the PICU based at Glenfield Hospital (X1) was moved across sites to the Children's Hospital based at Leicester Royal Infirmary on 08 August 2021. This unit is shown in the tables and figures as X3X1.

Changes to the tables and figures

We are currently reviewing the way we capture and present data for our report, including undertaking a review of the way that we capture Referrals data. As such the following tables are not included this year:

- R1 Number of Referrals for Transport by Transport Organisation & Outcome

- Table 4.15 Number of Individual Children by Health Organisation and Diagnostic Group of First Admission

- Table 2.1 Retrievals / Transfers by Team Type and Age

- Table 2.2 Specialist Team Retrievals / Transfers by Diagnostic Group and Age

- Table 2.3 Non-Specialist Team Retrievals / Transfers by Diagnostic Group and Age

- Table 2.4 Admissions by Organisation and Transport Team Type for Retrievals and Transfers

- R1 Number of Referrals for Transport by Transport Organisation and Outcome

- R1a Number of Referrals for Transport by PIC Transport Organisation and Outcome

- R2 Number of Referrals for PICU Admission by Healthcare Organisation & Outcome

This year we have included a number of new sensitivity analyses related to the Outlier Policy as well as a small expansion of the activity data section. As such the following tables have been added to this report:

- Table 4.13 Single Year Standardised Mortality Ratios by Health Organisation (0-15 years), 2022

- Table 4.15 Three-year Standardised Mortality Ratios by Health Organisation (0-15 years, intensive care level admissions)

- Table 4.16 Three-year Standardised Mortality Ratios by Health Organisation (0-15 years, excluding palliative care discharge)

- Table 4.17 Three-year Standardised Mortality Ratios by Health Organisation (0-15 years, invasively ventilated)

- Table 6.4 Highest Level of Care During Admission by Health Organisation

Links with the clinical community

PICANet is overseen and guided by the PICANet Steering Group. The Steering Group oversees the wider governance of the project, providing advice and guidance on policy and operation to ensure that PICANet provides a sound evidence-base for audit, service evaluation and research in paediatric critical care. The Steering Group has representatives from a broad range of organisations across the UK and Republic of Ireland with an interest in PCC and includes parent/carer representation, the Paediatric Critical Care Society, and the Royal Colleges of Paediatrics and Child Health, Anaesthetists and Nursing.

PICANet has a dedicated Clinical Advisory Group (CAG), whose members represent the paediatric critical care teams that submit data to PICANet. The CAG has the following functions: to provide practical clinical advice to the PICANet team; to act as a forum in which PCC staff can raise practical operational issues about data entry and transmission and validation; to contribute to discussions about the long-term strategic development of PICANet; to identify important audit and research questions that the PICANet database could address; and to review the results and interpretation of analyses from a clinical perspective. It also acts as the natural forum for the co-ordination of multi-centre clinical research studies and reviews requests for access to PICANet data to ensure feasibility, prevent duplication of activity and to encourage collaboration.

PICANet has the support of the Paediatric Critical Care Society and the associated PCCS Study Group and the Clinical Reference Group which oversees Paediatric Critical Care, including PCC transport.

Patient and Public Involvement

Patient and Public Involvement (PPI) refers to the inclusion of patients, parents, carers, children and young people, and members of the public in the activities and development of PICANet's outputs.

In 2022 PICANet produced a detailed long term plan to reinvigorate this important area to ensure that PPI is embedded into the development of new projects and extensions of the remit of PICANet and outputs (e.g., public-facing reports and infographics) and to ensure that this work will enhance and support the experience of children being cared for in PCC and their families.

The initial plans were to revisit, in a series of workshop sessions held in 2023 with parents/ carers and children and young people, the fundamental working arrangements of PICANet to ensure these remained appropriate. These include the role of PICANet and how data are collected; the exemption from the National Data Opt-Out (England) for the clinical audit and the application of it to research if we need to process identifiable data; how we anonymise data and audit/research that uses PICANet data (the use of confidential patient information without consent).

To date, all communication that we have had with parents, carers, children and young people has been very positive, supporting PICANet and its work and has guided PICANet's provision of information. We have ongoing plans to continue to develop and expand our PPI work further in the upcoming years.

Participating Organisation & Unit Characteristics 2022

NHS Trust / Organisation	Participating Hospital	Unit / Ward[1]	Number of IC beds	Number of HD beds	Type of unit
Barts Health NHS Trust	The Royal London Hospital	PCCU	6	2	General
Birmingham Women's and Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital	PICU	29	0	General including cardiac, liver, neurosurgical, ECLS, ENT, oncology, metabolic and spinal
Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital	PICU	8	5	General
Cardiff & Vale University Health Board	Noah's Ark Children's Hospital for Wales	PCCU	7	4	General
Manchester University NHS Foundation Trust	Royal Manchester Children's Hospital	PICU	17	14	General
Great Ormond Street Hospital for Children NHS Trust	Great Ormond Street Hospital for Children	CICU	20	0	Cardiac
		PICU	17	0	General
		NICU	10	0	Neonatal
Guy's & St. Thomas' NHS Foundation Trust	Evelina London Children's Hospital	PICU	21	0	General & Cardiac
HSE (Health Service Executive)	Children's Health Ireland at Temple Street, Dublin	PICU	9	0	General
	Children's Health Ireland at Crumlin, Dublin	PICU	20	3	General & Cardiac
King's College Hospital NHS Foundation Trust	King's College Hospital	PICU	8	8	General, Hepatic & Neurosurgical
The Leeds Teaching Hospitals NHS Trust	Leeds Children's Hospital	PICU	16	0	General & Cardiac
Newcastle upon Tyne Hospitals NHS Foundation Trust	Great North Children's Hospital	PICU	11	0	General & Surgical ICU
	Freeman Hospital	CICU	12	0	Cardiothoracic surgery, heart failure, ECMO & ENT
NHS Lothian	Royal Hospital for Children and Young People, Edinburgh (formerly Royal Hospital for Sick Children)	PICU	10	9	General, Neurosurgical & Spinal
NHS Greater Glasgow and Clyde	Royal Hospital for Children, Glasgow	PICU	22	0	General, Neurosurgical Cardiac & ECMO

NHS Trust / Organisation	Participating Hospital	Unit / Ward[1]	Number of IC beds	Number of HD beds	Type of unit
Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital	PCCU	8	9	General including neurosurgical, craniofacial and major trauma
Nottingham University Hospitals NHS Trust	Nottingham Children's Hospital	PICU	8[2]	6	General (plus regional oncology, major trauma, ENT, paediatric surgery, regional neurosurgical, spinal, supraregional renal service and cleft lip & palate services)
Royal Brompton & Harefield NHS Foundation Trust	Royal Brompton Hospital	PICU	16	4	Cardiac & Respiratory
Alder Hey Children's NHS Foundation Trust	Alder Hey Children's Hospital	PICU	24	0	General & Cardiac
Sheffield Children's NHS Foundation Trust	Sheffield Children's Hospital	PCCU	7	8	General (plus major trauma, neurosurgery, ENT, oncology, metabolic, paediatric surgery, spinal)
University Hospitals Southampton NHS Foundation Trust	Southampton Children's Hospital	PICU	14	0	General, Cardiac & Neurosurgery
South Tees Hospitals NHS Foundation Trust	James Cook University Hospital	PCCU	0	6[3]	General
St. George's University Hospitals NHS Foundation Trust	St. George's Hospital	PICU	6	6	General, Neurosurgical, Oncology & Paediatric Surgery
Imperial College Healthcare NHS Trust	St. Mary's Hospital	PICU	11	4	General
Belfast Health and Social Care Trust	Royal Belfast Hospital for Sick Children	PICU	12[4]	0	General
University Hospitals Bristol NHS Foundation Trust	Bristol Royal Hospital for Children	PICU	18	0	General, Cardiac, Neurosurgery, Burns and Major Trauma
University Hospitals of Leicester NHS Trust	Leicester Royal Infirmary CICU	CICU	6[2]	0	General (Children's Intensive Care Unit)
	Leicester Royal Infirmary CPICU (previously Glenfield Hospital)	CPICU	7	0	Cardiac & ECMO
University Hospitals of North Midlands NHS Trust	Royal Stoke University Hospital	PICU	6	1	General
HCA Healthcare UK (non-NHS)	The Portland Hospital	PICU	9	9	General

This table is updated with information gathered during the virtual validation meetings.

1. Cardiac Intensive Care Unit (CICU), Cardiac Paediatric Intensive Care Unit (CPICU) Neonatal Intensive Care Unit (NICU), Paediatric Critical Care Unit (PCCU), Paediatric Intensive Care Unit (PICU), Extracorporeal Membrane Oxygenation (ECMO), Ear nose and throat (ENT), Extracorporeal Life Support (ECLS)
2. IC/ HD beds are used flexibly if required.
3. The James Cook University Hospital, Middlesbrough were redesignated as a Level 2 unit in 2019.

4. PICU Royal Belfast Hospital for Sick Children routinely admit children up to 14 years of age.

   For a list of all participating organisations including transport services please see our website. A list of included units and SPTS contributing data for this reporting period is published in the front of the report Tables and Figures 2023.

Clinical Advisory Group Membership 2020 - 2022

Name	Position	NHS Trust / Hospital	Period served
Dr Peter Davis (Chair to 2020)	Consultant in Paediatric Intensive Care	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	2006 - Ongoing
Simon Chiles	Advanced Nurse Practitioner	University Hospitals of Leicester NHS Trust Glenfield Hospital	2014 - Ongoing
Dr Mark Terris (representing Northern Ireland)	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	2014 - Ongoing
Judith Gray (representing Nursing)	Sister	Newcastle upon Tyne Hospitals NHS Foundation Trust Newcastle Freeman Hospital	2015 - Ongoing
Dr Hari Krishnan	Consultant Paediatric Intensivist	Birmingham Women's and Children's NHS Foundation Trust Birmingham Children's Hospital	2018 - Ongoing
Prof Mark Peters (Chair from 2020)	Clinical Unit Chair	Great Ormond Street Hospital for Children NHS Trust Great Ormond Street Hospital for Children	2018 - Ongoing
Dr Andrew Nyman	Consultant in Paediatric Intensive care	Guy's and St Thomas' Foundation Trust Evelina Children's Hospital, South Thames Retrieval service (STRS)	2019 - Ongoing
Dr Sara Ali (representing Wales)	Consultant in Paediatric Intensive Care	Cardiff University Hospital, Noah's Ark Children's Hospital of Wales	2020 – Ongoing
Dr Catherine McDougall (representing Scotland)	Consultant in Paediatric Intensive Care	Royal Hospital for Children and Young People, Edinburgh	2021 - Ongoing
Rachel Neal	PICU Data & Audit Manager	St George's Hospitals NHS Foundation Trust	2021 - Ongoing
Dr Padmanabhan Ramnarayan (representing PCCS SG)	Reader in Paediatric Intensive Care & Honorary Consultant	Imperial College London & Imperial College Healthcare NHS Trust	2022 - Ongoing
Annette Shaw	Data and Quality Nurse	Royal Hospital for Children, Glasgow	2021 - Ongoing
Dr Dora Wood (representing Transport Organisations)	Consultant in Paediatric Intensive Care	Bristol Paediatric Intensive Care Unit and WATCh	2021 - Ongoing
Dr Martina Healy (representing ROI)	Clinical Lead for Irish Paediatric Critical Care Audit	Children's Health Ireland at Crumlin	2022 - Ongoing
Katie Higgins	Clinical Nurse Specialist	North West and North Wales Paediatric Transport Service (NWTS)	2022 - Ongoing
Kathryn Claydon-Smith	Clinical Nurse Specialist	North West and North Wales Paediatric Transport Service (NWTS)	2009 - 2022

Name	Position	NHS Trust / Hospital	Period served
Dr Padmanabhan Ramnarayan (representing Transport Organisations)	Consultant	Great Ormond Street Hospital NHS Trust Children's Acute Transport Service	2012 - 2021
Lesley Molony	Information Officer	Southampton Universities Hospital NHS Trust Southampton Children's Hospital	2013 - 2021
Dr Rachel Agbeko	Paediatric Intensivist	Newcastle upon Tyne Hospitals NHS Foundation Trust Great North Children's Hospital	2012 - 2020
Dr John Alexander	Consultant in Paediatric Intensive Care	University Hospitals of North Midlands NHS Trust Royal Stoke University Hospital	2012 - 2020
Dr John Pappachan	Anaesthetics and Paediatric Intensive Care Medicine	University Hospitals Southampton NHS Foundation Trust Southampton Children's Hospital	2012 - 2020
Dr Alistair Turner (representing Scotland)	Consultant in Paediatric Intensive Care	NHS Greater Glasgow and Clyde Royal Hospital for Children, Glasgow	2016 - 2020
Dr Roddy O'Donnell	Consultant in Paediatric Intensive Care	Cambridge University Hospitals NHS Foundation Trust Addenbrooke's Hospital	2002 - 2020
Dr Shane Tibby	Consultant in Paediatric Intensive care	Guy's and St Thomas' Foundation Trust Evelina Children's Hospital	2011 - 2019
Dr Peter Wilson	PICU Consultant	University Hospitals Southampton NHS Foundation Trust Southampton Children's Hospital	2011 - 2019

Ongoing as of 31st December 2022.

Steering Group Membership 2020 - 2022

Name	Position	Organisation	Representation	Period Served
Dr Michael Marsh (Chair)	Regional Medical Director & CCIO Higher Level Responsible Officer South West Region	NHS England & NHS Improvement	Royal College of Paediatrics and Child Health National Commissioner for Paediatric Intensive Care Clinical Reference Group	2002 - Ongoing
Dr Peter Davis	Consultant in Paediatric Intensive Care	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	Chair of Paediatric Intensive Care Clinical Reference Group	2011 - Ongoing
Lucy Wheeler	Parent	N/A	Parents and Carers Representation	2011 - Ongoing
Dr Mark Terris	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	Northern Ireland	2012 - Ongoing
Andrew Fleming	National Clinical Audit Manager	Intensive Care National Audit & Research Centre (ICNARC)	Intensive Care National Audit & Research Centre (ICNARC)	2017 - Ongoing
James Fraser	Consultant Paediatrician	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	Paediatric Intensive Care Society President (2019 -)	2019 - Ongoing
Dr Mark Peters	Consultant in Paediatric Intensive Care	Great Ormond Street Hospital, London	Chair of PICANet Clinical Advisory Group	2020 - Ongoing
James Campbell	Associate Director of Quality and Development	Health Quality Improvement Partnership (HQIP)	Commissioning body for PICANet in England	2021 - Ongoing
Donna Webb	Matron for Critical Care and Cardiology	Leeds Children's Hospital	PCCS Nurse Managers Group	2021 - Ongoing
Padmanabhan Ramnarayan	Reader in Paediatric Critical Care	Imperial College London	Chair of PCCS Study Group	2022 - Ongoing
Karina Hamilton	Paediatric Programme Assistant Audit Manager	National Office of Clinical Audit	Republic of Ireland	2022 - Ongoing

Name	Position	Organisation	Representation	Period Served
Natalia Plejic	HQIP PICANet Project Manager	Health Quality Improvement Partnership (HQIP)	Commissioning body for PICANet in England	2022 - Ongoing
Roseanne McDonald	Programme Associate Director: Nursing and Quality Adviser	National Services Division (NSD), NHS National Services Scotland	Scotland	2022 - Ongoing
Freddie Drew	National Programme of Care Manager – Women & Children	NHS England	NHS England	2022 - Ongoing
Vivien Dunne	HQIP PICANet Project Manager	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2022 - 2022
Daniel Eve	National Programme of Care Manager, Specialised Commissioning	NHS England and NHS Improvement	National Commissioner for Paediatric Intensive Care Clinical Reference Group	2021 - 2022
Sam Harper	HQIP PICANet Project Manager	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2018 - 2022
Sasha Hewitt	Associate Director for Quality and Development and Data Protection Officer	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2017 - 2021
Louise Dewsbury	Senior Nurse	Guy's and St Thomas' NHS Foundation Trust Evelina London Children's Hospital	PICS Nurse Managers Group	2017 - 2021
Rachel Lundy	Senior Commissioning Manager	NHS England & NHS Improvement	National Commissioner for Paediatric Intensive Care Clinical Reference Group	2016 - 2021
Dr Jillian McFadzean	Clinical Lead	NHS Lothian, Royal Hospital for Children and Young People, Edinburgh	Scotland	2005 - 2021
Dr Gale Pearson	Consultant in Paediatric Intensive care	Birmingham Women's and Children's NHS Foundation Trust Birmingham Children's Hospital	Chair of Paediatric Intensive Care Clinical Reference Group	2015 - 2021
Dr Barney Scholefield	Consultant Intensivist	Birmingham Childrens Hospital	Chair of Paediatric Intensive Care Study Group	2016 - 2021

Ongoing as of 31st December 2022.

Data Collection Form in use 2022 – Admission

PICA Net Paediatric Intensive Care Audit Network · Data Collection Form **Admission**

Patient details (or hospital label)

Family name

First name

Address

Postcode

NHS/CHI/H&C number
☐ Tick if patient is not eligible for number

Case note number

Date of birth (dd/mm/yyyy)

Indicate if date of birth is
☐ Estimated ☐ Anonymised ☐ Unknown

Sex
☐ Male ☐ Female ☐ Ambiguous ☐ Unknown

Ethnic category
☐ White British
☐ White Irish
☐ White other (specify below)
☐ Mixed White and Black Caribbean
☐ Mixed White and Black African
☐ Mixed White and Asian
☐ Mixed other (specify below)
☐ Asian Indian
☐ Asian Pakistani

☐ Asian Bangladeshi
☐ Asian other (specify below)
☐ Black Caribbean
☐ Black African
☐ Black other (specify below)
☐ Chinese
☐ Other (specify below)
☐ Not stated (declined)
☐ Unknown

Other ethnic category

Gestational age at delivery (if patient is under 2 years old)
_____ weeks

Birth order   **Multiplicity**
_____ of _____

Admission details

Date and time of admission to unit (dd/mm/yyyy)
__ __ / __ __ / 2 0 __ __   __ __ : __ __

Admission number

Type of admission to unit
☐ Planned – following surgery
☐ Unplanned – following surgery
☐ Planned – other
☐ Unplanned – other

Previous ICU admission (during current hospital stay)
☐ ICU
☐ PICU
☐ NICU
☐ None
☐ Unknown

Source of admission
☐ Same hospital ☐ Clinic
☐ Other hospital ☐ Home

Care area admitted from (includes transfers in)
☐ X-ray / endoscopy / CT scanner ☐ ICU / PICU / NICU
☐ Recovery only ☐ Ward
☐ HDU (step up/step down unit) ☐ Theatre and recovery
☐ Other intermediate care area ☐ A & E

Retrieval / transfer?
☐ Yes ☐ No

Type of transport team
☐ PICU ☐ Other specialist team
☐ Centralised transport service (PIC) ☐ Non-specialist team
☐ Transport team from neonates ☐ Unknown

Transport team

Collection unit

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PIM

This applies to observations recorded between the first face-to-face contact with ICU doctor until one hour after admission. Always use the first recorded measurement during this time period.

Elective admission

☐ Tick if this is an elective admission

Main reason for PICU admission

☐ Asthma

☐ Bronchiolitis

☐ Croup

☐ Obstructive sleep apnoea

☐ Recovery from surgery → ☐ Bypass cardiac procedure
☐ Non-bypass cardiac procedure
☐ Elective liver transplant
☐ Other procedure

☐ Diabetic ketoacidosis

☐ Seizure disorder

☐ Other (none of the above)

Is evidence available to assess past medical history?

☐ Yes   ☐ No

If yes, tick all that apply

☐ Cardiac arrest before ICU admission
  └→ ☐ Cardiac arrest OUT of hospital

☐ Cardiomyopathy or myocarditis

☐ Severe combined immune deficiency

☐ Hypoplastic left heart syndrome

☐ Leukaemia or lymphoma after first induction

☐ Liver failure main reason for ICU admission

☐ Acute NEC main reason for ICU admission

☐ Spontaneous cerebral haemorrhage

☐ Neurodegenerative disorder

☐ Human Immunodeficiency Virus (HIV)

☐ Bone marrow transplant recipient

Systolic blood pressure

☐☐☐ mmHg

SpO_2 (via pulse oximetry)   **FiO_2 (at the time SpO_2 measured)**

☐☐☐ % → ☐.☐☐

Blood gas measured?

☐ Yes   ☐ No

Arterial PaO_2   **Arterial PaO_2**

☐☐.☐☐ kPa   OR   ☐☐☐ mmHg

FiO_2

☐.☐☐

Intubation?

☐ Yes   ☐ No   *At the time of arterial PaO_2 sample*

Headbox?

☐ Yes   ☐ No

Base excess *(specify source)*

☐☐☐.☐ mmol/l → ☐ Arterial
☐ Capillary
☐ Venous

Lactate *(specify source)*

☐☐.☐☐ mmol/l → ☐ Arterial
☐ Capillary
☐ Venous

Mechanical ventilation?

☐ Yes   ☐ No

CPAP?

☐ Yes   ☐ No

Pupil reaction

☐ Both fixed and dilated

☐ Other reaction

☐ Unknown

Diagnoses and procedures

Primary diagnosis for this admission

_____

Other reasons for this admission

_____
_____
_____

Operations and procedures performed during and prior to this admission

_____
_____
_____

Co-morbidity

_____
_____
_____

Was a tracheostomy performed during this admission?

☐ Yes   ☐ No

Daily interventions

Please record all interventions given on each day of admission using a cross ☒ unless otherwise specified.
If no interventions given, select **No defined critical care activity**.

Admission date: _____

		Day	0	1	2	3	4	5	6	7	8	9	10	11	12	13
Basic	No defined critical care activity	Code 99														
	Continuous ECG monitoring	50														
	Continuous pulse oximetry	73														
Airway and ventilatory	Invasive ventilation via endotracheal tube	51														
	Invasive ventilation via tracheostomy tube	52														
	Non-invasive ventilatory support	53														
	Advanced ventilatory support (jet ventilation)	56														
	Advanced ventilatory support (oscillatory ventilation)	56														
	Nasopharyngeal airway	55														
	Tracheostomy cared for by nursing staff	13														
	Supplemental oxygen therapy (irrespective of ventilatory state)	09														
	High flow nasal cannula therapy (record maximum daily flow in l/min)	88														
	Upper airway obstruction requiring nebulised adrenaline (epinephrine)	57														
	Apnoea requiring intervention (>3 in 24 hours or need for bag-mask ventilation)	58														
	Acute severe asthma requiring IV bronchodilator therapy or continuous nebuliser	59														
	Unplanned extubation (record number of unplanned extubations)	90														
Cardio-vascular	Arterial line monitoring	60														
	External pacing	61														
	Central venous pressure monitoring	62														
	Continuous infusion of inotrope, vasodilator or prostaglandin	06														
	Bolus IV fluids (>80 ml/kg/day) in addition to maintenance IV fluids	63														
	Cardio-pulmonary resuscitation	64														
	Extracorporeal membrane oxygenation (ECMO)	65														
	Ventricular assist device (VAD)	65														
	Aortic balloon pump	65														
	Arrhythmia requiring intravenous anti-arrhythmic therapy	94														
Renal	Peritoneal dialysis	05														
	Haemofiltration	16														
	Haemodialysis	66														
	Plasma filtration	67														
	Plasma exchange	67														
Neuro-logical	ICP-intracranial pressure monitoring	68														
	Intraventricular catheter or external ventricular drain	69														
	Status epilepticus requiring treatment with continuous infusion of anti-epileptic drugs	97														
	Reduced conscious level (GCS ≤ 12) AND hourly (or more frequent) GCS monitoring	95														
Analgesia/ sedation	Epidural catheter in situ	85														
	Continuous intravenous infusion of a sedative agent	96														
Metabolic	Diabetic ketoacidosis (DKA) requiring continuous infusion of insulin	70														
Other	Exchange transfusion	04														
	Intravenous thrombolysis	71														
	Extracorporeal liver support using molecular absorbent recirculating system (MARS)	72														
	Patient nursed in single occupancy cubicle (state reason for isolation below)	74														
High cost drugs	Medical gases Band 1 - nitric oxide	X841														
	Surfactant	X842														

Reason for isolation (if patient nursed in single occupancy cubicle)

_____

Clinical trial (if required by your unit)

Is the patient on a clinical trial?
☐ Yes (specify name of trial) ☐ No

Name of trial

[　　　　　　　　　　　　　　　　　　　]

Growth measurements (if required by your unit)

Height
[　][　][　] . [　] cm

Weight
[　][　][　] . [　][　][　] kg

Abdominal circumference
[　][　][　] . [　] cm

Discharge information

Status at discharge from your unit
☐ Alive ☐ Dead

Date and time of discharge (dd/mm/yyyy hh:mm)
[　][　] / [　][　] / 2 0 [　][　] [　][　] : [　][　]

┌ If alive at discharge

Discharged for palliative care?
☐ Yes ☐ No

Destination following discharge from your unit
☐ Normal residence ☐ Same hospital ⎤   ☐ ICU
☐ Hospice   ☐ Other hospital ⎦ →   ☐ PICU
                                            ☐ NICU
                                            ☐ HDU
                                            ☐ SCBU
                                            ☐ Ward
                                            ☐ Other

┌ If dead at discharge

Date and time of death (dd/mm/yyyy hh:mm)
[　][　] / [　][　] / 2 0 [　][　] [　][　] : [　][　]

Mode of death
☐ Treatment withdrawn
☐ Treatment limitation
☐ Brain stem death
☐ Failed cardiopulmonary resuscitation

Transplant donor?
☐ No
☐ Yes – solid organs only
☐ Yes – tissues only
☐ Yes – both solid organs and tissues

Follow-up 30 days post-discharge from your unit

Status
☐ Alive ☐ Dead ☐ Unknown

Date of death (dd/mm/yyyy)
[　][　] / [　][　] / 2 0 [　][　]

Location
☐ Normal residence ☐ Same hospital ⎤   ☐ ICU
☐ Hospice   ☐ Other hospital ⎦ →   ☐ PICU
                                            ☐ NICU
                                            ☐ HDU
                                            ☐ SCBU
                                            ☐ Ward
                                            ☐ Other

Comments

Customised data collection (for local use)

Form completed by

Data Collection Form in use 2022 – Referral

PICANet · Paediatric Intensive Care Audit Network · Data Collection Form   **Referral**

Please complete this form for all requests for **transport within the PIC service** and/or a **PICU admission** when clinicians agree that the patient requires PIC transport and/or a PICU bed

Patient details *(or hospital label)*

Family name

First name

Postcode

NHS/CHI/H&C number

☐ Tick if patient is not eligible for number

Date of birth *(dd/mm/yyyy)*

[ ] / [ ] / [   ]

Indicate if date of birth is
☐ Estimated   ☐ Anonymised   ☐ Unknown

Sex
☐ Male   ☐ Female   ☐ Ambiguous   ☐ Unknown

Referral details *(complete only when clinicians agree that the patient requires PIC transport and/or a PICU bed)*

Date and time when clinicians agreed that the patient required PIC transport and/or a PICU bed

[ ] / [ ] / 2 0 [ ]   [ ] : [ ]

Referral number

Referring unit *(from where the patient was transferred)*

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

Referring speciality

Grade of referring doctor or nurse
☐ Consultant / Associate Specialist / Staff Grade
☐ ST 4 – 8
☐ ST 1 – 3
☐ F1 / F2
☐ GP
☐ Nurse practitioner
☐ Nurse
☐ Unknown

Was the patient receiving invasive ventilation (by ET tube, laryngeal mask or tracheostomy) at time of referral call?
☐ Yes
☐ No – not indicated
☐ No – advised to intubate
☐ Unknown

Outcome of this referral event
*Record the outcomes for **both** transport and admission; if either not requested of your organisation, tick "not requested"*

Transport outcome
☐ Accepted for PIC transport
☐ Refused – no transport team available
☐ Refused – time critical transfer
☐ Refused – out of scope of care
☐ PIC transport not requested

Admission outcome
☐ Accepted for PICU admission
☐ Refused – no staffed bed available
☐ Refused – out of scope of care
☐ PICU admission not requested

Transport team

Destination unit *(or location)*

If transport and/or admission outcome is refused, record the name of the transport team and/or destination unit who refused this referral.

Comments

Form completed by

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Data Collection Form in use 2022 – Transport

PICANet · Paediatric Intensive Care Audit Network · Data Collection Form **Transport**

Patient details *(or hospital label)*

Family name

First name

Address

Postcode

NHS/CHI/H&C number

☐ Tick if patient is not eligible for number

Case note number *(destination PICU)*

Date of birth *(dd/mm/yyyy)*

Indicate if date of birth is
☐ Estimated   ☐ Anonymised   ☐ Unknown

Sex
☐ Male   ☐ Female   ☐ Ambiguous   ☐ Unknown

Transport details

Date and time accepted for transport

/ / 2 0 :

Transport number

Type of transport team
☐ PICU
☐ Centralised transport service (PIC)
☐ Transport team from neonates
☐ Other specialist team
☐ Non-specialist team

Transport team

Grade of clinical team leader
☐ Consultant/Associate Specialist/Staff Grade
☐ ST 4 – 8
☐ ST 1 – 3
☐ Nurse practitioner

Speciality of clinical team leader

Grade of most senior nurse
☐ 5   ☐ 6   ☐ 7   ☐ 8
☐ Nurse not present

Collection area
☐ X-ray/endoscopy/CT scanner   ☐ ICU
☐ Recovery only   ☐ PICU
☐ HDU (step up/step down unit)   ☐ NICU
☐ Other intermediate care area   ☐ Ward
☐ Theatre and recovery   ☐ A & E
☐ Other transport service

Collection unit *(or location)*

Most senior member of medical staff present at collection unit
☐ Consultant/Associate Specialist/Staff Grade
☐ ST 4 – 8
☐ ST 1 – 3
☐ None

Did a medical technician accompany the patient?
☐ Yes   ☐ No

Did a parent accompany the patient?
☐ Yes
☐ No – parent not present
☐ No – parent declined to accompany
☐ No – parent not permitted to accompany

Transport classification
☐ Planned
☐ Unplanned

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

Destination type
☐ PICU
☐ NICU
☐ ICU
☐ HDU
☐ Ward
☐ Theatre
☐ Other transport service
☐ Normal residence
☐ Hospice

Destination unit *(or location)*

Critical incidents

Identify all critical incidents while transport team in attendance *(tick all that apply)*
☐ No critical incidents
☐ Accidental extubation
☐ Required intubation in transit
☐ Complete ventilator failure
☐ Loss of medical gas supply
☐ Loss of all IV access
☐ Cardiac arrest
☐ Medication administration error
☐ Equipment failure or incompatibility impacting on patient care
☐ Other critical incident *(specify)*

Comments

Form completed by

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Transport times

BASE TO COLLECTION UNIT	PATIENT JOURNEY	DESTINATION UNIT TO BASE
☐ Tick if this section of the trip is not applicable	☐ Tick if this section of the trip is not applicable	☐ Tick if this section of the trip is not applicable

Mode of transport *(tick all that apply)*
☐ Dedicated ambulance ☐ RRV ☐ Taxi
☐ Other ambulance ☐ Air ✈ ☐ Other

Depart base *(dd/mm/yyyy hh:mm)*
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Arrive base airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Aircraft type**
☐ Unpressurised fixed-wing ☐ Dedicated helicopter
☐ Pressurised fixed-wing ☐ Other helicopter

→ **Takeoff base airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Land collection airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Depart collection airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Arrive collection unit *(or location)*
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Blue light or siren used or requested?
☐ Yes ☐ No

Organisational delay
☐ None ☐ Team out ☐ Staffing ☐ Vehicle

Vehicle incident
☐ None ☐ Vehicle accident ☐ Vehicle breakdown

Mode of transport *(tick all that apply)*
☐ Dedicated ambulance ☐ RRV ☐ Taxi
☐ Other ambulance ☐ Air ✈ ☐ Other

Depart collection unit *(or location)*
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Arrive collection airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Aircraft type**
☐ Unpressurised fixed-wing ☐ Dedicated helicopter
☐ Pressurised fixed-wing ☐ Other helicopter

→ **Takeoff collection airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Land destination airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Depart destination airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Arrive destination unit *(or location)*
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Blue light or siren used or requested?
☐ Yes ☐ No

Organisational delay
☐ None ☐ Team out ☐ Staffing ☐ Vehicle

Vehicle incident
☐ None ☐ Vehicle accident ☐ Vehicle breakdown

Mode of transport *(tick all that apply)*
☐ Dedicated ambulance ☐ RRV ☐ Taxi
☐ Other ambulance ☐ Air ✈ ☐ Other

Depart destination unit *(or location)*
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Arrive destination airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Aircraft type**
☐ Unpressurised fixed-wing ☐ Dedicated helicopter
☐ Pressurised fixed-wing ☐ Other helicopter

→ **Takeoff destination airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Land base airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

→ **Depart base airport**
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Arrive base
☐☐/☐☐/2 0☐☐ ☐☐:☐☐

Blue light or siren used or requested?
☐ Yes ☐ No

Organisational delay
☐ None ☐ Team busy ☐ Staffing ☐ Vehicle

Vehicle incident
☐ None ☐ Vehicle accident ☐ Vehicle breakdown

Interventions *(retrievals only)*

Interventions by local team prior to arrival of transport team *(tick all that apply)*
☐ Primary intubation
☐ Re-intubation
☐ Other airway
☐ Non-invasive ventilation
☐ High flow nasal cannula therapy
☐ Primary central venous access
☐ Additional central venous access
☐ Arterial access
☐ Inotrope or vasopressor infusion
☐ Prostaglandin infusion
☐ Primary intraosseus access
☐ Additional intraosseus access
☐ Chest drain insertion
☐ ICP monitoring
☐ ECMO

Interventions while transport team in attendance *(tick all that apply)*
☐ Primary intubation
☐ Re-intubation
☐ Other airway
☐ Non-invasive ventilation
☐ High flow nasal cannula therapy
☐ Primary central venous access
☐ Additional central venous access
☐ Arterial access
☐ Inotrope or vasopressor infusion
☐ Prostaglandin infusion
☐ Primary intraosseus access
☐ Additional intraosseus access
☐ Chest drain insertion
☐ ICP monitoring
☐ ECMO

PIM *(retrievals only)*

This applies to observations recorded in the first hour after first face-to-face contact with transport team doctor

Elective admission
☐ Tick if this is an elective admission

Main reason for admission
☐ Asthma
☐ Bronchiolitis
☐ Croup
☐ Obstructive sleep apnoea
☐ Recovery from surgery →
☐ Diabetic ketoacidosis
☐ Seizure disorder
☐ Other (none of the above)

☐ Bypass cardiac proc.
☐ Non-bypass cardiac proc.
☐ Elective liver transpl't
☐ Other procedure

Is evidence available to assess past medical history?
☐ Yes ☐ No

If yes, tick all that apply
☐ Cardiac arrest before admission
→ ☐ Cardiac arrest OUT of hospital
☐ Cardiomyopathy or myocarditis
☐ Severe combined immune deficiency
☐ Hypoplastic left heart syndrome
☐ Leukaemia or lymphoma after first induction
☐ Liver failure main reason for ICU admission
☐ Acute NEC main reason for ICU admission
☐ Spontaneous cerebral haemorrhage
☐ Neurodegenerative disorder
☐ Human Immunodeficiency Virus (HIV)
☐ Bone marrow transplant recipient

Systolic blood pressure
☐☐☐ mmHg *(at time SpO_2 measured)*

SpO_2 ☐☐☐ % → FiO_2 ☐.☐☐

Blood gas measured?
☐ Yes ☐ No

Arterial PaO_2 ☐☐.☐ kPa   or **Arterial PaO_2** ☐☐☐ mmHg

FiO_2 ☐.☐☐

Intubation?
☐ Yes ☐ No

Headbox?
☐ Yes ☐ No
At the time of PaO_2 sample

Base excess
☐☐☐.☐ mmol/l → ☐ Arterial ☐ Capillary ☐ Venous

Lactate
☐☐.☐ mmol/l → ☐ Arterial ☐ Capillary ☐ Venous

Mechanical ventilation?
☐ Yes ☐ No

CPAP?
☐ Yes ☐ No

Pupil reaction
☐ Both fixed and dilated
☐ Other reaction
☐ Unknown

PICANet Information Leaflets for Families and Carers 2022

The leaflet below (v7.0 Jul 2022) was in place at the last date of the reporting period (31 December 2022) for those in England.

What does PICANet do?

PICANet is a project helping to continually improve how we treat and care for very sick children in paediatric critical care (PCC).

PCC units collect information during your child's admission. We use this information to find out the best treatment and care for children. This will enable organisations to plan and continue to provide high quality services in the future.

How is PICANet funded?

Funding is provided by the National Clinical Audit & Patient Outcomes Programme administered by the Healthcare Quality Improvement Partnership (HQIP) for England, Welsh Health Specialised Services Committee, NHS Lothian – University Hospitals Division, The Royal Belfast Hospital for Sick Children, National Office of Clinical Audit Ireland (NOCA), and HCA International.

How is information collected?

A member of staff records information about your child's condition or illness from their medical notes which is then sent to the PICANet database.

What information is collected?

Personal details, like name and date of birth, help us to follow your child's critical care journey and treatment including admission to other PCC units. We can use your postcode to help plan future PCC services in a geographical area.

Will the information be safe?

We send and receive all information in a very safe way and the University of Leeds store this confidential information in a secure electronic environment. No-one can see the information, unless it is their job to do so. For further information please see the PICANet

Privacy and Fair Processing Statement on the PICANet website www.picanet.org.uk.

What are the benefits of collecting data?

PICANet's international data collection ensures a UK and Ireland-wide overview of paediatric critical care as well as national and local views, including critical care referral and transport services. During the past few years, we have shown that over 19,000 children are admitted to the PICUs in the United Kingdom and Ireland each year and there are over 5,000 transports to PICU annually.

As well as writing reports and informing planning of children's critical care for the future, PICANet supports quality improvement at national levels by providing data and specialist input into reports and reviews. PICANet can monitor the impact of the COVID-19 pandemic nationally. PICANet is able to report on patient characteristics, treatment, and outcomes of confirmed COVID-19 cases.

On a more local level, each PCC can review their own data collected within PICANet. Regular reports to each unit by PICANet allows identification of potential risk factors. This allows each unit to minimise complications and drive improvements in clinical practice to reduce mortality and physiological impact.

Does my child have to be included in the clinical audit database?

Yes. You don't need to do anything for your child to be included. The National Data Opt-Out is not applied to clinical audit data received from English paediatric critical care services. This is because the absence of even one child's data can lead to inaccurate conclusions.

Does my child have to be included in the research database?

No. PICANet applies the National Data Opt-Out to the research database for data received from English hospitals. Therefore, you do not need to contact PICANet if you have set a National Data Opt-Out. This will mean that your child's data will not be included in any approved research projects.

If you have NOT set a National Data Opt-Out BUT do not want any of the data about your child to be used for approved research purposes please contact PICANet.

Can I opt out of my child's personally identifiable information being included in PICANet?

Yes. If you do not want information included which identifies your child, please tell the nurse or doctor caring for your child or contact PICANet (details provided overleaf). Your child's anonymised information will remain in the PICANet database for audit (non-research) and approved research purposes.

You are free to withdraw your child's personal identifiers or all data from the research database at any time. Any decision will not alter the care your child receives in this or any other hospital.

For more information please see the PICANet clinical audit and research database opt out policy on our website.

The leaflet below (v6.4 Apr 2021) was in place at the last date of the reporting period (31 December 2022) for those in Wales, Scotland and Northern Ireland.

HQIP
Healthcare Quality
Improvement Partnership

PICANet

**Paediatric Intensive Care
Audit Network**

If you would like to know
more about PICANet you can:

Talk to the **Doctors and Nurses**

Email **picanet@leeds.ac.uk**

Visit our website at
www.picanet.org.uk

Or

Call our **Research Nurse,** Lyn Palmer,
on

0116 252 5475

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre for Medicine
University of Leicester
University Road
Leicester,
LE1 7RH

Principal investigators:

Professor Elizabeth Draper
PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre for Medicine
University of Leicester
University Road
Leicester, LE1 7RH

0116 252 5468

Dr Richard Feltbower
PICANet
School of Medicine
University of Leeds
LIDA, Worsley Building
Leeds, LS2 9JT

0113 343 4841

www.picanet.org.uk

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Information Leaflet for families and
carers of children admitted to
paediatric intensive care.

What does PICANet do?

PICANet collects information on all children who are admitted to a paediatric (childrens) intensive care service. You don't need to do anything for your child to be included.

Why is PICANet important?

The information that we collect for PICANet is helping to find out the best ways to treat and care for children who are very ill, so that intensive care services can be better planned for and provided in the future.

How is PICANet funded?

Funding is provided by the National Clinical Audit & Patient Outcomes Programme administered by the Healthcare Quality Improvement Partnership (HQIP) for England, Welsh Health Specialised Services Committee, NHS Lothian – University Hospitals Division, The Royal Belfast Hospital for Sick Children, National Office of Clinical Audit Ireland (NOCA) and HCA International.

How is information collected?

A member of staff records details about your child's condition or illness from information in their medical notes. This information is then entered onto a computer, sent to the University of Leeds and kept securely there on a computer.

What information is needed?

PICANet collects exactly the same information on all children cared for in paediatric intensive care units and by the specialist paediatric intensive care transport services.
Personal details, like name and date of birth, help us to follow your child's progress if they are moved to another paediatric intensive care unit. Information about your child's care, treatment and condition is also collected. We can use your postcode to help plan future paediatric intensive care services in your area.

What will the information be used for?

We use the information to help us write reports and to decide what further information on childrens intensive care is needed to help hospitals plan for the future. Because we collect a lot of information, it means that we can look at what is happening all over the country and not just in this hospital.
We have also linked up with the other databases; so that we can see how your child's health is after they have left the intensive care unit.

Will the information be safe?

We send all information in a very safe way and keep it stored confidentially on a main computer, which is kept in a secure room. No-one can see the information, unless it is their job to do so.
There is no way at all that your child can be identified in any of our reports.

Please see the PICANet Privacy and Fair Processing statement available on our Policies page of the PICANet website- www.picanet.org.uk.

What have we found out so far?

During the past few years, we have shown that over 19,000 children are admitted to the paediatric intensive care service in the United Kingdom and Ireland each year. Almost half of these children are less than one year old.
This type of information is useful, because it helps the hospitals and the people who plan health services to know what to expect and to be better prepared.

Does my child have to be included?

If you do not want information which would identify your child included in PICANet, please tell the nurse or doctor caring for your child. Alternatively, please contact PICANet by telephone or email (details provided overleaf) and we will ensure that your child's personal data is removed from the database. You are free to withdraw at any time and any decision to withdraw will not alter the care your child receive in this or any other hospital.

PICANet Information Leaflet for Children 2022

The leaflet below (v7.0 Jul 2022) was in place at the last date of the reporting period (31 December 2022) for those in England.

If you would like to know more about PICANet you can:

Talk to the **doctors and nurses**

Or

Email **picanet@leeds.ac.uk**
Call **0113 343 8125**

Visit our website at
www.picanet.org.uk

Or

Call our **Research Nurse,** Dr Lyn Palmer, on

0116 252 5414

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre
University of Leicester
University Road
Leicester
LE1 7RH

Principal investigators:

Professor Elizabeth Draper
PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre
University of Leicester
University Road
Leicester, LE1 7RH

Professor Richard Feltbower
PICANet
School of Medicine
University of Leeds
LIDA, Worsley Building
Leeds, LS2 9JT

www.picanet.org.uk

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PICA Net

Paediatric Intensive Care
Audit Network

Information leaflet for children
admitted to paediatric critical care

What is a paediatric critical care unit?

This is a children's hospital ward where very poorly children are looked after by lots of special doctors and nurses who work together to help every child. It can also be called a children's intensive or critical care unit.

What is PICANet?

PICANet is a project which collects lots of information about how children are looked after in children's critical care units in England, Wales, Scotland, Northern Ireland, and the Republic of Ireland. We also collect information if you are moved to another children's critical care unit.

Why is PICANet important?
We need this information so that we can try and help to improve the care of all children who are looked after in children's critical care.

How is information collected?

Doctors and nurses put information from your hospital notes onto a computer in the hospital and send it to the University of Leeds, who keep it safe.

What information is collected?

PICANet collects the same information on all children who are looked after in children's critical care. Information about you, such as your name, birthday, and hospital number, helps us to follow your journey through children's critical care. We also collect information about why you are in hospital and how you are looked after.

What will my information be used for?

PICANet collects information from all the children's critical care units. We get information on a lot of children, over 19,000 each year. This means that we can look at what is happening across the whole country and not just in this hospital.

The information is used to write reports which help doctors and nurses to decide the best way to look after children who need critical care. No-one will be able to tell that your details are in the report, because we do not use any names or details that could identify you.

Will my information be safe?

All information is kept in a very safe way on a secure computer. No-one can see the information, unless it is their job to look.

Please see the PICANet Privacy and Fair Processing statement available on our website www.picanet.org.uk for more information.

Do I have to be included?

The National Data Opt-Out Policy (in England) allows you to stop the sharing of information from your hospital notes. This does not apply to PICANet data because this information is used to find out the best way to look after very poorly children.

However, if you do not want information that would identify you included in PICANet, please tell the nurse or doctor caring for you or contact PICANet by email (details are on the other side of this leaflet). We will ensure that this information is taken off the database.

If you do not want any of your data to be used for approved research projects please contact PICANet. You do not need to contact us if you have set a National-Data Opt-Out (in England). PICANet does apply the National Data Opt-Out to data used for research.

You are free to do this at any time and it will not change the care you receive in any hospital.

The leaflet below (v6.4 Apr 2021) was in place at the last date of the reporting period (31 December 2022) for those in Wales, Scotland and Northern Ireland.

If you would like to know more about PICANet you can:

Talk to your **nurse or doctor**

Send us an email us at
picanet@leeds.ac.uk

Visit our website at
www.picanet.org.uk

Or

Call our **Research Nurse,**
Lyn Palmer on

0116 252 5475

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

**PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre for Medicine
University of Leicester
University Road
Leicester, LE1 7RH**

HQIP
Healthcare Quality
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Principal investigators:

Professor Elizabeth Draper
PICANet
Department of Health Sciences
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George Davies Centre for Medicine
University of Leicester
University Road
Leicester, LE1 7RH

0116 252 5468

Dr Richard Feltbower
PICANet
School of Medicine
University of Leeds
LIDA, Worsley Building
Leeds, LS2 9JT

0113 343 4841

www.picanet.org.uk

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PICA Net

Paediatric Intensive Care Audit Network

Information leaflet for children admitted to paediatric intensive care.

What is a paediatric intensive care unit?

This is a children's hospital ward where very poorly children are looked after by lots of special doctors and nurses who work together to help every child. It can also be called a children's intensive care unit.

What is PICANet?

PICANet is a project, paid for by the Government and hospitals, run by the Universities of Leeds and Leicester.

What does PICANet do?

PICANet collects lots of information about how children are looked after in children's intensive care units in England, Wales, Scotland, Northern Ireland and the Republic of Ireland. We also collect information if you are moved to a different children's intensive care unit.

Why is PICANet important?

We need this information, so that we can try and help to improve the care of all children who are looked after in children's intensive care.

What information is needed?

Information about you, such as your name, your birthday and your hospital number, helps us to follow your progress whilst you are being looked after in children's intensive care. We also collect information about why you are in hospital and how you are looked after.

How is information collected?

Doctc   and nurses put information from your hospital notes onto a computer in the hospital and send it to the University of Leeds, where it is kept on a main computer. PICANet collects the same information on all children who are looked after in children's intensive care. We get information on a lot of children, over 19,000 each year. This means that we can look at what is happening across the whole country and not just in your hospital.

What happens to my information?

The information is used to write reports which help doctors and nurses to decide the best way to look after children who need intensive care. No-one will be able to tell that your details are in the report, because we do not use any names or details that could identify you.

Will the information be safe?

All information is kept in a safe room on a computer. No-one can see the information, unless it is their job to look. Please see the PICANet Privacy and Fair Processing statement available on our Policies page of the PICANet website- www.picanet.org.uk

Do I have to be included?

If you do not want information that would identify you included in PICANet, please tell the nurse or doctor caring for you. If you want, you can contact PICANet by telephone or email (details provided below) and we will ensure that your personal data is taken off the database. You are free to withdraw at any time and any decision to withdraw will not alter the care you receive in this or any other hospital.

The Families and Carers and Children's information leaflets were/are also available in Welsh and for patients and families in the Republic of Ireland. The leaflets above are those in place at the latest date of the reporting period – 31st December 2021.

PICANet Privacy and Fair Processing Statement

The Statement below (v5.0 29 Jul 2022) was in place at the latest date of the reporting period – 31 December 2022.

PICANet Patient Privacy Notice and Fair Processing Statement

Paediatric Intensive Care Audit Network (PICANet) is an international database of paediatric intensive care in the United Kingdom and Republic of Ireland run by the University of Leeds and the University of Leicester.

This statement explains how we use any personal information we collect about you (child / young person) or the child you care for.

Contents

What data are being collected?

PICANet collects data on every child and young person referred or admitted to a Paediatric Intensive Care Unit (PICU) in the UK and the Republic of Ireland. The data are sent to us over a very secure web application by each PICU or specialist transport team on a regular basis. Data are collected for each individual for the whole period of their PICU stay and also about what happened to them if they had a critical care transport (this means that a specialist team of nurses and doctors travelled in an ambulance to pick them up and take them to a PICU).

What are the data being used for?

We collect this data for clinical audit, research, and service evaluation and planning to improve the care given to children and young people admitted to PICU. Each year we produce a report on activity and outcomes for paediatric intensive care in the UK and Ireland. No personal or identifiable information will ever be made public in any report or publication.

The PICANet research database supports high quality research in the areas of paediatric intensive care, specific conditions affecting children and young people accessing paediatric intensive care services, epidemiology of critical illness, and public health. Following a rigorous data request process, and providing the appropriate research ethics approvals and legal bases for data processing and sharing are in place, baseline data can be provided for research studies and clinical trials to extend the available knowledge with a view to ultimately providing benefits to patients.

Our legal basis for processing the data

PICANet has permission to collect personal data including identifiers and special category data of children and young people admitted to or referred for Paediatric Intensive Care without taking explicit (written) consent from the children or their carers. The personal identifiers include name, address, date of birth, and health record identifier number (e.g. NHS number)*. Special category data include ethnicity and data concerning health.

* We do not receive name, address or health record identifier number for data from Northern Ireland or the Republic of Ireland.

Throughout the UK, the disclosure of confidential information is lawful under the Common Law Duty of Confidentiality. This is because the work of ensuring high standards of quality and safety of healthcare is in the public interest. Our lawful basis for processing personal data is Public Task as set out in Article 6 of the General Data Protection Regulation (GDPR):
- Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

The Data Protection Act 2018 legal basis is, Schedule 1(1)(3) 'public health' underpinned by Health and Social Care Act 2021 Part 1 section 2.

PICANet has the following support to process confidential patient information without consent for both non-research and research purposes under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support' of the NHS Act 2006) for data collected in England and Wales:

- The clinical audit activity falls within the management of health and social care services in the public interest. Therefore, the Health Research Authority and The Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group, an advisory body which provides independent expert advice on the use of confidential patient information without consent in England and Wales, has provided support for PICANet to process confidential patient information without consent for non-research purposes.

- The medical research database is approved by a research ethics committee and contributes to medical research in the public interest. Therefore, the Health Research Authority, on advice from the Confidentiality Advisory Group, has provided support regarding research purposes.

Summaries of the approved non-research and research applications for PICANet are available on the register of approvals on the HRA website. The references are: 21/CAG/0090 (non-research) and 21/CAG/0098 (research).

For the participating organisations in Scotland, local and Caldicott approvals are in place and PICANet await approval from the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (NHS HSC-PBPP).

A Data Access Agreement for personal identifiable data is in place between PICANet and Belfast Health and Social Care Trust for data from organisations in Northern Ireland.

Participating organisations in the Republic of Ireland send data PICANet without identifiers which does not require legal basis under the Common Law Duty of Confidentiality.

The legal basis set out in GDPR for processing special categories of personal data is:
- Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.

For the research database, the legal basis set out in GDPR is:
- Article 9 (2) (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

Where are the data held and for how long?

All of the data is held at the University of Leeds in a highly secure environment. As we are an audit, we keep this data permanently so we can check on what has happened in the past. We do remove personal identifiers from our data base once an individual is older than 18 years and has not been in PICU for the last five years.

Sharing data with other organisations

PICANet may share data held on its database with researchers, other audits, or other healthcare providers in order to help improve patient care. We will NOT share personal identifiers (such as name, address, date of birth or NHS number) with anyone else unless the appropriate legal, ethical, and security arrangements are in place to keep your personal details safe and secure. Very occasionally, personal data may be processed by an authorised third party such as NHS Digital, but again, only with the necessary regulatory permissions. They have very high levels of security and will keep these data very safe.

We have a rigorous process of assessing the merit of requests for data and information and publish details of these requests each year in our Annual Report. Data collected in English NHS paediatric intensive care units and specialist transport teams are controlled by the Healthcare Quality Improvement Partnership (HQIP) and all requests go through their Data Access Request Group. More details about the HQIP data request process can be found at: https://www.hqip.org.uk/national-programmes/accessing-ncapop-data/.

How to request that your/your child's personally identifiable information are removed from the PICANet database

If you do not want information which could identify you or your child included in PICANet, please tell the nurse or doctor caring for your child. They will make sure your child's personally identifiable information are removed before being sent to PICANet.

Any decision will not alter the care your child receives in this or any other hospital.

If you have left hospital and decide that you do not want information which could identify you/your child included in PICANet, please call us directly at PICANet on 0113 3438125 or email picanet@leeds.ac.uk.

PICANet will remove the identifiable information within 25 working days of your request and let you know once this has been done.

Please note that your anonymised information will remain in the PICANet database for audit (non-research) and approved research purposes.
You do have the right to request access to and to request to rectify information held about you or the child you care for.

Does the National Data Opt-Out in England apply to PICANet?

Clinical audit data

The National Data Opt Out is not applied to PICANet clinical audit data received from English paediatric critical care services. PICANet have received permission from the Heath Research Authority Confidentiality Advisory Group for England and Wales not to apply the National Data Opt-Out. This application was made as an amendment to our existing approval 21/CAG/0090. Permission was granted because the absence of even one child's data can lead to inaccurate conclusions.

Research data

PICANet applies the National Data Opt-Out to the research database for data received from English hospitals. This means that, where a National Data Opt-Out has been set/ applied, data will not be included in any approved research projects.

Please note that Data collected from Level 2 Paediatric Critical Care units are not included in research and therefore this and the following section do not apply.

How to opt out of the PICANet research database

If you have not set a National Data Opt-Out and you are considering opting out of the PICANet research dataset please see the PICANet clinical audit and research database opt out policy available on our website (www.picanet.org.uk/) for full details.

You are free to withdraw your/your child's data from the research database at any time. Any decision will not alter the care your child receives in this or any other hospital.

Who is responsible for the data?

NHS England is joint Data Controller with Healthcare Quality Improvement Partnership for data collected in English NHS PICUs and transport teams.

Healthcare Quality Improvement Partnership
Healthcare Quality Improvement Partnership Ltd.
27A Harley Place
London W1G 8LZ
(Charity Reg No. 1127049)

Data Protection Officer: Sasha Hewitt (E: data.protection@hqip.org.uk)
Data controller registration number provided by the Information Commissioner's Office: Z1780946

The NHS Commissioning Board (NHS England)
NHS England London
Skipton House
80 London Road
London
SE1 6LH

Data Protection Officer: Carol Mitchell (E: england.dpo@nhs.net)
Data controller registration number provided by the Information Commissioner's Office: Z2950066

The University of Leeds and the University of Leicester are joint data processors for the data collected in English NHS PICUs and transport teams.

The joint Data Controllers and Data Processors for data collected in all private PICUs and PICUs and transport teams in Scotland, Wales, Northern Ireland and the Republic of Ireland are:

University of Leeds
Leeds
LS2 9JT
Data Protection Officer: Alice Temple
T: +44(0) 113 34 37641
E: a.c.temple@leeds.ac.uk

Data controller registration number provided by the Information Commissioner's Office: Z553814X

University of Leicester
University Road
Leicester, LE1 7RH
Data Protection Officer: Parmjit Gill
T: +44(0)116 229 7945
E: pg170@le.ac.uk

Data controller registration number provided by the Information Commissioner's Office: Z6551415

What if I have concerns about the way the personal data are processed?

If you wish to raise a complaint about how we have handled your or your child's personal data, please contact the Data Protection Officers (above) who will investigate the matter. If you are not satisfied with our response or believe we are processing the data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).
https://ico.org.uk/

Publications & Abstracts 2020-2022

Publications

Journal	Title	Authors
Archives of Disease in Childhood (2020). Published online: 06 October 2020. doi: 10.1136/archdischild-2020-319396	Tracheostomy trends in paediatric intensive care.	Powell, J., Buckley, H.L., Agbeko, R., et al.
BMC Pediatrics 20, 301 (2020). https://doi.org/10.1186/s12887-020-02195-6	Does time taken by paediatric critical care transport teams to reach the bedside of critically ill children affect survival? A retrospective cohort study from England and Wales	Seaton, S.E., Ramnarayan, P., Davies, P. et al.
BMJ Open. 2020 Sep 25;10(9):e037517. doi: 10.1136/bmjopen-2020-037517. PMID: 32978195; PMCID: PMC7520830.	NEUROlogical Prognosis After Cardiac Arrest in Kids (NEUROPACK) study: protocol for a prospective multicentre clinical prediction model derivation and validation study in children after cardiac arrest.	Scholefield BR, Martin J, Penny-Thomas K, Evans S, Kool M, Parslow R, Feltbower R, Draper ES, Hiley V, Sitch AJ, Kanthimathinathan HK, Morris KP, Smith F; NEUROPACK Investigators for the Paediatric Intensive Care Society-Study Group (PICS-SG).
Health Technology Assessment 2020;24(23). doi: 10.3310/hta24230	Routine gastric residual volume measurement to guide enteral feeding in mechanically ventilated infants and children: the GASTRIC feasibility study	Tume LN, Woolfall K, Arch B, Roper L, Deja E, Jones AP, et al.
BMJ Open 2020;10:e033208. doi: 10.1136/bmjopen-2019-033208	How, in what contexts, and why do quality dashboards lead to improvements in care quality in acute hospitals? Protocol for a realist feasibility evaluation	Randell R, Alvarado N, McVey L, et al
Intensive Care Med 46, 1953–1955 (2020). https://doi.org/10.1007/s00134-020-06149-5	Impact on 30-day survival of time taken by a critical care transport team to reach the bedside of critically ill children	Seaton, S.E., Ramnarayan, P., Pagel, C. et al.
BMJ Open 2020;10:e038974. doi: 10.1136/bmjopen-2020-038974	Study protocol for a multicentre longitudinal mixed methods study to explore the Outcomes of ChildrEn and fAmilies in the first year after paediatric Intensive Care: the OCEANIC study	Manning JC, Latour JM, Curley MA for the OCEANIC Study Investigators, et al
Sci Rep 11, 21838 (2021). https://doi.org/10.1038/s41598-021-01173-x	A study of sex difference in infant mortality in UK pediatric intensive care admissions over an 11-year period.	Almossawi, O., O'Brien, S., Parslow, R. *et al.*
Crit Care 25, 399 (2021). https://doi.org/10.1186/s13054-021-03779-z	In the eye of the storm: impact of COVID-19 pandemic on admission patterns to paediatric intensive care units in the UK and Eire.	Kanthimathinathan, H.K., Buckley, H., Davis, P.J. *et al.*

Journal	Title	Authors
medRxiv 2021.06.30.21259763; doi: https://doi.org/10.1101/2021.06.30.21259763	Which children and young people are at higher risk of severe disease and death after SARS-CoV-2 infection: a systematic review and individual patient meta-analysis	Harwood, R et al.
medRxiv 2021.07.01.21259785; doi: https://doi.org/10.1101/2021.07.01.21259785	Risk factors for intensive care admission and death amongst children and young people admitted to hospital with COVID-19 and PIMS-TS in England during the first pandemic year	Ward, J L et al.
Nat Med **28**, 185–192 (2022). https://doi.org/10.1038/s41591-021-01578-1	Deaths in Children and Young People in England following SARS-CoV-2 infection during the first pandemic year: a national study using linked mandatory child death reporting data	Smith C et al.
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Abstracts

Published Abstracts	Title	Authors
8th Congress of the European Academy of Paediatric Societies 2020, Virtual 16 -19 October 2020	Epidemiology of cardiopulmonary resuscitation in critically ill children admitted to Paediatric Intensive Care Units across England.	Mustafa, K., Buckley, H., Feltbower, R., et al.
Archives of Disease in Childhood; London Vol. 105, Iss. Suppl 1, (Oct 2020): A99-A99. DOI:10.1136/archdischild-2020-rcpch.235	G272 Intensive care admissions in children with down syndrome: trends in incidence and outcome	Rapaport, B; Marder, E; Smyth, A R; Parslow, R C; Vyas, H; et al.
Accepted Abstracts	Title	Authors
World Federation of Pediatric Intensive and Critical Care Society 2020, Mexico.	Factors associated with unplanned readmissions to paediatric intensive care units in England	Buckley, H., Plunkett, A., Morris, K., et al.
World Federation of Pediatric Intensive and Critical Care Society 2020, Virtual.	Epidemiology of cardiopulmonary resuscitation in critically ill children admitted to Paediatric Intensive Care Units across England	Mustafa, K., Buckley, H., Feltbower, R., et al.

Data Access Requests Fulfilled (sent to applicant) January 2022 - December 2022

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P091	Tiffany Watson-Koszel, Policy Manager, NHS England	COVID-19 and PIMS-TS data	Identifiable data for linkage
P007 HQIP274 Amendment	Elizabeth S Draper, Professor of Perinatal and Paediatric Epidemiology, University of Leicester	The changing demographic of preterm born children admitted to paediatric intensive care	De-identified Individual (additional fields to supplement an earlier data provision)
P083 HQIP406	Lorna Fraser, Professor of Epidemiology, University of York	Trends in the Prevalence and Complexity of Children with a Life-Limiting or Life-Threatening condition in Wales	De-identified Individual + Identifiable for Linkage
P092 HQIP416	Paul Mouncey, Head of Research, Intensive Care National Audit & Research Centre (ICNARC)	PICnIC: A pilot cluster randomised clinical trial of the use of selective gut decontamination in critically ill children (Paediatric Intensive Care and Infection Control)	Summary data
P096 ISR091	Reinout Mildner, NIHR Clinical Trials Scholar and PICU Consultant, Birmingham Children's Hospital	Duration of invasive ventilation against diagnosis, for Invasive ventilation weaning NAVA mode RCT	Summary data

If you require further details of the Data Requests made to PICANet please contact the team by email.

University of Leeds

Richard Feltbower	PICANet
Hannah Buckley	Leeds Institute for Data Analytics
Christopher Leahy	School of Medicine
Hannah Lever	University of Leeds
Paul Micklethwaite	Clarendon Way
Lee Norman	Leeds
Georgina Tayler-Barrett	LS2 9JT
Thomas Simpson	
Laura Stubbs	

University of Leicester

Elizabeth Draper	PICANet
Emily Evans	Department of Health Sciences
Hari Krishnan	University of Leicester
Lyn Palmer	George Davies Centre
Martin Perkins	University Road
Sarah Seaton	Leicester
Rachel Shorthose	LE1 7RH

PCCS Paediatric Critical Care Society