



Paediatric Intensive Care Audit Network State of the Nation Report 2022



Appendices

Data collection period January 2019 – December 2021















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Acknowledgements

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

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

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

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

HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes

Glossary

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

Organisation Key

- A Addenbrooke's Hospital, Cambridge
- C Noah's Ark Children's Hospital for Wales, Cardiff
- D Royal Manchester Children's Hospital
- E1 Great Ormond Street Hospital, London (PICU/NICU)
- E2 Great Ormond Street Hospital, London (CICU)
- F Evelina London Children's Hospital
- H King's College Hospital, London
- Leeds General Infirmary
- K2 Freeman Hospital, Newcastle upon Tyne
- K3 Great North Children's Hospital, Newcastle upon Tyne
- L Royal Stoke University Hospital
- M Nottingham Children's Hospital, Queens Medical Centre, Nottingham
- N John Radcliffe Hospital, Oxford
- O Royal Brompton Hospital, London
- P Alder Hey Children's Hospital, Liverpool
- Q Sheffield Children's Hospital
- **R** Southampton Children's Hospital
- S James Cook University Hospital, Middlesbrough
- T St George's Hospital, London
- U St Mary's Hospital, London
- V Birmingham Children's Hospital
- W Bristol Royal Hospital for Children
- X1 Glenfield Hospital, Leicester
- X2 Leicester Royal Infirmary
- X3 Leicester Royal Infirmary CICU
- Y Royal Hospital for Children and Young People, Edinburgh
- Z The Royal London Hospital
- ZA Royal Hospital for Children, Glasgow
- **ZB** Royal Belfast Hospital for Sick Children
- **ZC** Children's Health, Ireland, Crumlin formerly Our Lady's Children's Hospital, Crumlin, Dublin
- **ZD** Children's Health, Ireland, Temple Street, formerly Temple Street Children's University Hospital, Dublin
- ZE Harley Street Clinic, London
- **ZF** The Portland Hospital, London
- T001 Children's Acute Transport Service (CATS)
- T002 Embrace: Yorkshire & Humber Infant & Children's Transport Service
- **T003** North West and North Wales Paediatric Transport Service (NWTS)
- **T004** South Thames Retrieval Service (STRS)
- **T005** KIDS Intensive Care and Decision Support
- **T008** Southampton Oxford Retrieval Team (SORT)
- T010 Northern Ireland Specialist Transport and Retrieval (NISTAR) Paediatric
- T020 Scotland Specialist Transport and Retrieval (ScotSTAR)
- **T022** Irish Paediatric Acute Transport Service (IPATS)
- T024 Wales and West Acute Transport for Children (WATCh)
- **T026** North East Children's Transport and Retrieval Service (NECTAR)
- T027 Children's Medical Emergency Transport Service (CoMET)
- **T028** Heart Link ECMO Children's Service (Inc. in Tables & Figures only)
- T032 Paediatric and Neonatal Decision Support and Retrieval Service (PaNDR)

Background

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

A full list of participating PICUs can be found in the <u>Participating Organisation & Unit</u> <u>Characteristics 2021</u> section.

Governance

PICANet continues to receive support from the NHS Health Research Authority Confidentiality Advisory Group (NHS HRA CAG) (formerly the NIGB) to collect personally identifiable data without consent on infants and children admitted to paediatric intensive care. The references are: 21/CAG/0090 (non-research) and 21/CAG/0098 (research).

See <u>https://www.hra.nhs.uk/planning-and-improving-research/application-</u> <u>summaries/confidentiality-advisory-group-registers/</u>

The Secretary of State for Health and Social Care, having considered the advice from the Health Research Authority Confidentiality Advisory Group 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 Trent Medical Research Ethics Committee, ref. 18/EM/0267.

PICANet have conditional 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.

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

PICANet receives support and advice from a Clinical Advisory Group (CAG) drawing on the expertise of doctors and nurses working within the speciality and a Steering Group (SG), whose membership includes Health Services Researchers, representatives from the Royal Colleges of Paediatrics and Child Health, Nursing and Anaesthetics, a lay member and commissioners. For a full list of CAG and SG members, see <u>Clinical Advisory Group Membership 2019 – 2021</u> and <u>Steering Group Membership 2019 - 2021</u>. Additional support from the clinical community is provided through the UK Paediatric Critical Care Society.

Methods

Basic methodology

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

PICANet is an audit that collects personal, organisational and clinical data on all children with a clinically determined need for paediatric intensive care in the UK and Ireland, to compare outcomes and activity between PICUs and specialist transport organisations and also between health regions and nations.

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

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

Participating organisations and data submission

PICANet has collected data from all PICUs in England and Wales since 2002. The two PICUs in Scotland, one from Northern Ireland and two from the Republic of Ireland, along with two non-NHS units based in London have joined PICANet at different times (one of which has now closed) so that coverage is now for the whole of the UK and the Republic of Ireland. During the reporting period there were 33 PICUs and 13 specialist transport organisations submitting data to PICANet. A full list of participating PICUs can be found in the <u>Participating Organisation & Unit</u> <u>Characteristics 2021</u> section. Changes to participation are detailed in the <u>Important notes</u> section.

Data are submitted by individual PICUs prospectively, using our secure web-based data collection application with real-time online validation reporting, systematic six-weekly validation review by our research nurse and regular virtual validation visits. Data submission can involve direct entry of patient data or an upload of a data file from an existing clinical information system. PICANet provides full documentation on data definitions, which have been developed in collaboration with our Clinical Advisory Group, as well as technical specifications for IT and database professionals. In addition, standardised data collection forms are supplied to all organisations where there is no in-house provision for data collection.

Data collected

PICANet collects three core datasets:

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

are recorded as part of the audit and to help NHS organisations in England to supply information on the cost of their activity.

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

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

- * Not collected for data from Northern Ireland or the Republic of Ireland
- ** Limited to month and year for Northern Ireland

Analytical techniques

The <u>Statistical Analysis Plan</u> for the State of the Nation Report 2022 is available on the PICANet website. Statistical techniques used include simple cross tabulations, the calculation of crude and risk-adjusted SMRs and 95% confidence intervals; the construction of crude and risk-adjusted funnel plots of SMRs; and local provision of risk adjusted Resetting Sequential Probability Ratio Test (RSPRT) plots to assess real-time performance related to in-PICU mortality. Risk-adjusted SMRs were calculated using the latest version of the Paediatric Index of Mortality (PIM3)¹ recalibrated based on data within the current reporting period.

Assessing case ascertainment, data quality and validation

PICANet Web allows PICU staff to obtain reports on their own data to check monthly admissions totals. In addition, PICANet carry out a series of case ascertainment, quality assurance and data validation checks. Every 6 weeks PICANet carry validation checks with all units and transport organisations comprising of timing of data entry, alerting them to validation queries for resolution for admission, referral and transport data, and any customised data collection audits. Twice a year these checks also involve passive case ascertainment by checking admission records with those recorded on PICANet Web.

PICANet were unable to carry out face-to-face validation visits in 2020 and 2021 due to the COVID-19 pandemic. In 2021, PICANet put plans in place to conduct virtual validation visits when and where appropriate. These will involve a cross check carried out against records at source held on the PICU or transport organisation (such as admission books and in house data collection), and PICANet Web. Each organisation will have a virtual validation visit every 18 months. These validation visits will allow an in depth review of case ascertainment, data quality and validation and are a core element of our data quality assurance. In addition, quarterly RSPRT plots are sent to each unit to address any immediate concerns if applicable. All of the validation reports are available in an interactive format on PICANet Web.

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

Data are validated online via PICANet Web using logic and range checks as well as flagging missing data items. 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.

Collaborative working supporting policy, commissioning, research and clinical trials

PICANet has become established as the definitive source of data on paediatric intensive care activity in the UK and Ireland. Its 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 a number of other funded studies, including DEPICT, FIRST-ABC, GIRFT, LAUNCHES-QI, NEURO-PACK, OCEANIC, Oxy-PICU, PERMIT, and PICnIC. PICANet have also supported the NHS response to the pandemic by providing key data to inform the modelling of bed occupancy rates.

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 is still the case in aggregated data where small groups of individuals are presented. These are reviewed and in some cases, categories are combined or cells anonymised where necessary.

Outlier policy

PICANet recalibrate 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 <u>Outlier policy</u> (updated 2022). The process within the policy allows PICANet and the unit to better understand the reason(s) behind their outlier status, and improves knowledge of good practice/areas for improvement which can be shared across providers.

How we present our results

Results are presented in tables and figures. This Report focuses on children aged 0–15 years (unless otherwise specified). We report on five key metrics: case ascertainment including timeliness of data submission, retrieval mobilisation times, emergency readmissions within 48 hours of discharge, unplanned extubation in PICU and mortality in PICU. Unplanned extubation is introduced as a new metric this year although not yet measured against a standard or target. This is planned to be introduced in the 2023 report following agreement of a standard. The infographic highlights the main findings of the report.

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

Data are presented in more granular detail in the "Tables and Figures". In general, data are presented for children aged 0–15 years and do not include any admissions where the child's age is unknown, however, some tables also include data relating to all patients admitted to PICU (including those who are 16 years and older or where we don't know the patient's age; these tables will have footnotes explaining this.

Rates

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

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

Deaths

We measure how poorly children were at the point when they were admitted to PICU using the Paediatric Index of Mortality version 3 (PIM3)². This takes into account many factors (such as whether the child was admitted as an emergency and whether they needed help breathing) to estimate how likely each child is of dying.

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

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

Important notes

COVID-19

All the PICUs are now open fully for paediatric admissions following full/part closures during the pandemic. This is reflected in the increase in both PICU admission numbers and increase in non-elective transport to PICU. However, the UK units continue to report the number of new admissions with SARS-CoV-2 and clinically diagnosed PIMS-TS in the UK on a monthly basis (frequency dictated by demand), and complete the COVID-19 II custom audit where appropriate.

Closure of ZE – Harley Street PICU

One non-NHS PICU (ZE) closed to paediatric admissions permanently in March 2020 such that 2020 data presented for this unit does not represent a full calendar year. Data for 2020 for this unit is therefore not directly comparable to 2019.

Addition of T032 – PaNDR

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

Changes to the units in Leicester

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

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. PICANet were unable to complete the data freeze (soft lock) which typically occurs on the 31st March of each year, this was delayed until summer 2022. The outage affected both PICANet and the units, and so additional time was allowed in 2022 for units to ensure their 2021 data were up to date for the State of the Nation Report 2022.

Case ascertainment

The Portland Hospital were identified as having low case ascertainment due to a resourcing issue at the unit. Following identification of the issue, efforts were made to ensure that backlog of data entry was undertaken during Summer 2022. As such, the unit is included in the 2022 State of the Nation Report.

Data collection issues

The PICUs in the Republic of Ireland, Children's Health Ireland at Crumlin (ZC) and at Temple Street (ZD), had low levels of timely data completion and submission in 2021 due to the Health Service Executive (HSE) experiencing a major ransomware cyberattack on 14 May 2021. This

caused all IT systems nationwide to be shut down and Children's Health Ireland were heavily impacted by the cyberattack.

Links with the clinical community, patients and their families

PICANet has until recently had an active PICU Families Group comprising both Lay representatives (parents of children who are currently or have previously received paediatric intensive care) and a multidisciplinary group of health professionals including Family Liaison Sisters, critical care nurses, audit staff, PIC consultants and members of the PICANet team. Availability of Lay representatives has become difficult over recent years and so we involve existing lay and other stakeholder groups encompassing any PIC or disease specific support group that deals with parent or child PIC related issues to feed into the future development of PICANet. In addition, we have a standing lay representative on our Steering Group and work closely with the charity Well Child. To date, all communications we have had from patients/parents have been very positive, supporting PICANet and its work and requesting further information.

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

Participating Organisation & Unit Characteristics 2021

NHS Trust / Organisation	Participating Hospital	Unit / Ward ¹	Number of IC beds	Number of HD beds	Type of unit
Barts Health NHS Trust	The Royal London Hospital	PCCU	6	2	General
Birmingham Women's and Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital	PICU	30	0	General including cardiac, liver, neurosurgical, ECLS, ENT, oncology, metabolic and spinal
Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital	PICU	8	5	General
Cardiff & Vale University Health Board	Noah's Ark Children's Hospital for Wales	PCCU	7	4	General
Manchester University NHS Foundation Trust	Royal Manchester Children's Hospital	PICU	17	14	General
		CICU	20	0	Cardiac
Great Ormond Street Hospital for Children NHS Trust	Great Ormond Street Hospital for Children	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
	Children's Health Ireland at Temple Street, Dublin	PICU	9	0	General
HSE (Health Service Executive)	Children's Health Ireland at Crumlin, Dublin	PICU	18	5	General & Cardiac
King's College Hospital NHS Foundation Trust	King's College Hospital	PICU	7	8	General, Hepatic & Neurosurgical
The Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary	PICU	16	0	General & Cardiac
Newcastle upon Tyne Hospitals NHS	Great North Children's Hospital	PICU	11	0	General & Surgical ICU
Foundation Trust	Freeman Hospital	CICU	12	0	Cardiothoracic surgery, heart failure, ECMO & ENT
NHS Lothian	Royal Hospital for Children and Young People, Edinburgh (formerly Royal Hospital for Sick Children)	PICU	10	9	General, Neurosurgical & Spinal
NHS Greater Glasgow and Clyde	Royal Hospital for Children, Glasgow	PICU	22	0	General, Neurosurgical Cardiac & ECMO

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

Cardiac Intensive Care Unit (CICU), Neonatal Intensive Care Unit (NICU), Paediatric Critical Care Unit (PCCU), Paediatric Intensive Care Unit (PICU)
 IC/ HD beds are used flexibly if required.
 The James Cook University Hospital, Middlesbrough were redesignated as a Level II unit in 2019.

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

For a list of all participating organisations including transport services please see our website. A list of included units and PIC / centralised Transport Services contributing data for this reporting period is published in the front of the report Tables and Figures 2022 The above information was recorded in June 2021.

Clinical Advisory Group Membership 2019 - 2021

Name	Position	NHS Trust / Hospital	Period served
Dr Peter Davis (Chair to 2020)	Consultant in Paediatric Intensive Care	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	2006 - Ongoing
Kathryn Claydon-Smith (representing Transport Organisations)	Clinical Research Nurse Specialist	North West and North Wales Paediatric Transport Service (NWTS)	2009 - Ongoing
Simon Chiles	Advanced Nurse Practitioner	University Hospitals of Leicester NHS Trust Glenfield Hospital	2014 - Ongoing
Dr Mark Terris (representing Northern Ireland)	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	2014 - Ongoing
Judith Gray (representing Nursing)	Sister	Newcastle upon Tyne Hospitals NHS Foundation Trust Newcastle Freeman Hospital	2015 - Ongoing
Dr Hari Krishnan	Consultant Paediatric Intensivist	Birmingham Women's and Children's NHS Foundation Trust Birmingham Children's Hospital	2018 - Ongoing
Prof Mark Peters (Chair from 2020)	Clinical Unit Chair	Great Ormond Street Hospital for Children NHS Trust Great Ormond Street Hospital for Children	2018 - Ongoing
Dr Andrew Nyman	Consultant in Paediatric Intensive care	Guy's and St Thomas' Foundation Trust Evelina Children's Hospital, South Thames Retrieval service (STRS)	2019 - Ongoing
Dr Sara Ali (representing Wales)	Consultant in Paediatric Intensive Care	Cardiff University Hospital, Noah's Ark Children's Hospital of Wales	2020 - Ongoing
Dr Catherine McDougall (representing Scotland)	Consultant in Paediatric Intensive Care	Royal Hospital for Children and Young People, Edinburgh	2021 - Ongoing
Rachel Neal	PICU Data & Audit Manager	St George's Hospitals NHS Foundation Trust	2021 - Ongoing
Dr Padmanabhan Ramnarayan (representing PCCS SG)	Reader in Paediatric Intensive Care & Honorary Consultant	Imperial College London & Imperial College Healthcare NHS Trust	2021 - Ongoing
Annette Shaw	Data and Quality Nurse	Royal Hospital for Children, Glasgow	2021 - Ongoing
Dr Dora Wood (representing Transport Organisations)	Consultant in Paediatric Intensive Care	Bristol Paediatric Intensive Care Unit and WATCh	2021 - Ongoing
Dr Padmanabhan Ramnarayan (representing Transport Organisations)	Consultant	Great Ormond Street Hospital NHS Trust Children's Acute Transport Service	2012 - 2021
Lesley Molony	Information Officer	Southampton Universities Hospital NHS Trust Southampton Children's Hospital	2013 - 2021

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

Ongoing relates to as at 31st December 2021. The above membership covers the period of 2019-2021.

Steering Group Membership 2019 - 2021

Name	Position	Organisation	Representation	Period Served
Dr Michael Marsh (Chair)	Regional Medical Director & CCIO Higher Level Responsible Officer South West Region	NHS England & NHS Improvement	Royal College of Paediatrics and Child Health National Commissioner for Paediatric Intensive Care Clinical Reference Group	2002 - Ongoing
Dr Peter Davis	Consultant in Paediatric Intensive Care	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	Chair of Paediatric Intensive Care Clinical Reference Group	2011 - Ongoing
Lucy Wheeler	Parent	N/A	Parents and Carers Representation	2011 - Ongoing
Dr Mark Terris	Consultant Anaesthetist	Belfast Health and Social Care Trust Royal Belfast Hospital for Sick Children	Northern Ireland	2012 - Ongoing
Andrew Fleming	National Clinical Audit Manager	Intensive Care National Audit & Research Centre (ICNARC)	Intensive Care National Audit & Research Centre (ICNARC)	2017 - Ongoing
Sasha Hewitt	Associate Director for Quality and Development and Data Protection Officer	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2017 - Ongoing
Sam Harper	HQIP PICANet Project Manager	Healthcare Quality Improvement Partnership (HQIP)	Commissioning and funding body (England)	2018 - Ongoing
James Fraser	Consultant Paediatrician	University Hospitals Bristol NHS Foundation Trust Bristol Royal Hospital for Children	Paediatric Intensive Care Society President (2019 -)	2019 - Ongoing

Name	Position	Organisation	Representation	Period Served
Dr Mark Peters	Consultant in Paediatric Intensive Care	Great Ormond Street Hospital, London	Chair of PICANet Clinical Advisory Group	2020 - Ongoing
James Campbell	Associate Director and Interim Data Protection Officer	Health Quality Improvement Partnership (HQIP)	Commissioning body for PICANet in England	2021 - Ongoing
Daniel Eve	National Programme of Care Manager, Specialised Commissioning	NHS England and NHS Improvement	National Commissioner for Paediatric Intensive Care Clinical Reference Group	2021 - Ongoing
Donna Webb	Matron for Critical Care and Cardiology	Leeds Children's Hospital	PCCS Nurse Managers Group	2021 - Ongoing
Louise Dewsbury	Senior Nurse	Guy's and St Thomas' NHS Foundation Trust Evelina London Children's Hospital	PICS Nurse Managers Group	2017 - 2021
Rachel Lundy	Senior Commissioning Manager	NHS England & NHS Improvement	National Commissioner for Paediatric Intensive Care Clinical Reference Group	2016 - 2021
Dr Jillian McFadzean	Clinical Lead	NHS Lothian, Royal Hospital for Children and Young People, Edinburgh	Scotland	2005 - 2021
Dr Gale Pearson	Consultant in Paediatric Intensive care	Birmingham Women's and Children's NHS Foundation Trust Birmingham Children's Hospital	Chair of Paediatric Intensive Care Clinical Reference Group	2015 - 2021
Dr Barney Scholefield	Consultant Intensivist	Birmingham Childrens Hospital	Chair of Paediatric Intensive Care Study Group	2016 - 2021
Peter-Marc Fortune	Consultant Paediatric Intensivist Associate Clinical Head	Manchester University NHS Foundation Trust Royal Manchester Children's Hospital	Paediatric Intensive Care Society President (2016-2019)	2016 - 2019

Ongoing relates to as at 31st December 2021. The above membership covers the period of 2019-2021

Data Collection Form in use 2021 – Admission

Paediatric Intensive Care Audit Network - Data Collection Form

Admission

Patient details (or hospital label)

PICA

Family name	NHS/CHI/H&C number
	Tick if patient is not eligible for number
First name	Case note number
Address	Date of birth (dd/mm/yyyy)
	Indicate if date of birth is
Postcode	Estimated Anonymised Unknown
	Sex Male Female Ambiguous Unknown
Ethnic category	Gestational age at delivery (if patient is under 2 years old)
White British Asian Bangladeshi	weeks
White Irish Asian other (specify below	
White other (specify below) Black Caribbean	Birth order Multiplicity
Mixed White and Black Caribbean Black African	of
Mixed White and Black African Black other (specify below	GP practice code
Mixed White and Asian Chinese	GP practice code
Mixed other (specify below) Asian Indian Not stated (declined)	
Asian Pakistani Unknown	
Other ethnic category	
Admission details	
Date and time of admission to unit (dd/mm/yyyy)	Source of admission Same hospital Clinic
	Other hospital Home
Admission number	Care area admitted from (includes transfers in)
	X-ray/endoscopy/CT scanner ICU / PICU / NICU
	Recovery only Ward
Type of admission to unit	HDU (step up/step down unit) Theatre and recovery
Planned - following surgery	Other intermediate care area
Unplanned – following surgery	Retrieval / transfer?
Planned – other	
	Yes No
Unplanned – other	
Previous ICU admission (during current hospital stay)	□ Yes
Previous ICU admission (during current hospital stay)	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team
Previous ICU admission (during current hospital stay) ICU PICU	Yes No Type of transport team Other specialist team
Previous ICU admission (during current hospital stay) ICU PICU NICU NICU	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team
Previous ICU admission (during current hospital stay) ICU PICU	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team Transport team from neonates Unknown
Previous ICU admission (during current hospital stay) ICU PICU NICU None	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team Transport team from neonates Unknown
Previous ICU admission (during current hospital stay) ICU PICU NICU None	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team Transport team from neonates Unknown Transport team
Previous ICU admission (during current hospital stay) ICU PICU NICU None Unknown	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team Transport team from neonates Unknown Transport team
Previous ICU admission (during current hospital stay) ICU PICU NICU None	Yes No Type of transport team Other specialist team PICU Other specialist team Centralised transport service (PIC) Non-specialist team Transport team from neonates Unknown Transport team

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PIM	
This applies to observations recorded between the first face-to- face contact with ICU doctor until one hour after admission . Always use the first recorded measurement during this time period. Elective admission Tick if this is an elective admission Main reason for PICU admission Asthma Bronchiolitis Croup	Systolic blood pressure mmHg SpO2 (via pulse oximetry) FiO2 (at the time SpO2 measured) % Blood gas measured? Yes No Arterial PaO2 KPa OR mmHg
 Obstructive sleep apnoea Bypass cardiac procedure Non-bypass cardiac procedure Non-bypass cardiac procedure Elective liver transplant Other procedure Other procedure Seizure disorder Other (none of the above) Is evidence available to assess past medical history? 	FiO ₂ Fi
Yes No If yes, tick all that apply Cardiac arrest before ICU admission Cardiac arrest OUT of hospital Cardiomyopathy or myocarditis	Yes No Base excess (specify source) □ . □ mmol/l □ . □
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	Mechanical ventilation? Capillary Yes No CPAP? No
Spontaneous cerebral haemorrhage Neurodegenerative disorder Human Immunodeficiency Virus (HIV) Bone marrow transplant recipient Diagnoses and procedures	Pupil reaction Both fixed and dilated Other reaction Unknown
Primary diagnosis for this admission Other reasons for this admission	
Operations and procedures performed during and prior to thi	s admission
Co-morbidity	
Was a tracheostomy performed during this admission?	
Yes No No	ies of Leeds and Leicester Page 2 of

The second second

	d all interventions given on each day of admission using a cross 🗵	Admis	ssion	n da	ate:										
	vise specified.														
t no interver	ntions given, select No defined critical care activity.		*												
		Day	0	1	2	3	4	5	6	7	8	9	10 1	1	12
Basic	No defined critical care activity	Code 99	П	1		- 2						- 1	-	Т	Т
Dasic	Continuous ECG monitoring	50	\vdash	- 20		1						-20		+	-
	Continuous pulse oximetry	73		3	- 8	- 3			3	8	-	3	8		
Aimana	Invasive ventilation via endotracheal tube	51		-		-		-				100		1	÷
Airway and	Invasive ventilation via tracheostomy tube	52		-				-		-	1		-	+	-
ventilatory	Non-invasive ventilatory support	53						-			-			+	-
10	Advanced ventilatory support (jet ventilation)	56	H	- 30		-27					Č.	-	- 20		
	Advanced ventilatory support (oscillatory ventilation)	56		- 20	- 8	3			3	8	3	-	- 3	8	1
	Nasopharyngealairway	55		- 2	- 8	- 3			<u></u>	51	8-	989	- 24	- 2	
	Tracheostomy cared for by nursing staff	13		3	- 8	8			8	1	8		- 3	8	
	Supplemental oxygen therapy (irrespective of ventilatory state)	09		3	- 0		_	a		5	2	305		-	
	High flow nasal cannula therapy (record maximum daily flow in l/min)	88													
	Upper airway obstruction requiring nebulised adrenaline (epinephrine)	57		20	- 2	-		-		-	65		- 20		-
	Apnoea requiring intervention (>3 in 24 hours or need for bag-mask ventilation)	58		1						Î.	1				
	Acute severe asthma requiring IV bronchodilator therapy or continuous nebulise	r 59		1						Ĩ.	1				
	Unplanned extubation (record number of unplanned extubations)	90		ĺ		10				Î	ĺ				
Cardio-	Arterial line monitoring	60		- 23	- 2	- 3			5	8 8	8	 (**)	- 21	3	
vascular	External pacing	61		- 21	- 2	- 2		2		1	l.			-	
	Central venous pressure monitoring	62	H	Ĩ		- 3			¥		×		-		
	Continuous infusion of inotrope, vasodilator or prostaglandin	06		1		1		-		1	i.				1
	Bolus IV fluids (>80 ml/kg/day) in addition to maintenance IV fluids	63		1						î l	Ĩ.				1
	Cardio-pulmonary resuscitation	64		1						Ĩ.	Î				
	Extracorporeal membrane oxygenation (ECMO)	65		- î		1					1				
	Ventricular assist device (VAD)	65		- î		- 22			1	Ĩ.	Č.				
	Aortic balloon pump	65	2002	1	10	3	1		3	1	5	33	10	- 5	- 3
	Arrhythmia requiring intravenous anti-arrhythmic therapy	94		1	- 3	- 3				3 -				2	
Renal	Peritoneal dialysis	05	Ē							U	L				
itonui	Haemofiltration	16	H	Ĩ		- 2				1	1				
	Haemodialysis	66		1						Ť.	Î.				1
	Plasma filtration	67								Î	1				
	Plasma exchange	67	1000	Î		10				1		1			
Neuro-	ICP-intracranial pressure monitoring	68	П	12		- 2	Ξ				87		- 22	1	
logical	Intraventricular catheter or external ventricular drain	69				3	: :	5-1	3	9	ŝ	502	- 3	-	- 3
- giour	Status epilepticus requiring treatment with continuous infusion of anti-epileptic d		H	- 33	-2	-8		-	5	1	8		- 3	-2	-3
	Reduced conscious level (GCS ≤ 12) AND hourly (or more frequent) GCS monit			1		- 2						 			
Analgesia/	Epidural catheter in situ	85										- 20		T	
sedation	Continuous intravenous infusion of a sedative agent	96		_			_	_				_	_	_	_
Metabolic	Diabetic ketoacidosis (DKA) requiring continuous infusion of insulin	70	Π											1	
Other	Exchange transfusion	04		- 10									- 12		
10	Intravenous thrombolysis	71		2	- 5	3		2	3	8	ŝ	3.82			
	Extracorporeal liver support using molecular absorbent recirculating system (MA			3	10	3	2	8	3	- 8	5	558			
	Patient nursed in single occupancy cubicle (state reason for isolation below)	74		1	- 2	- 33			8				1		
High cost	Medical gases Band 1 - nitric oxide	X841		- 12		- 2								Т	
drugs	Surfactant	X842	1	- 3	- 2	3	5	8	<u></u>	<u>6</u>	2	225		-	- 3

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

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Clinical trial (if required by your unit)	Follow-up 30 days post-discharge from your unit
Is the patient on a clinical trial? Yes (specify name of trial) No	Status
Name of trial	Date of death (dd/mm/yyyy)
Growth measurements (if required by your unit)	Location
Height	Normal residence Same hospital
- cm	Hospice Other hospital PICU
Weight	
kg	П зсви
Abdominal circumference	Ward
cm	C Other
Discharge information	Comments
Status at discharge from your unit	8
Alive Dead	
Date and time of discharge (dd/mm/yyyy hh:mm)	
┌ If alive at discharge	
Discharged for palliative care?	
Yes No	
Destination following discharge from your unit	
☐ Hospice ☐ Other hospital	
Ward	
Other	
L .	Customised data collection (for local use)
r /f dead at discharge Date and time of death (dd/mm/yyyy hh:mm)	
Mode of death	
Treatment withdrawn Treatment limitation	
Brain stem death	
Failed cardiopulmonary resuscitation	
Transplant donor?	
Yes-solid organs only	
Yes-tissues only	
Yes-both solid organs and tissues	
	Form completed by
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Data Collection Form in use 2021 – Referral



Paediatric Intensive Care Audit Network · Data Collection Form

Referral

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

Patient details (or hospital label)	
Family name First name Postcode	NHS/CHI/H&C number Image: Constraint of the strength of the strenge strength of the strength of the strengt o
Referral details (complete only when clinicians agree that t	he patient requires PIC transport and/or a PICU bed)
Date and time when clinicians agreed that the patient required PIC transport and/or a PICU bed Image: PIC transport and PICU bed Image: PICU bed Im	Was the patient receiving invasive ventilation (by ET tube, laryngeal mask or tracheostomy) at time of referral call? Yes No – not indicated No – advised to intubate Unknown Outcome of this referral event Record the outcomes for both transport and admission; if either not requested of your organisation, tick "not requested"
Referring area X-ray/endoscopy/CT scanner ICU Recovery only PICU HDU (step up/step down unit) NICU Other intermediate care area Ward Theatre and recovery A & E Other transport service Referring speciality Grade of referring doctor or nurse Consultant / Associate Specialist / Staff Grade ST 4 – 8	Transport outcome Accepted for PIC transport Refused – no transport team available Refused – time critical transfer Refused – out of scope of care PIC transport not requested Admission outcome Accepted for PICU admission Refused – no staffed bed available Refused – out of scope of care PICU admission not requested
 ST 1 − 3 F1 / F2 GP Nurse practitioner Nurse Unknown 	Destination unit (or location) If transport and/or admission outcome is refused, record the name of the transport team and/or destination unit who refused this referral.
Comments	Form completed by
	Contact us • picanet@leeds.ac.uk • 0113 343 8125 For more contact details, go to www.picanet.org.uk/contact-us For forms, dataset manuals and guidance, go to www.picanet.org.uk/data-collection

PICANet Referral data collection form - Version 2.4.1 - October 2017 - Copyright © 2017. Universities of Leeds and Leicester

Data Collection Form in use 2021 – Transport



Paediatric Intensive Care Audit Network · Data Collection Form

Transport

Patient details (or hospital label)

Family name	50	NHS/CHI/H&C numb	er	
			Tick if patient is not eligible for number	
First name		Case note number (
Address		Date of birth (dd/mm		
1	3			
		Indicate if date of bi	th is	
		Estimated	Anonymised Unknown	
Postcode		Sex		
		Male Fema	ale 🗌 Ambiguous 🗌 Unknown	
Transport details		S		
Date and time accepted for transport	Collection area		Transport classification	
	X-ray/endoscopy/C	Tscanner 🔲 ICU	Planned	
	Recovery only	PICU	Unplanned	
Transport number	HDU (step up/step	영상 () 이상 ⁽) () () () () () () () () ()	Outcome of this transport event	
	Other intermediate		Patient transported Not transported	
Type of transport team	Theatre and recover Other transport ser	58 IS-16	Not transported – condition improved Not transported – condition deteriorated	
PICU Controlleged transport service (PIC)		39.040.04	Not transported – other reason	
Centralised transport service (PIC)	Collection unit (or l	ocalioni	Patient died before transport team arrived	
Other specialist team		8	Patient died while transport team present	
Non-specialist team	Most senior member		Patient died during transit	
Transport team	present at collectio		Destination time	
8 8 8	ST 4 – 8	ate Specialist/Staff Grade	Destination type	
	□ 31 4 - 0 □ ST 1 - 3			
Grade of clinical team leader Consultant/Associate Specialist/Staff Grade				
□ ST 4 - 8				
□ ST 1-3	Did a medical techr the patient?	lician accompany	Ward	
Nurse practitioner	Yes No		Theatre	
Speciality of clinical team leader	Did a parent accom	pany the patient?	Other transport service	
	Yes		Hospice	
Grade of most senior nurse	No – parent not pre		Destination unit (or (section)	
	No – parent decline		Destination unit (or location)	
Nurse not present		inition to accompany		
Critical incidents				
Identify all critical incidents while transp			Equipment failure or incompatibility	
No critical incidents	Loss of medical gas		impacting on patient care	
Accidental extubation Loss of all IV acces		ess Other critical incident (specify)		
Required intubation in transit Cardiac arrest			8. 8	
Complete ventilator failure	Medication adminis	tration error		
Comments		Form completed I	by	
		Contact us · picar	net@leeds.ac.uk · 0113 343 8125	
		For more contact det		
		www.picanet.org.uk	c/contact-us nanuals and guidance, go to	
		www.picanet.org.ul		

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Transport times		
BASE TO COLLECTION UNIT	PATIENT JOURNEY Tick if this section of the trip is not applicable	DESTINATION UNIT TO BASE
Mode of transport (tick all that apply) □ Dedicated ambulance □ RRV □ Taxi □ Other ambulance □ Air → □ Other	Mode of transport (tick all that apply) Dedicated ambulance RRV Taxi Other ambulance Air + Other	Mode of transport (tick all that apply) Dedicated ambulance RRV Taxi Other ambulance Air + Other
Depart base (dd/mm/yyyy hh:mm) / / 20	Depart collection unit (or location)	Depart destination unit (or location)
	Arrive collection airport ///20 ///20 ·· Aircraft type Unpressurised fixed-wing Pressurised fixed-wing Other helicopter	Arrive destination airport ///20 //20 ·
	Takeoff collection airport / / 2	Takeoff destination airport //20 : //20 : + Land base airport : //20 : + Depart base airport //20 :
Arrive collection unit (or location) Arrive collection unit (or location) Arrive collection unit (or location) Arrive collection Blue light or siren used or requested? Yes No Organisational delay None Team out Staffing Vehicle Vehicle incident	Arrive destination unit (or location) Blue light or siren used or requested? Yes No Organisational delay None Team out Staffing Vehicle Vehicle incident	Arrive base Arrive
None Vehicle accident Vehicle breakdown	None Vehicle accident Vehicle breakdown	None Vehicle accident Vehicle breakdown
Interventions (retrievals only)	PIM (retrievals only)	24
Interventions (retrievals only) Interventions by local team prior to arrival of transport team (tick all that Primary intubation apply) Re-intubation apply) Re-intubation apply) Re-intubation apply) Primary intubation apply) Re-intubation apply) Re-intubation apply) Primary invasive ventilation High flow nasal cannula therapy Primary central venous access Additional central venous access Additional central venous access Aterial access Inotrope or vasopressorinfusion Prostaglandin infusion Primary intraosseus access Chest drain insertion ICP monitoring ECMO Interventions while transport team in attendance (tick all that apply) Primary intraose ventilation Re-intubation Other airway Non-invasive ventilation High flow nasal cannula therapy Primary central venous access Additional central venous access Additional central venous access Interventions of vasopressorinfusion Primary central venous access Inotrope or vasopressorinf	PIM (retrievals only) This applies to observations recorded in the first hour after first face-to-face contact with transportearn doctor Elective admission Tick if this is an elective 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 Liver failure main reason for ICU admission Liver failure main reason for ICU admission Acute NEC main reason for ICU admission Spontaneous cerebral haemorrhage Neurodegenerative disorder	Systolic blood pressure mmHg (at time SpO2 SpO2 FiO2 measured) Wes No Atterial PaO2 or Arterial PaO2 Arterial PaO2 or Arterial PaO2 mmHg FiO2 Immediate mmHg Intubation? At the time of PaO2 sample Headbox? No Base excess Arterial Capillary Venous Lactate mmol/I+ . mmol/I+ Yes No Pres No Pao2 No Base excess Arterial Capillary Venous Lactate No Yes No Pres No Pupil reaction No Pupil reaction Both fixed and dilated

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PICANet Information Leaflets for Families and Carers 2021

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

Talk to the Doctors and Nurses

Email picanet@leeds.ac.uk

Visit our website at www.picanet.org.uk

Or

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

0116 252 5475

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

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



Principal investigators:

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

0116 252 5468

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

0113 343 4841

www.picanet.org.uk

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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 <u>PICANet Privacy and Fair Processing</u> <u>statement</u> available on our Policies page of the PICANet website-<u>www.picanet.org.uk</u>.

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 2021

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

Talk to your nurse or doctor

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

Visit our website at www.picanet.org.uk

Or

Call our Research Nurse, Lyn Palmer on

0116 252 5475

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

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



Principal investigators:

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

0116 252 5468

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

0113 343 4841

www.picanet.org.uk

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Paediatric Intensive Care Audit Network



Information leaflet for children admitted to paediatric intensive care.

0

What is a paediatric intensive care unit?

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

What is PICANet?

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

What does PICANet do?

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

Why is PICANet important?

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

What information is needed?

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

How is information collected?

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

What happens to my information?

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

Will the information be safe?

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

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



The Families and Carers and Children's information leaflets were/are also available for Welsh and Irish patients and families. 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 (v4.1 17 Dec 2021) was in place at the latest date of the reporting period – 31st December 2021.

PICANet Patient Privacy Notice and Fair Processing Statement.

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

What data are being collected?

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

PICANet has permission to also collect personal identifiers of children or young people admitted to or referred for Paediatric Intensive Care without taking explicit (written) consent from the children or their carers. This was granted by the NHS Health Research Authority Confidentiality Advisory Group. A summary of the entry for PICANet is available on the register of approvals on the <u>HRA website</u> (the references are: 21/CAG/0090 (non-research) and 21/CAG/0098 (research)). The personal identifiers include name, address, date of birth and health record identifier number (e.g. NHS number)*.

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

What are the data being used for?

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

Where are the data held and for how long?

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

Sharing data with other organisations

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

We have a rigorous process of assessing the merit of requests for data and information and publish details of these requests each year in our annual report. Data collected in English NHS paediatric intensive care units and specialist transport teams are controlled by the Healthcare Quality Improvement Partnership and all requests go through their Data Access Request Group. More details about the HQIP data request process can be found at: <u>http://www.hqip.org.uk/national-programmes/a-z-of-nca/audits-and-data-gov-uk/</u>.

What if I don't want information about me or about the child I care for included?

If you do not want information that would identify you or the child you care for included in PICANet, please tell the nurse or doctor in the paediatric intensive care unit. Alternatively, you can contact PICANet by telephone or email (details provided below) and we will ensure that your personal identifiers are taken off the database. You are free to request this at any time and any decision request removal of your or your child's identifiers will not alter the care you receive in this or any other hospital.

Please note that your child's anonymised information will remain in the PICANet national clinical audit database for non-research purposes.

You also have the right to request access to and to request to rectify information held about you or the child you care for.

Richard Feltbower Professor of Epidemiology School of Medicine University of Leeds Clarendon Way LS2 9JT, UK Tel +44 (0)113 343 4841

Elizabeth S Draper Professor of Perinatal & Paediatric Epidemiology Department of Health Sciences

College of Life Sciences University of Leicester George Davies Centre University Road, Leicester LE1 7RH, UK

Email: picanet@leeds.ac.uk

Who is responsible for the data?

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

Healthcare Quality Improvement

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

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

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

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

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

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

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

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

University of Leicester

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

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

What is the legal basis for processing the data?

The data are needed to carry out a task in the public interest to ensure high standards of quality and safety of healthcare.*

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

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

* General Data Protection Regulation:

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.

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.

Publications & Abstracts 2019-2021

Publications

Journal	Title	Authors
Acta Medica Lituanica (2019); 26(1), 64-71 doi: 10.6001/actamedica.v26i1.3957		Veģeris, I., Daukšte, I., Bārzdiņa, A., Parslow R. C., Balmaks, R.
Journal of Clinical Virology (2019); 112, 15- 19 doi: 10.1016/j.jcv.2019.01.006.	Human metapneumovirus in paediatric intensive care unit (PICU) admissions in the United Kingdom (UK) 2006-2014.	Barr, R., McGalliard, R., Drysdale, S. B.
Critical Care 23, 69 (2019). https://doi.org/10.1186/s13054-019-2354-4		Peters, M.J., Woolfall, K., Khan, I. et al.
BMJ Open 2019;9:e031630. doi: 10.1136/bmjopen-2019-031630	(SANDWICH): protocol for a cluster randomised stepped wedge trial	Blackwood B, Agus A, Boyle R On behalf of the Paediatric Intensive Care Society Study Group (PICS-SG), et al
Pediatric Critical Care Medicine: March 2019 - Volume 20 - Issue 3 - p 223-232 doi: 10.1097/PCC.000000000001805	Flow Nasal Cannula Therapy in PICUs in the United Kingdom and Republic of Ireland*	Morris, Jenny V. MSc ¹ ; Kapetanstrataki, Melpo PhD ¹ ; Parslow, Roger C. PhD ¹ ; Davis, Peter J. FRCPCH ² ; Ramnarayan, Padmanabhan FRCPCH ^{3,4}
Archives of Disease in Childhood 2019;104:962-966	intensive care retrieval teams in England	King M, Ramnarayan P, Seaton SE on behalf of the DEPICT Study Group, et al
BMJ Open 2019;9:e028000. doi: 10.1136/bmjopen-2018-028000	Paediatric Intensive Care and care during	Ramnarayan P, Evans R, Draper ES DEPICT Study Investigators, et al
Intensive Care Med 45, 1272–1274 (2019). https://doi.org/10.1007/s00134-019-05714-x	Doing more of less: what registry data tell us about death in PICU.	Brick, T., Parslow, R.C.
Archives of Disease in Childhood (2020). Published online: 06 October 2020. doi: 10.1136/archdischild-2020-319396	Tracheostomy trends in paediatric intensive care.	Powell, J., Buckley, H.L., Agbeko, R., et al.
BMC Pediatrics 20, 301 (2020). https://doi.org/10.1186/s12887-020-02195-6	Does time taken by paediatric critical care transport teams to reach the bedside of critically ill children affect survival? A retrospective cohort study from England and Wales	Seaton, S.E., Ramnarayan, P., Davies, P. et al.
BMJ Open. 2020 Sep 25;10(9):e037517. doi: 10.1136/bmjopen-2020-037517. PMID: 32978195; PMCID: PMC7520830.	NEUROlogical Prognosis After Cardiac Arrest in Kids (NEUROPACK) study: protocol for a prospective multicentre clinical	Scholefield BR, Martin J, Penny- Thomas K, Evans S, Kool M, Parslow R, Feltbower R, Draper

Journal	Title	Authors
	study in children after cardiac arrest.	ES, Hiley V, Sitch AJ, Kanthimathinathan HK, Morris KP, Smith F; NEUROPACK Investigators for the Paediatric Intensive Care Society-Study Group (PICS-SG).
Health Technology Assessment 2020;24(23). doi: 10.3310/hta24230	Routine gastric residual volume measurement to guide enteral feeding in mechanically ventilated infants and children: the GASTRIC feasibility study	Tume LN, Woolfall K, Arch B, Roper L, Deja E, Jones AP, et al.
BMJ Open 2020;10:e033208. doi: 10.1136/bmjopen-2019-033208		Randell R, Alvarado N, McVey L, et al
Intensive Care Med 46, 1953–1955 (2020). https://doi.org/10.1007/s00134-020-06149-5	Impact on 30-day survival of time taken by a critical care transport team to reach the bedside of critically ill children	Seaton, S.E., Ramnarayan, P., Pagel, C. et al.
BMJ Open 2020;10:e038974. doi: 10.1136/bmjopen-2020-038974	mixed methods study to explore the	Manning JC, Latour JM, Curley MA for the OCEANIC Study Investigators, et al
Sci Rep 11, 21838 (2021). https://doi.org/10.1038/s41598-021-01173-x		Almossawi, O., O'Brien, S., Parslow, R. <i>et al.</i>
<i>Crit Care</i> 25, 399 (2021). https://doi.org/10.1186/s13054-021-03779-z	In the eye of the storm: impact of COVID-19 pandemic on admission patterns to paediatric intensive care units in the UK and Eire.	Kanthimathinathan, H.K., Buckley, H., Davis, P.J. <i>et al.</i>
medRxiv 2021.06.30.21259763; doi: https://doi.org/10.1101/2021.06.30.2125976 3	Which children and young people are at higher risk of severe disease and death after SARS-CoV-2 infection: a systematic review and individual patient meta-analysis	Harwood, R et al.
medRxiv 2021.07.01.21259785; doi: https://doi.org/10.1101/2021.07.01.2125978 5		Ward, J L et al.
<i>Nat Med</i> 28 , 185–192 (2022). https://doi.org/10.1038/s41591-021-01578-1		Smith C et al.

Abstracts

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

Data Access Requests Fulfilled (sent to requester) January 2021-December 2021

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P044 HQIP332	Katie Harron (Ofran Almossawi), Non- Clinical Senior Lecturer, Universitry College London	Investigating gender mortality differences in children admitted to UK PICU	De-identified Individual + Identifiable for Linkage
P045 IS042	Richard Chin, Reader in Paediatric Neuroscience, Edinburgh University	Status Epilepticus – Feasibility work for Trial	Summary
P054 IS057	Bronagh Blackwood, SANDWICh Lead, Queens University Belfast, SANDWICh	SANDWICh (Sedation AND Weaning In CHildren): IMV Trial	Summary
P058	Richard Dobbie, Information Consultant, NHS National Services Scotland, Information Services Division	Review of Paediatric Intensive Care in Scotland	De-identified Individual
P060 IS055	Oliver Rivero-Arias, Associate Professor inHealth Economics, National Perinatal Epidemiology Unit, University of Oxford	Tracking the Impact of Gestational Age on Health, Educational and Economic outcomes: a Longitudinal Record Linkage Study (TIGAR)	Summary

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P063 IS064	Lorna Fraser, Professor of Epidemiology, University of York	Outcomes after PICU admission in children who have received a Haematopoietic Stem Cell Transplant (HSCT)	Summary
P064 HQIP365	Sarah Seaton, Research Fellow in Perinatal and Paediatric Research, University of Leicester	Understanding the transition from neonatal to paediatric care: a data linkage study	De-identified Individual + Identifiable for Linkage
P066 -	Simon Kenny/CMO, National Clinical Director, Children and Young People, NHS England	COVID-19 Vaccine Planning	De-identified Individual + Identifiable for Linkage
P067 IS075	Lucy Dove, Trustee, Lee Sparks Foundation	Incidence of Necrotising Fasciitis in Paediatric Intensive Care	Summary
P068 -	Peter Davis, Chair of NHS E PIC CRG, NHS England	PIMS-TS cases reported to PICANet by week	Summary (by Unit)
P070 -	Simon Kenny, National Clinical Director, Children and Young People, NHS England	Ethnicity in PICU Admissions	Summary

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P072 IS076	Laura Drikite, FIRST ABC Trial coordinator, ICNARC (Intensive Care National Audit & Research Centre)	FIRST-line support for Assistance in Breathing in Children (FIRST-ABC) Trial	Summary
P075 -	Dr Jon Lillie/ Dr Marilyn McDougall, PICU Consultants , Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Diabetic ketoacidosis (DKA) admissions to paediatric critical care over the last decade	De-identified Individual
P076, IS073	Peter Davis, Chair of NHS E PIC CRG, NHS England	Maximum Level of Care – To assist with planning to deal with a possible extreme surge in paediatric respiratory viral illness and response to the COVID-19 pandemic	Summary
P077, IS074	Peter Davis, Chair of NHS E PIC CRG, NHS England	Elective Activity in PICU - To assist with planning to deal with a possible extreme surge in paediatric respiratory viral illness and response to the COVID-19 pandemic	Summary
P080 HQIP387	Thomas Finnie / Hannah Williams, Principal Modeller / Senior Mathematical Modeller, Public Health England	RSV (Respiratory syncytial virus) Modelling - Estimating disease burden post COVID-19 mitigation	De-identified Individual
P084 IS077	Peter Davis, Chair of NHS E PIC CRG, NHS England	BPSU PIMS-TS ODN (Operational Delivery Network) numbers - To compare to the regional figures reported via BPSU for the study of PIMS-TS/MIS-C to help estimate case ascertainment for COVID-19 second wave	Summary

Reference numbers	Requester (Name, Position and Place of work/study):	Data Request:	Data Level of Request
P085 IS081	Kevin Morris, Prof / Consultant in Paediatric Critical Care, University of Birmingham	Optimising the Healthcare Resource Group (HRG) classification of cases receiving extra-corporeal membrane oxygenation (ECMO and ventricular assist device (VAD support)	Summary
P088 IS084	Kali Barrett, Assistant Scientific Director, Ontario COVID-19 Science Advisory Table Secretariat	COVID-19 Length of Stay (LOS) - Planning for 4th Wave	Summary
P090 ISO85	John Pappachan, Associate Professor, University Hospital Southampton NHS Foundation Trust	Bicarbonates in neonates - work-up to Randomised Clinical Trial	Summary
P091 -	Tiffany Watson-Koszel, Policy Manager, NHS England	COVID-19 Delta Wave Analysis	Summary

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

www.picanet.org.uk

picanet@leeds.ac.uk

University of Leeds

Richard Feltbower Hannah Buckley Zoe Cosker Kirsten Cromie Christopher Leahy Hannah Lever Lee Norman Thomas Simpson Laura Stubbs PICANet Leeds Institute for Data Analytics School of Medicine University of Leeds Clarendon Way Leeds LS2 9JT

University of Leicester

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

