

# Paediatric Intensive Care Audit Network

## National Paediatric Critical Care Audit State of the Nation Report 2024



## Appendices

Data Collection Period: January 2021 - December 2023

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# Acknowledgements

The Paediatric Intensive Care Audit Network (PICANet) gathers information on all children admitted to designated Level 3 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 and healthcare professionals who support and contribute to PICANet from their PICUs and SPTS.

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.

PICANet acknowledges the use of the LASER data storage platform and assistance provided by the Data Analytics Team in Leeds Institute for Data Analytics, University of Leeds to facilitate production of this report.

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 NHS Wales Joint Commissioning Committee, NHS Lothian and 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

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

# Organisation Key

<b>A</b>	Addenbrooke's Hospital, Cambridge
<b>C</b>	Noah's Ark Children's Hospital for Wales, Cardiff
<b>D</b>	Royal Manchester Children's Hospital
<b>E1</b>	Great Ormond Street Hospital, London (PICU/NICU)
<b>E2</b>	Great Ormond Street Hospital, London (CICU)
<b>F1</b>	Evelina London Children's Hospital (previously F)
<b>F2</b>	Royal Brompton Hospital, London (previously O)
<b>H</b>	King's College Hospital, London
<b>I</b>	Leeds Children's Hospital
<b>K2</b>	Freeman Hospital, Newcastle upon Tyne
<b>K3</b>	Great North Children's Hospital, Newcastle upon Tyne
<b>L</b>	Royal Stoke University Hospital
<b>M</b>	Nottingham Children's Hospital, Queens Medical Centre, Nottingham
<b>N</b>	John Radcliffe Hospital, Oxford
<b>P</b>	Alder Hey Children's Hospital, Liverpool
<b>Q</b>	Sheffield Children's Hospital
<b>R</b>	Southampton Children's Hospital
<b>T</b>	St George's Hospital, London
<b>U</b>	St Mary's Hospital, London
<b>V</b>	Birmingham Children's Hospital
<b>W</b>	Bristol Royal Hospital for Children
<b>X2</b>	Leicester Royal Infirmary CICU
<b>X3X1</b>	Leicester Royal Infirmary CPICU (previously known as Glenfield Hospital, Leicester)
<b>Y</b>	Royal Hospital for Children and Young People, Edinburgh
<b>Z</b>	The Royal London Hospital
<b>ZA</b>	Royal Hospital for Children, Glasgow
<b>ZB</b>	Royal Belfast Hospital for Sick Children
<b>ZC</b>	Children's Health, Ireland, Crumlin formerly Our Lady's Children's Hospital, Crumlin, Dublin
<b>ZD</b>	Children's Health, Ireland, Temple Street, formerly Temple Street Children's University Hospital, Dublin
<b>ZF</b>	The Portland Hospital, London
<b>T001</b>	Children's Acute Transport Service (CATS)
<b>T002</b>	Embrace: Yorkshire & Humber Infant & Children's Transport Service
<b>T003</b>	North West and North Wales Paediatric Transport Service (NWTS)
<b>T004</b>	South Thames Retrieval Service (STRS)
<b>T005</b>	KIDS Intensive Care and Decision Support
<b>T008</b>	Southampton Oxford Retrieval Team (SORT)
<b>T010</b>	Northern Ireland Specialist Transport and Retrieval (NISTAR) Paediatric
<b>T020</b>	Scotland Specialist Transport and Retrieval (ScotSTAR)
<b>T022</b>	Irish Paediatric Acute Transport Service (IPATS)
<b>T024</b>	Wales and West Acute Transport for Children (WATCH)
<b>T026</b>	North East Children's Transport and Retrieval Service (NECTAR)
<b>T027</b>	Children's Medical Emergency Transport Service (CoMET)
<b>T028</b>	<i>Heart Link ECMO Children's Service (included in Tables &amp; Figures only)</i>
<b>T032</b>	Paediatric and Neonatal Decision Support and Retrieval Service (PaNDR)

# Background and participating organisations

PICANet was established in 2001 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 Children and Young People, Edinburgh (was Royal Hospital for Sick Children) 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 at Crumlin and Children's Health Ireland at Temple Street, both based in Dublin, have submitted pseudonymised data to PICANet since January 2009 and March 2010, respectively. The Harley Street Clinic PICU started contributing data in September 2010 until closure in March 2020, and the PICU at the Portland Hospital from June 2013, allowing these non-NHS units to compare their performance against the national benchmark provided by PICANet.

During the reporting period there were 30 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 2023](#) section. Changes to participation are detailed in the [Important notes](#) section.

## Governance

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 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. 23/EM/0189.

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 professionals 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 2021 – 2023](#) and [Steering Group Membership 2021 - 20223](#). 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 another PICU, 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 PICANet NPCCA collects personal, organisational and clinical data on all children with a clinically determined need for paediatric intensive care in the UK and Republic of 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 the 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 SPTS but are not admitted to a PICU includes child 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 and SPTS 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 available on our website for organisations to download and complete on site if required.

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.

Routine validation reports are provided to participating organisations every 6 weeks via email and virtual validation visits are conducted by PICANet staff every 12 – 18 months per participating organisation.

The six-weekly validation reports highlight to organisations their adherence to the 2021 PCCS Quality Standard for the timeliness of data entry, any outstanding validation queries for resolution and any customised data collection audits requiring completion. In every other routine validation report (this works out as quarterly), case ascertainment is also assessed. Units are asked to confirm the admission count in their admission book/electronic system over a two-month period and these numbers are compared to the number of admissions on the PICANet Web database.

The way case ascertainment is measured was updated during this reporting period. Initially, a 2-month period was assessed during virtual validation visits, which began in June 2022. This then moved to the routine validation reviews to increase the frequency, being established as quarterly in March 2024.

The virtual validation visits allow for an in-depth review of data quality and validation and are a core element of our data quality assurance. Any issues highlighted in the routine validation reviews and case ascertainment checks can also be discussed. 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.

Quarterly risk-adjusted Resetting Sequential Probability Ratio Test (RSPRT) plots of in-PICU mortality 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](#). If they are identified as have a potential cause for concern due to high mortality the PICANet team will guide them through the steps to explore this further.



# 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 Republic of 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, PICnIC and PRESSURE. PICANet 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 2024 is available on the PICANet website. Statistical techniques used include 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. Risk-adjusted SMRs were calculated using the latest version of the Paediatric Index of Mortality (PIM3)<sup>1</sup> 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 using a risk-based approach.

## Outlier policy

PICANet recalibrate the 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](#) (v4.0, 2024). 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.

## Changes to the tables and figures - 2024

This year we have moved away from static tables and figures presented in Excel towards interactive charts with associated data tables, aiming to improve accessibility and user friendliness. We have also rationalised the information we present and increased standardisation to improve ease of navigation. Following this approach, we have focused on increasing the depth of information provided for a smaller number of outcomes. PICANet will adapt the outcomes presented in future years in response to requirements of the PCC community; an online form is in place for stakeholders to request additional information be presented in future years.

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<sup>1</sup> 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.

The new range of [PICANet State of the Nation Report 2024 Tables](#) are available in the Reports section of our website.

## How we present our results

Results are presented in an annual Summary Report and in interactive figures with associated data tables. These mainly focus on children aged 0–15 years, apart from tables capturing the workload of the PICU (e.g. how many bed days the PICU provided) which include all PICU admissions regardless of age; we state where this is the case. Where we present data on 0-15 year olds only 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 in our Summary Report: case ascertainment including timeliness of data submission, transport mobilisation times, emergency readmissions within 48 hours of discharge, unplanned extubation in PICU and in-PICU mortality. We highlight the main findings of the Summary Report in an infographic.

In the interactive figures with associated data tables we also present further data relating to our key metrics as well as information on overall admission numbers, bed days provided, length of stay in PICU, crude mortality rates and data quality. We present data by year, PICU, country of admission, operational delivery network (ODN), age, sex, ethnicity, deprivation, primary diagnosis group and severity of illness (via PIM3). We present an additional transport metric of time taken to reach the bedside of the child by SPTS by year, transport team, age and severity of illness (via PIM3).

## Rates

We present the rate of unplanned extubations per 1,000 ventilated days to allow us to compare between units as the more children that are ventilated on a PICU, the more likely an unplanned extubation will occur.

When we want to compare two rates we divide one rate by the other, to get a 'relative rate'. For example, to compare the emergency readmission rate in one PICU with the overall rate calculated from all PICUs then we would divide the PICU's emergency readmission rate by the combined rate. If the PICU's rate was the same as the overall rate then the relative rate would be one. If the PICU's rate was higher than the overall rate then the relative rate would be greater than one. If the PICU's rate was lower than the overall rate then the relative rate would be less than one. Using this relative rate allows us to talk about a given PICU's rate in comparison (or relative) to the overall rate.

## Risk-adjusted mortality

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 and allows us to compare across PICUs with different case-mixes.

We measure how poorly children were at the point when they were admitted to PICU using PIM3. 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.

We use present funnel plots which tell us what range of values we might expect to see for the SMR in each PICU given its number of admissions and 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.

## Timeliness of data collection in 2023

The following units have a lower percentage of admission records completed (submitted to PICANet) within two months of discharge from PICU in 2023 per the 2021 PCCS Quality Standard for the timeliness of data entry. However, there are a variety of reasons which can lead to this with local resource pressures and IT issues being the most common. Ultimately, all units have good data completeness to be included in the report.

The PICUs in the Republic of Ireland, Children's Health Ireland at Crumlin (ZC) and at Temple Street (ZD), were affected by the Health Service Executive (HSE) experiencing a major ransomware cyberattack on 14 May 2021. This caused all IT systems nationwide to be shut down. Children's Health Ireland were heavily impacted by the cyberattack. This has caused backlogs which continued to impact the 2023 data.

The Freeman Hospital CICU (K2) experienced local IT issues from April 2022 to June 2023 which hindered the usual data submission and validation routine and contributed to low levels of timely data completion. This has been addressed and data submission is now within the 2021 PCCS Quality Standard for the timeliness of data entry.

King's College Hospital PICU (H) are experiencing IT issues which has resulted in a pause in data imports and temporary switch to manual data entry, hindering timely data completion.

The Royal Belfast Hospital for Sick Children PICU (ZB) are experiencing IT and resource issues which is hindering timely data completion.

Sheffield Children's Hospital PCCU (Q) have experienced resourcing issues, with other areas needing to take precedence over data completion.

The Portland Hospital PICU (ZF) has experienced data completion resource pressures following an expansion of beds and the addition of a long term ventilation unit.

## 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. Subsequently, these units also ceased COVID-19 II custom audit data collection on 31<sup>st</sup> January 2024. We are grateful to the PICU teams for the work put into the COVID-19 data collection.

## Change to Royal Brompton Hospital PICU in the Organisation Key

Royal Brompton & Harefield NHS Foundation Trust merged as a single Trust with Guy's & St. Thomas' NHS Foundation Trust in February 2021 and as a single directorate in April 2022. They are now Guy's & St. Thomas' NHS Foundation Trust. Evelina London Children's Hospital PICU (F1, previously F) and Royal Brompton Hospital PICU (F2, previously O) are now part of the

same Trust and the Organisation Key for the Royal Brompton Hospital PICU has been updated accordingly.

## Redesignation of S – James Cook University Hospital (Middlesbrough)

The 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 the 2024 report (it was previously excluded from key metrics only). Their participation in the level 3 NPCCA ended in February 2023 and the children's critical care unit began participating in the level 2 PICANet data collection.

## 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.

## Links with the clinical community

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 communications 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 plans to continue to develop and expand our PPI work further in the upcoming years. Our next short-term aim is to co-produce, with parents, carers, children and young people, infographics highlighting key findings from the State of the Nation report for families and children/young people. We aim to complete this in early 2025.

# Participating Organisation & Unit Characteristics 2023

NHS Trust / Organisation	Participating Hospital	Unit / Ward	Number of funded IC beds	Number of funded HD beds	Type of unit
Barts Health NHS Trust	The Royal London Hospital	PCCU	8	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	19	14	General
Great Ormond Street Hospital for Children NHS Trust	Great Ormond Street Hospital for Children	CICU	20	0	Cardiac & ECMO
		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 & ECMO
	Royal Brompton Hospital	PICU	16	4	Cardiac & Respiratory
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 & ECMO
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 Trust / Organisation	Participating Hospital	Unit / Ward	Number of funded IC beds	Number of funded HD beds	Type of unit
NHS Lothian	Royal Hospital for Children and Young People, Edinburgh (formerly Royal Hospital for Sick Children)	PICU	10	6	General, Neurosurgical & Spinal
NHS Greater Glasgow and Clyde	Royal Hospital for Children, Glasgow	PICU	22	0	General, Neurosurgical Cardiac & ECMO
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 <sup>1</sup>	6	General (plus regional oncology, major trauma, ENT, paediatric surgery, regional neurosurgical, spinal, supraregional renal service and cleft lip & palate services)
Alder Hey Children's NHS Foundation Trust	Alder Hey Children's Hospital	PICU	21	0	General, Cardiac & ECMO
Sheffield Children's NHS Foundation Trust	Sheffield Children's Hospital	PCCU	8	9	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
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 <sup>2</sup>	0	General
University Hospitals Bristol NHS Foundation Trust	Bristol Royal Hospital for Children	PICU	17	0	General, Cardiac, Neurosurgery, Burns and Major Trauma
University Hospitals of Leicester NHS Trust	Leicester Royal Infirmary CICU	CICU	6 <sup>1</sup>	0	General (Children's Intensive Care Unit)
	Leicester Royal Infirmary CPICU (previously Glenfield Hospital)	CPICU	7	0	Cardiac & ECMO

NHS Trust / Organisation	Participating Hospital	Unit / Ward	Number of funded IC beds	Number of funded HD beds	Type of unit
University Hospitals of North Midlands NHS Trust	Royal Stoke University Hospital	PICU	8	0	General
HCA Healthcare UK (non-NHS)	The Portland Hospital	PICU	14	9	General

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

Abbreviations: 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)

1. IC/ HD beds are used flexibly if required.
2. 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 [Organisation key](#).

# Clinical Advisory Group Membership 2021 – 2023

Name	Position	NHS Trust / Hospital	Period served
Mark Peters (Chair from 2020)	Clinical Unit Chair	Great Ormond Street Hospital for Children NHS Trust Great Ormond Street Hospital for Children	2018 - Ongoing
Sara Ali (representing Wales)	Consultant in Paediatric Intensive Care	Cardiff University Hospital, Noah's Ark Children's Hospital of Wales	2020 – Ongoing
Colin Begg	National Medical Advisor	National Specialist & Screening Services Directorate (NSD), NHS National Services Scotland.	2023 - Ongoing
Simon Chiles	Advanced Nurse Practitioner	University Hospitals of Leicester NHS Trust Glenfield Hospital	2014 - Ongoing
Kathryn Claydon-Smith	Clinical Nurse Specialist	North West and North Wales Paediatric Transport Service (NWTS)	2009 - 2022
Karen Coxon	Sister	James Cook University Hospital, Middlesbrough	2023 - Ongoing
James Edelman	Paediatric Consultant and PDHU Lead	Southampton HDU	2023 - Ongoing
Judith Gray (representing Nursing)	Sister	Newcastle upon Tyne Hospitals NHS Foundation Trust Newcastle Freeman Hospital	2015 - Ongoing
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
Margaret Hufton	Paediatric Consultant and Paediatric HDU Medical Lead	University Hospitals Coventry and Warwickshire	2023 - Ongoing
Hari Krishnan (Deputy Chair)	Consultant Paediatric Intensivist	Birmingham Women's and Children's NHS Foundation Trust Birmingham Children's Hospital	2018 - Ongoing
Graham Mason	PCCS HDU Lead	Paediatric Critical Care Society	2023 - Ongoing
Catherine McDougall (representing Scotland)	Consultant in Paediatric Intensive Care	Royal Hospital for Children and Young People, Edinburgh	2021 - Ongoing
Lesley Molony	Information Officer	Southampton Universities Hospital NHS Trust Southampton Children's Hospital	2013 - 2021
Rachel Neal	PICU Data & Audit Manager	St George's Hospitals NHS Foundation Trust	2021 - 2023

Name	Position	NHS Trust / Hospital	Period served
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
Mark Peters (Chair from 2020)	Consultant in Paediatric Intensive Care Medicine	Cardiff University Hospital, Noah's Ark Children's Hospital of Wales	2023 - Ongoing
Mohammad Oli Rahman	Lead Consultant	Brighton Royal Alexandra Hospital	2023 - Ongoing
Padmanabhan Ramnarayan (representing PCCS SG)	Reader in Paediatric Intensive Care & Honorary Consultant	Imperial College London & Imperial College Healthcare NHS Trust	2022 - Ongoing
Padmanabhan Ramnarayan (representing Transport Organisations)	Consultant	Great Ormond Street Hospital NHS Trust Children's Acute Transport Service	2012 - 2021
Annette Shaw	Data and Quality Nurse	Royal Hospital for Children, Glasgow	2021 - 2023
Mark Terris (representing Northern Ireland)	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	2014 - Ongoing
Dora Wood (representing Transport Organisations)	Consultant in Paediatric Intensive Care	Bristol Paediatric Intensive Care Unit and WATCH	2021 - Ongoing

Ongoing as of 31st December 2023.

## Steering Group Membership 2021 – 2023

Name	Position	Organisation	Representation	Period Served
Michael Marsh (Chair)	Regional Medical Director & CClO 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
James Campbell	Associate Director of Quality and Development	Health Quality Improvement Partnership (HQIP)	Commissioning body for PICANet in England	2021 - Ongoing
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 - 2023
Louise Dewsbury	Senior Nurse	Guy's and St Thomas' NHS Foundation Trust Evelina London Children's Hospital	PICS Nurse Managers Group	2017 - 2021
Freddie Drew	National Programme of Care Manager – Women & Children	NHS England	NHS England	2022 - 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 - 2022)	2019 - 2023
Karina Hamilton	Paediatric Programme Assistant Audit Manager	National Office of Clinical Audit	Republic of Ireland	2022 - Ongoing
Sam Harper	HQIP PICANet Project Manager	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2018 - 2022

Name	Position	Organisation	Representation	Period Served
Sasha Hewitt	Associate Director for Quality and Development and Data Protection Officer	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2017 - 2021
Rachel Lundy	Senior Commissioning Manager	NHS England & NHS Improvement	National Commissioner for Paediatric Intensive Care Clinical Reference Group	2016 - 2021
Roseanne McDonald	Programme Associate Director: Nursing and Quality Adviser	National Services Division (NSD), NHS National Services Scotland	Scotland	2022 - 2023
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
Mark Peters	Consultant in Paediatric Intensive Care	Great Ormond Street Hospital, London	Chair of PICANet Clinical Advisory Group	2020 - Ongoing
Natalia Plejic	HQIP PICANet Project Manager	Health Quality Improvement Partnership (HQIP)	Commissioning body for PICANet in England	2022 - Ongoing
Padmanabhan Ramnarayan	Reader in Paediatric Critical Care	Imperial College London	Chair of PCCS Study Group	2022 - Ongoing
Dr Barney Scholefield	Consultant Intensivist	Birmingham Childrens Hospital	Chair of Paediatric Intensive Care Study Group	2016 - 2021
Ruchi Sinha	Consultant Paediatric Intensivist	St Mary's Hospital, London	NHS England Chair of the Clinical Reference Group	2023 - Ongoing
Helen Staes	Parent	Lay Member	Parents and Carers Representation	2023 – Ongoing



Name	Position	Organisation	Representation	Period Served
Mark Terris	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	Northern Ireland	2012 - Ongoing
Donna Webb	Matron for Critical Care and Cardiology	Leeds Children's Hospital	PCCS Nurse Managers Group	2021 - Ongoing
Lucy Wheeler	Parent	Lay Member	Parents and Carers Representation	2011 - Ongoing
Carli Whittaker	Critical Care Educator	Nottingham Children's Hospital	PCCS President	2023 - Ongoing

Ongoing as of 31<sup>st</sup> December 2023



**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<sub>2</sub> (via pulse oximetry)**

% → **FI<sub>O<sub>2</sub></sub>** (at the time SpO<sub>2</sub> measured)

**Blood gas measured?**

Yes  No

**Arterial PaO<sub>2</sub>**

kPa

**Arterial PaO<sub>2</sub>**

OR    mmHg

**FI<sub>O<sub>2</sub></sub>**

**Intubation?**

Yes  No

**Headbox?**

Yes  No

At the time of arterial PaO<sub>2</sub> sample

**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**

**Comorbidity**

**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

		Code	0	1	2	3	4	5	6	7	8	9	10	11	12	13	
<b>Basic</b>	No defined critical care activity	99															
	Continuous ECG monitoring	50															
	Continuous pulse oximetry	73															
<b>Airway and ventilatory</b>	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																
<b>Cardio-vascular</b>	Arterial line monitoring	60															
	External pacing	61															
	Central venous catheter in situ	-															
	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																
<b>Renal</b>	Urine catheter in situ	-															
	Peritoneal dialysis	05															
	Haemofiltration	16															
	Haemodialysis	66															
	Plasma filtration	67															
Plasma exchange	67																
<b>Neuro-logical</b>	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															
Delirium screening result (record P=positive, N=negative, U=unable to assess)	-																
<b>Analgesia/ sedation</b>	Epidural catheter in situ	85															
	Continuous intravenous infusion of a sedative agent	96															
<b>Metabolic</b>	Diabetic ketoacidosis (DKA) requiring continuous infusion of insulin	70															
<b>Other</b>	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															
<b>High cost drugs</b>	Medical gases Band 1 – nitric oxide	X841															
	Surfactant	X842															

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

---

**Additional information****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**HEALTHCARE ASSOCIATED INFECTIONS (HCAI)**For guidance on completing this section, see [picanet.org.uk](http://picanet.org.uk)

Number of episodes of central line associated blood stream infection (CLABSI)

Number of episodes of catheter associated urinary tract infection (CAUTI)

Use the daily interventions section to record whether a **central venous catheter** and/or a **urine catheter** were in situ on each day of admission.**Discharge information**

Status at discharge from your unit

 Alive  Dead

Date and time of discharge (dd/mm/yyyy hh:mm)

 /  / 20  : 

If alive at discharge

Discharged for palliative care?

 Yes  No

Destination following discharge from your unit

- |   |   |                                |
|---|---|--------------------------------|
| <input type="checkbox"/> Normal residence | } | <input type="checkbox"/> ICU   |
| <input type="checkbox"/> Hospice          |   | <input type="checkbox"/> PICU  |
| <input type="checkbox"/> Same hospital    |   | <input type="checkbox"/> NICU  |
| <input type="checkbox"/> Other hospital   |   | <input type="checkbox"/> HDU   |
|   |   | <input type="checkbox"/> SCBU  |
|   |   | <input type="checkbox"/> Ward  |
|   |   | <input type="checkbox"/> Other |

If dead at discharge

Date and time of death (dd/mm/yyyy hh:mm)

 /  / 20  : 

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)

 /  / 20

Location

- |   |   |                                |
|---|---|--------------------------------|
| <input type="checkbox"/> Normal residence | } | <input type="checkbox"/> ICU   |
| <input type="checkbox"/> Hospice          |   | <input type="checkbox"/> PICU  |
| <input type="checkbox"/> Same hospital    |   | <input type="checkbox"/> NICU  |
| <input type="checkbox"/> Other hospital   |   | <input type="checkbox"/> HDU   |
|   |   | <input type="checkbox"/> SCBU  |
|   |   | <input type="checkbox"/> Ward  |
|   |   | <input type="checkbox"/> Other |

**Form completed by****Comments**









**Transport times**

BASE TO COLLECTION UNIT	PATIENT JOURNEY	DESTINATION UNIT TO BASE
<input type="checkbox"/> Tick if this section of the trip is not applicable	<input type="checkbox"/> Tick if this section of the trip is not applicable	<input type="checkbox"/> Tick if this section of the trip is not applicable
<b>Mode of transport (tick all that apply)</b> <input type="checkbox"/> Dedicated ambulance <input type="checkbox"/> RRV <input type="checkbox"/> Taxi <input type="checkbox"/> Other ambulance <input type="checkbox"/> Air → <input type="checkbox"/> Other	<b>Mode of transport (tick all that apply)</b> <input type="checkbox"/> Dedicated ambulance <input type="checkbox"/> RRV <input type="checkbox"/> Taxi <input type="checkbox"/> Other ambulance <input type="checkbox"/> Air → <input type="checkbox"/> Other	<b>Mode of transport (tick all that apply)</b> <input type="checkbox"/> Dedicated ambulance <input type="checkbox"/> RRV <input type="checkbox"/> Taxi <input type="checkbox"/> Other ambulance <input type="checkbox"/> Air → <input type="checkbox"/> Other
<b>Depart base (dd/mm/yyyy hh:mm)</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>Depart collection unit (or location)</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>Depart destination unit (or location)</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>→ Arrive base airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Arrive collection airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Arrive destination airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>→ Aircraft type</b> <input type="checkbox"/> Unpressurised fixed-wing <input type="checkbox"/> Dedicated helicopter <input type="checkbox"/> Pressurised fixed-wing <input type="checkbox"/> Other helicopter	<b>→ Aircraft type</b> <input type="checkbox"/> Unpressurised fixed-wing <input type="checkbox"/> Dedicated helicopter <input type="checkbox"/> Pressurised fixed-wing <input type="checkbox"/> Other helicopter	<b>→ Aircraft type</b> <input type="checkbox"/> Unpressurised fixed-wing <input type="checkbox"/> Dedicated helicopter <input type="checkbox"/> Pressurised fixed-wing <input type="checkbox"/> Other helicopter
<b>→ Takeoff base airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Takeoff collection airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Takeoff destination airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>→ Land collection airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Land destination airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Land base airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>→ Depart collection airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Depart destination airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>→ Depart base airport</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>Arrive collection unit (or location)</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>Arrive destination unit (or location)</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>	<b>Arrive base</b> <input type="text"/> / <input type="text"/> / <input type="text"/> 20 <input type="text"/> : <input type="text"/>
<b>Blue light or siren used or requested?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	<b>Blue light or siren used or requested?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	<b>Blue light or siren used or requested?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No
<b>Organisational delay</b> <input type="checkbox"/> None <input type="checkbox"/> Team out <input type="checkbox"/> Staffing <input type="checkbox"/> Vehicle	<b>Organisational delay</b> <input type="checkbox"/> None <input type="checkbox"/> Team out <input type="checkbox"/> Staffing <input type="checkbox"/> Vehicle	<b>Organisational delay</b> <input type="checkbox"/> None <input type="checkbox"/> Team busy <input type="checkbox"/> Staffing <input type="checkbox"/> Vehicle
<b>Vehicle incident</b> <input type="checkbox"/> None <input type="checkbox"/> Vehicle accident <input type="checkbox"/> Vehicle breakdown	<b>Vehicle incident</b> <input type="checkbox"/> None <input type="checkbox"/> Vehicle accident <input type="checkbox"/> Vehicle breakdown	<b>Vehicle incident</b> <input type="checkbox"/> None <input type="checkbox"/> Vehicle accident <input type="checkbox"/> 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)

**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

**SpO<sub>2</sub>**    **FiO<sub>2</sub> (at time SpO<sub>2</sub> measured)**  
 %    →     .

**Blood gas measured?**  
 Yes     No

**Arterial PaO<sub>2</sub> or Arterial PaO<sub>2</sub>**  
 .  kPa     mmHg

**FiO<sub>2</sub>**  
 .

**Intubation?**  
 Yes     No

**Headbox?**  
 Yes     No

**Base excess**  
 .  mmol/l →

**Lactate**  
 .  mmol/l →

**Mechanical ventilation?**  
 Yes     No

**CPAP?**  
 Yes     No

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

# PICANet Information Leaflets for Families and Carers 2023

The leaflet below (v7.0 Jul 2022) was in place at the last date of the reporting period (31 December 2023) 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](mailto:picanet@leeds.ac.uk)  
Call 0113 343 8125

Visit our website at [www.picanet.org.uk](http://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](mailto:slp60@leicester.ac.uk)

Or by post at:  
**PICANet**  
**Department of Health Sciences**  
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[www.picanet.org.uk](http://www.picanet.org.uk)



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**UNIVERSITY OF LEEDS**



**Paediatric Intensive Care  
Audit Network**



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

#### **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](http://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 2023) for those in Wales, Scotland and Northern Ireland.

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

Talk to the **Doctors and Nurses**

Email [picanet@leeds.ac.uk](mailto:picanet@leeds.ac.uk)

Visit our website at [www.picanet.org.uk](http://www.picanet.org.uk)

Or

Call our **Research Nurse**, Lyn Palmer, on **0116 252 5475**

Or write to Lyn at: [slp60@leicester.ac.uk](mailto: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](http://www.picanet.org.uk)

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**Paediatric Intensive Care  
Audit Network**

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](http://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 2023

The leaflet below (v7.0 Jul 2022) was in place at the last date of the reporting period (31 December 2023) 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](mailto:picanet@leeds.ac.uk)  
Call **0113 343 8125**

Visit our website at [www.picanet.org.uk](http://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](mailto: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](http://www.picanet.org.uk)



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**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](http://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 2023) 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](mailto:picanet@leeds.ac.uk)**

Visit our website at **[www.picanet.org.uk](http://www.picanet.org.uk)**


Or

Call our **Research Nurse**, Lyn Palmer on **0116 252 5475**

Or write to Lyn at: **[slp60@leicester.ac.uk](mailto: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](http://www.picanet.org.uk)**


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**Paediatric Intensive Care  
Audit Network**



Information leaflet for children  
admitted to paediatric intensive care.

 UNIVERSITY OF LEICESTER

 UNIVERSITY OF LEEDS

### 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?

Doctors 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](http://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 (v6.2 09 Nov 2023) was in place at the latest date of the reporting period – 31 December 2023.



## PICANet Patient Privacy Notice and Fair Processing Statement

Paediatric Intensive Care Audit Network (PICANet) is an international database of paediatric critical 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.

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### What data are being collected?

PICANet collects paediatric critical care (PCC) data. We run the National Paediatric Critical Care Audit (NPCCA) and data are collected for every child and young person referred, transported or admitted to a Paediatric Intensive Care Unit (PICU) in the UK and the Republic of Ireland. From February 2023, data are also collected on children and young people admitted to a designated NHS level 2 paediatric critical care unit (sometimes called a High Dependency Unit) in England. The PICANet Level 2 expansion of data collection is taking place on a progressive course from February 2023.

The data are sent to us over a very secure web application by each participating unit or specialist transport team on a regular basis. Data are collected for each individual for the whole period of their critical care unit stay. Data are also collected 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, service evaluation and commissioning purposes (which means the continual process of planning, agreeing and monitoring services). These help to improve the care given to children and young people admitted to PCC. 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.

All data, except from data collected from the Level 2 PCC units, are also part of the PICANet research database which 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 referred, transported and admitted to a PICU and/or admitted to a level 2 PCC unit 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 from the UK and Republic of Ireland 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 approval from the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP). The reference is 1819-0107 Feltbower.

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.

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?*

The University of Leeds hold all data in a highly secure environment. The University of Leeds and the University of Leicester process all data, including confidential personally identifiable data, in highly secure environments. 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 commissioners, 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. PICANet regularly share data from the NHS PCC providers in England with NHS England for commissioning purposes. Very occasionally, personal data may be processed by an authorised third party, but again, only with the necessary regulatory permissions and data security measures in place.

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 State of the Nation 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 process. For more information on English NHS data sharing for uses outside of the NPCCA programme, please see: [NCAPOP Privacy Notice – HQIP](#).

#### *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](mailto: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?*

The National Data Opt-Out is not applied to PICANet clinical audit data received from English PCC services. PICANet have received permission from the Health 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.

PICANet applies the National Data Opt-Out to the processing and/or release of data received from English PCC services for secondary uses, such as approved research projects, where the identifier fields require processing specifically for this use. This means that, where a National Data Opt-Out has been set, data will not be included in any approved research projects if we need to process your child's identifiable data to do so. For such projects, the National Data Opt-Out is extended by PICANet to all data included from private PCC services in England to ensure compliance with the National Data Opt-Out.

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/](http://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 for the National Paediatric Critical Care Audit.

#### **Healthcare Quality Improvement Partnership**

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

Data controller registration number provided by the Information Commissioner's Office: Z1780946

Data Protection Officer:  
E: [data.protection@hqip.org.uk](mailto:data.protection@hqip.org.uk)

**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](mailto:england.dpo@nhs.net))

Data controller registration number  
provided by the Information  
Commissioner's Office: Z2950066

NHS England and PICANet (University of Leeds and University of Leicester) are the joint Data Controller for the English NHS level 2 PCC unit data collection. Their details are included above and below (respectively).

The University of Leeds and the University of Leicester are joint data processors for the data collected in English NHS Level 2 PCC units, PICUs and transport teams.

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

**University of Leeds**

Leeds  
LS2 9JT

Data Protection Officer: Rebecca  
Messenger-Clark  
T: +44(0) 113 343 3746  
E: [dpo@leeds.ac.uk](mailto:dpo@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: [dpo@leicester.ac.uk](mailto:dpo@leicester.ac.uk)

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

The joint Data Controllers and Data Processors for data collected in Republic of Ireland are the University of Leeds and the University of Leicester (details above) and the Royal College of Surgeons in Ireland through the National Office of Clinical Audit:

**National Office of Clinical Audit**

2nd Floor, Block B, Ardilaun House  
111 St Stephens Green  
Dublin 2, D02 VN51

Data Protection Officer: Brid Moran  
T: +353 1 4028577  
E: [dpo@noca.ie](mailto:dpo@noca.ie)

The joint Data Controllers and Data Processors for data collected in private PICUs are the University of Leeds (details above) and HCA International Limited:

**HCA International Limited (HCA UK)**

2 Cavendish Square  
London  
W1G 0PU  
E: [DPO@hcahealthcare.co.uk](mailto:DPO@hcahealthcare.co.uk)

Data controller registration number provided by the Information Commissioner's Office:  
Z5688794

*What if I have concerns about the way 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 2021-2023

Journal	Title	Authors
<i>Archives of Disease in Childhood - Fetal and Neonatal Edition</i> . 2023 Nov ;109:265-271	Paediatric intensive care admissions of preterm children born <32 weeks gestation: a national retrospective cohort study using data linkage	van Hasselt TJ, Gale C, Battersby C On behalf of the United Kingdom Neonatal Collaborative and the Paediatric Critical Care Society Study Group (PCCS-SG), <i>et al</i>
<i>Health Technol Assess</i> . 2023 Nov; 27(27):1-155. doi: 10.3310/HYRW5688	Implementing early rehabilitation and mobilisation for children in UK paediatric intensive care units: the PERMIT feasibility study	Barnaby R Scholefield, Julie C Menzies, Jennifer McAnuff, Jacqueline Y Thompson, Joseph C Manning, Richard G Feltbower, Michelle Geary, Sophie Lockley, Kevin P Morris, David Moore, Nazima Pathan, Fenella Kirkham, Robert Forsyth and Tim Rapley
<i>Front Pediatr</i> . 2023 Oct 9:11:1225684. doi: 10.3389/fped.2023.122568	Is there a sex difference in mortality rates in paediatric intensive care units?: a systematic review	Almossawi O, Friend A, Palla L, Feltbower RG, Sardo-Infiri S, O'Brien S, Harron K, Nadel S, Saunders P, De Stavola B.
<i>BMC Pediatr</i> . 2023 Aug. 24;23(1):421. doi: 10.1186/s12887-023-04254-0.	Impact of prematurity on long-stay paediatric intensive care unit admissions in England 2008-2018.	van Hasselt, T.J., Kanthimathinathan, H.K., Kothari, T. <i>et al</i>
<i>JAMA Pediatr</i> . 2023 Jul. 31;177(9):947-955. doi: 10.1001/jamapediatrics.2023.2357.	Pediatric Hospitalizations and ICU Admissions Due to COVID-19 and Pediatric Inflammatory Multisystem Syndrome Temporally Associated With SARS-CoV-2 in England	Ward JL, Harwood R, Kenny S, Cruz J, Clark M, Davis PJ, Draper ES, Hargreaves D, Ladhani SN, Gent N, Williams HE, Luyt K, Turner S, Whittaker E, Bottle A, Fraser LK, Viner RM
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<i>Southampton (UK): National Institute for Health and Care Research</i> ; 2022 Jun. doi: 10.3310/QBBZ1124	Interventions to optimise the outputs of national clinical audits to improve the quality of health care: a multi-method study including RCT.	Willis TA, Wright-Hughes A, Weller A, Alderson SL, Wilson S, Walwyn R, Wood S, Lorencatto F, Farrin A, Hartley S, Francis J, Seymour V, Brehaut J, Colquhoun H, Grimshaw J, Ivers N, Feltbower R, Keen J, Brown BC, Presseau J, Gale CP, Stanworth SJ, Foy R.

Journal	Title	Authors
<i>Pediatr Crit Care Med.</i> 2022 Jun 1;23(6):e268-e276. doi: 10.1097/PCC.0000000000002904. Epub 2022 Feb 28.	Lactate, Base Excess, and the Pediatric Index of Mortality: Exploratory Study of an International, Multicenter Dataset	Morris KP, Kapetanstrataki M, Wilkins B, Slater AJ, Ward V, Parslow RC.
<i>NIHR Open Res.</i> 2022 May 13;2:37. doi: 10.3310/nihropenres.13273.1.	End of life care for infants, children and young people (ENHANCE): Protocol for a mixed methods evaluation of current practice in the United Kingdom	Papworth A, Hackett J, Beresford B, Murtagh F, Weatherly H, Hinde S, Bedendo A, Walker G, Noyes J, Oddie S, Vasudevan C, Feltbower R, Phillips B, Hain R, Subramanian G, Haynes A, Fraser LK
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<i>NIHR.</i> 2022 May. <a href="https://doi.org/10.3310/WBKW4927">https://doi.org/10.3310/WBKW4927</a>	Design and evaluation of an interactive quality dashboard for national clinical audit data: a realist evaluation	Randell R, Alvarado N, Elshehaly M, McVey L, West RM, Doherty P, <i>et al.</i>
<i>JAMA.</i> 2022 Apr 26;327(16):1555-1565.	Effect of High-Flow Nasal Cannula Therapy vs Continuous Positive Airway Pressure Following Extubation on Liberation From Respiratory Support in Critically Ill Children: A Randomized Clinical Trial	Ramnarayan P, Richards-Belle A, Drikite L, <i>et al.</i>
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<i>Health Technol Assess.</i> 2022 Mar;26(18):1-114. doi: 10.3310/TCFX3817.	Co-ordinated multidisciplinary intervention to reduce time to successful extubation for children on mechanical ventilation: the SANDWICH cluster stepped-wedge RCT	Blackwood B, Morris KP, Jordan J, McIlmurray L, Agus A, Boyle R, Clarke M, Easter C, Feltbower RG, Hemming K, Macrae D, McDowell C, Murray M, Parslow R, Peters MJ, Phair G, Tume LN, Walsh TS, McAuley DF.



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<i>BMJ Open</i> . 2021 Aug 19;11(8):e047575. doi: 10.1136/bmjopen-2020-047575.	The road to hell is paved with good intentions: the experience of applying for national data for linkage and suggestions for improvement	Julie A Taylor, Sonya Crowe, Ferran Espuny Pujol, Rodney C Franklin, Richard G Feltbower, Lee J Norman, James Doidge, Doug William Gould, Christina Pagel
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<i>BMC Health Services Research</i> , July 2021. <a href="https://doi.org/10.1186/s12913-021-06657-0">https://doi.org/10.1186/s12913-021-06657-0</a>	Hidden labour: the skilful work of clinical audit data collection and its implications for secondary use of data via integrated health IT.	Lynn McVey, Natasha Alvarado, Joanne Greenhalgh, Mai Elshehaly, Chris P. Gale, Julia Lake, Roy A. Ruddle, Dawn Dowding, Mamas Mamas, Richard Feltbower, and Rebecca Randell
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Journal	Title	Authors
<i>Arch Dis Child.</i> 2021 Jun;106(6):548-557. doi: 10.1136/archdischild-2020-320962. Epub 2021 Jan 28.	Caring for critically ill adults in paediatric intensive care units in England during the COVID-19 pandemic: planning, implementation and lessons for the future	Sinha R, Aramburo A, Deep A, Bould EJ, Buckley HL, Draper ES, Feltbower R, Mitting R, Mahoney S, Alexander J, Playfor S, Chan-Dominy A, Nadel S, Suntharalingam G, Fraser J, Ramnarayan P
<i>J Am Heart Assoc.</i> 2021 May 4;10(9):e018177.	Epidemiology of Cardiopulmonary Resuscitation in Critically Ill Children Admitted to Pediatric Intensive Care Units Across England: A Multicenter Retrospective Cohort Study.	Mustafa K, Buckley H, Feltbower R, Kumar R, Scholefield BR.
<i>BMC Pediatrics.</i> May 2021; <a href="https://doi.org/10.1186/s12887-021-02689-x">https://doi.org/10.1186/s12887-021-02689-x</a>	The effect of care provided by paediatric critical care transport teams on mortality of children transported to paediatric intensive care units in England and Wales: a retrospective cohort study	Seaton SE, Draper ES, Pagel C, Rajah F, Wray J, Ramnarayan P.
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<i>Crit Care Explor.</i> 2021 Mar 15;3(3):e0362. doi: 10.1097/CCE.0000000000000362.	Characteristics of Severe Acute Respiratory Syndrome Coronavirus-2 Infection and Comparison With Influenza in Children Admitted to U.K. PICUs	Kanthimathinathan HK, Buckley H, Lamming C, Davis P, Ramnarayan P, Feltbower R, Draper ES.
<i>J Eval Clin Pract.</i> 2021 Feb; 27(1):143-150. doi: 10.1111/jep.13403. Epub 2020 Apr 20.	Institutional use of National Clinical Audits by healthcare providers	McVey L, Alvarado N, Keen J, Greenhalgh J, Mamas M, Gale C, Doherty P, Feltbower R, Elshehaly M, Dowding D, Randell R
<i>BMJ Open.</i> 2021 Jan. 11(2):e046794. doi:10.1136/bmjopen-2020-046794.	Is there a sex difference in mortality rates for deaths occurring in paediatric intensive care units? Systematic literature review protocol.	Almossawi O, Friend A, Palla L, Feltbower R, De Stavola B.

## Data Access Requests Fulfilled (sent to applicant) January 2023 - December 2023

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P024 HQIP299	Sally Cavanagh Clinical Information Manager NHS England	Paediatric critical care and specialist surgery in Children Service Review/ GIRFT Paediatric Critical Care Improvement Programme	Identifiable data for linkage
P040 HQIP346	Lahn Straney Adjunct Senior Research Fellow Monash University	PIM4; Model update for predicting mortality in paediatric intensive care: Paediatric Index of Mortality 4	De-identified individual level data
P081 HQIP397	Ramesh Kumar/Davinder Singh Consultant Paediatric Intensivists Leeds Teaching Hospitals	Trends in PICU admission secondary to bronchiolitis	De-identified individual level data
P082 HQIP410	Jonathan Round Consultant in Paediatric Intensive Care St George's NHS Foundation Trust	Mortality for oncology patients in English NHS PICUs	De-identified individual level data
P086 HQIP408	Cheryl Battersby Clinical Senior Lecturer and Consultant Neonatologist Imperial College London	NNRD Data Linkage - Outcomes for Preterm Children	Identifiable for linkage
P091	Tiffany Watson-Koszel Policy Manager NHS England	NHS England COVID Response Planning	Identifiable data for linkage



Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P095 ISO96	Meiling MacDonald-Nethercott Foundation Trainee Cambridge University Hospitals NHS Foundation Trust	Impact of COVID - 19 on paediatric appendicitis in PICU admission and outcome	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
P100 HQIP432	Padmanabhan Ramnarayan Reader in Paediatric Critical Care Imperial College London	Contribution of social determinants of health on illness severity and outcomes of critically ill children: a retrospective cohort study using national clinical audit data.	De-identified individual level data
P103 HQIP434	Emma Gray and Richard Feltbower Professor of Epidemiology University of Leeds	Impact of epidemiology on unplanned readmission to Paediatric Intensive Care Units	De-identified individual level data
P106 HQIP443	Prof David Harrison Head Statistician Intensive Care National Audit and Research Centre (ICNARC)	PICU Platform Development Grant	De-identified individual level data
P107 IS111	Prof David Harrison Head Statistician Intensive Care National Audit and Research Centre (ICNARC)	PICU Platform Development Grant	Summary data
P109 IS120	Peter Davis Consultant Paediatric Intensivist Bristol Children's Hospital, and University of the West of England	Severe Asthma Admissions	Summary data
P110 IS124	Dr Deepa Varghese Paediatric Registrar/Clinical Research Fellow University of Edinburgh	Near Fatal Asthma in Children and Young People	Summary data

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