

# The Paediatric Intensive Care Audit Network (PICANet)

## Project protocol

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### Document History

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## **BACKGROUND AND AIMS**

The Paediatric Intensive Care Audit Network (PICANet) is an international clinical audit of paediatric intensive care (PIC) activity in the UK and Republic of Ireland. It was established in 2001 with the aim of providing a secure and confidential, high quality clinical database of paediatric intensive care activity. It is now part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is recognised as the definitive source for paediatric intensive care data in the UK and Republic of Ireland.

PICANet collects data from NHS and private designated Paediatric Intensive Care Units (PICUs) providing paediatric Level 3 Critical Care<sup>1</sup> and Specialist Paediatric Critical Care Transport Services (see <https://www.picanet.org.uk/about/participating-organisations/> for a list of participating organisations).

The aims of PICANet are to support service evaluation, clinical audit and research.

### ***Service evaluation***

Objectives / Purpose:

Generating data to define the supply, demand and outcomes for current PIC services and the patient population using the service. This supports healthcare planning, quantifies resource requirements and provides contextual information to facilitate the review of the audit data at both national and individual PICU level. It also highlights areas for local audits, future research and generates baseline data for clinical trials.

Current measures include<sup>2</sup> :

- Numbers and types of admissions to PICU
- Prevalence of admissions to PICU
- Children receiving care in adult ICUs<sup>3</sup>
- Numbers and types of referrals for admission and/or transport and their outcomes (accepted or not)
- Numbers of patients admitted to PICU from outside the hospital and how they were transported
- Transport outcomes & journey duration

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<sup>1</sup> As defined in Time to Move On (RCPCH, 2014)

<sup>2</sup> This list is not exhaustive and is subject to change as appropriate (in line with the purpose stated)

<sup>3</sup> Data provided by ICNARC

- Interventions received (in PICU and during transport)
- Critical incidents for transports
- Level of care provided (by Health Resource Group<sup>4</sup>)
- Ventilator free days
- Bed activity and length of stay
- Wider health service resource use for patients using PIC services <sup>5</sup>

## **Audit**

Objectives / Purpose:

To improve the quality of care provided to patients as part of PIC services by measuring the quality of care and outcomes against pre-determined standards, benchmarking against other care teams and taking specific actions to improve quality of care.

Current measures include<sup>2</sup>:

- Outcome data:
  - o In-PICU mortality
  - o Longer term mortality <sup>6</sup>
  - o Emergency re-admissions within 48 hours
  - o Unplanned extubation
  
- Monitoring of PICS & other quality standards including:
  - o PICU Staffing data (for establishment and staff per occupied bed)
  - o Transport mobilisation time
  - o Transport to bedside time
  - o Clinical team leader grade for transports
  - o Parent present for transports
  - o Availability of other support services
  
- Custom audits (specific to an area of care):
  - o Delivery of renal interventions - providing information about the use of Continuous Renal Replacement Therapies (CRRT) in the critically ill child, an audit of current practice
  - o NET-PACK 3 – assessment of whether targeted temperature management (TTM) is following the ILCOR 2015 guidance and trial recent publications

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<sup>4</sup> As defined by National Casemix Office (commissioned by NHS England)

<sup>5</sup> Including linkage to Hospital Episode Statistics (HES) data

<sup>6</sup> Including linkage to Office for National Statistics (ONS) data

## **Research**

Objectives / Purpose:

To support high quality research in the areas of:

- paediatric intensive care
- specific conditions affecting children and young people accessing paediatric intensive care services (e.g. cardiac, neurological, infection, trauma)
- epidemiology of critical illness
- public health
- service evaluation, clinical audit or research methodology

to extend the available knowledge with a view to ultimately providing benefits to patients.

The project has had Research Ethics Committee (REC) approval as a Research Database since July 2005 (ref 05/MRE04/17). Under this approval, research can be carried out either by the PICANet Database Research Team or by sharing de-identified data with other researchers. Data may also be shared for the purposes of research if the recipient has their own project specific-research ethics approval in place and appropriate legal basis for data sharing.

Any use of data for research purposes is subject to approval as described in the Data Request and Publication Procedures section.

## **FUNDING**

PICANet is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit & Patient Outcomes Programme (NCAPOP), Welsh Health Specialised Services Committee, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, The National Office of Clinical Audit (NOCA), Republic of Ireland and HCA Healthcare.

## **MANAGEMENT AND GOVERNANCE**

The PICANet Management Team consists of the Principal Investigators (PIs) and staff from the Universities of Leeds (PI: Feltbower) and Leicester (PI: Draper). This team meets monthly to review progress against the timelines and contract deliverables, to consider any actual or potential barriers to satisfactory progress and to agree the work programme in the long and short term.

The entire project 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 service evaluation, audit and research in paediatric intensive care. The Steering Group has representatives from a broad range of organisations with an interest in PIC and includes lay representation, the Paediatric Intensive Care Society, and the Royal Colleges of Paediatrics and Child Health, Anaesthetists and Nursing. A full membership list is available on the PICANet website (<https://www.picanet.org.uk/people/steering-group/>).

In addition to these formal management structures, PICANet is overseen by a Clinical Advisory Group (CAG), whose members represent the paediatric intensive 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 PICU 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 service evaluation, audit or research activity and to encourage collaboration. The CAG has a representative on the Steering Group to give feedback from a clinical perspective. A full membership list is available on the PICANet website (<https://www.picanet.org.uk/people/clinical-advisory-group/>).

The PICANet Principal Investigators have regular contract review meetings with the main funder (HQIP) who monitor contract deliverables and finance and also provide advice on current Government quality improvement policy objectives.

HQIP are data controllers for the data collected from English NHS paediatric intensive care teams. The University of Leeds is data controller for data collected from paediatric intensive care teams in Wales, Scotland, Northern Ireland, Republic of Ireland and from the private hospitals.

## **CONSENT AND CONFIDENTIALITY**

PICANet processes directly identifiable patient information including names, addresses, and healthcare system number (e.g. NHS number, CHI number, local case note number) from PICUs and specialist transport and retrieval services in England, Wales and Scotland. With this information, PICANet can identify multiple admissions, referrals and transports for the same individual, making the dataset person and episode-based. Personally identifiable information is linked with death registration details held by the ONS to assess long-term mortality in children admitted to PIC. In addition, national census and other geographical data can be linked with individual children using validated postcodes, enabling PICANet to assess the association between geo-demographic and environmental information and PIC admissions as well as assess patient flows across the country.

Processing of personally identifiable data for the purposes of service evaluation, audit and research was approved by the Patient Information Advisory Group (now the Health Research Authority Confidentiality Advisory Group) in 2002 under Section 60 of the Health and Social Care Act (subsequently Section 251 of the NHS Act 2006) (reference PIAG 4-07(c) 2002). This approval has been renewed annually since this date. Data from Northern Ireland and the Republic of Ireland is submitted in a pseudonymised format with only indirect identifiers being collected. Data within the organisations in Northern Ireland and the Republic of Ireland can be linked but episodes of care for the same patient treated elsewhere cannot be linked.

Ethical approval was granted by the Trent Medical Research Ethics Committee, ref. 05/MRE04/17. A list of patient identifiable data items collected and stored by PICANet is given in Appendix A along with justification for their use.

## **DATASET DEVELOPMENT**

The original PICANet data set was established in consultation with members of the PICANet Clinical Advisory Group (CAG) and the Department of Health. The overriding criteria for inclusion of specific variables were that they provided key information on activity, case mix, demographics and outcome at a national and local level, that they were feasible to collect and that the wider PIC community supported their inclusion in the national database.



Subsequent additions to the dataset have been made to include data items that comprise the Paediatric Critical Care Minimum Data Set (PCCMDS)<sup>7</sup>, issued in February 2007 and the PICANet transport and referrals dataset. Data definitions are available in the PICANet Dataset Manuals available at: <https://www.picanet.org.uk/data-collection/data-manuals-and-guidance/>

In addition to the core datasets, customised data collection is carried out in a number of specific areas to address the needs of specific audit and service evaluation activity.

Data entry is via a secure web-based application called PICANet Web, either directly or via an upload facility for PIC teams that have their own in-house database systems. The system has in built automated validations and allows units to report on their own data. Training for data entry is carried out on site and at larger training sessions hosted by the PICANet project as required for major improvements or amendments to the data entry system. There is further guidance available for users on the PICANet website <https://www.picanet.org.uk/data-collection/data-manuals-and-guidance/>.

## **VALIDATION OF DATA**

Data validation is carried out at the point of data entry on the web system and centrally on the database. Validation checks for logical inconsistencies, out of range values and incorrect data are reported back to the individual PICUs on demand via the web interface. In addition, validation visits are also carried out by PICANet staff to verify submitted data against hospital notes and referral and transport records and also to cross-reference admissions reported against admission numbers at the units. These validation visits are vitally important to maintain contact with PIC staff and to pick up on systematic errors that may appear in the data, following staff changes.

## **REPORTING**

PICANet produces an annual report on all data for the previous 3 calendar years in the Autumn. All the reports that have been published are available on the PICANet website at [www.picanet.org.uk](http://www.picanet.org.uk). Local reports are available to contributing PIC teams with the option of downloading aggregated data from all PIC teams for comparison from PICANet Web.

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<sup>7</sup>[http://www.datadictionary.nhs.uk/data\\_dictionary/messages/supporting\\_data\\_sets/data\\_sets/paediatric\\_critical\\_care\\_minimum\\_data\\_set\\_fr.asp](http://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/data_sets/paediatric_critical_care_minimum_data_set_fr.asp)

## DATA REQUEST AND PUBLICATION PROCEDURES

All requests for processing of data by third parties (outside the Research Database Team) or for purposes outside the established audit and service evaluation are reviewed from a clinical perspective by representatives of the Clinical Advisory Group (CAG). Furthermore, all requests relating to research or clinical trials will be sent to the chair of the Paediatric Intensive Society Study Group to ensure that there is good collaboration in the clinical community and no overlap of effort. Both groups are able to give advice to applicants on their proposals and suggest collaborations.

To ensure all data requests have an appropriate legal basis for processing, have ethical approval (where appropriate) and sufficiently robust data security measures in place, requests are also reviewed by the PICANet team and, where requests involve data from English providers, will be subject to approval by the HQIP Data Access Review Group (DARG) (<https://www.hqip.org.uk/national-programmes/accessing-ncapop-data/#.Wz4sWtVKhhE>). Prior to any data access/processing a Data Sharing Agreement will be put in place between the data controller and the processor. The data requests process is outlined here: <https://www.picanet.org.uk/data-collection/data-requests/>

PICANet publishes all data and information requests on our website ([www.picanet.org.uk](http://www.picanet.org.uk)).

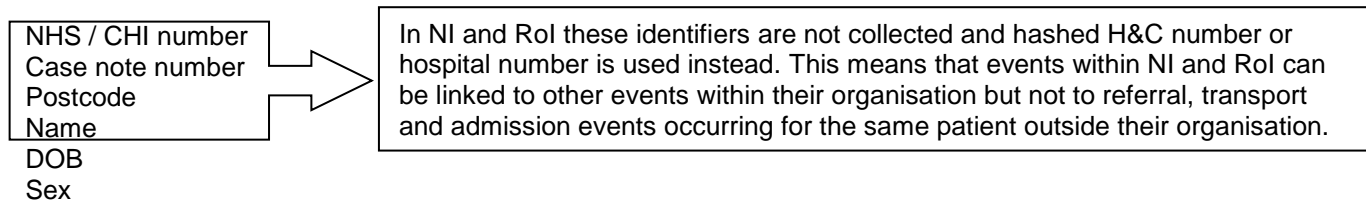
Anyone who receives data or information from PICANet must provide a written response on how the data has been used and acknowledge PICANet in all presentations and reports. In the case of publication, it is expected that a member of the PICANet team will be included as an author and therefore will have reviewed the manuscript and contributed to the analysis and interpretation.

## Appendix A: Patient identifiable data items collected by PICANet

Data Categories	Is this field used?					Justifications
	England	Wales	Scotland	Northern Ireland (NI)	Republic of Ireland (RoI)	
<b>Personal Data</b>						
Name	Y	Y	Y	N	N	<p>Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *.</p> <p>Used for data ascertainment purposes as part of routine data validation for the study</p> <p>Required for planned linkage to other routine data sets (e.g. ONS via NHS Digital) **</p> <p>To assign and verify ethnic group based on name recognition software (e.g. OnoMap)</p> <p>Children were historically given their mother's NHS number at the time of birth. In such cases other identifiers have been required to distinguish between twins and to link any early admissions for such patients to subsequent admissions using their own NHS number once issued.</p>
NHS number / CHI number / H&C number	Y	Y	Y	Submitted in hashed format	N	<p>Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *.</p> <p>Used for data ascertainment purposes as part of routine data validation for the study</p> <p>Required for planned linkage to other routine data sets (e.g. HES &amp; ONS via NHS Digital) **</p>
Address	Y	Y	Y	N	N	<p>Required for planned linkage to other routine data sets (e.g. HES &amp; ONS via NHS Digital) **</p> <p>Address is used to validate postcode in AFD Refiner software (or manually if not available in AFD Refiner).</p>
Postcode	Y	Y	Y	N	N	<p>Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *</p> <p>Required for planned linkage to other routine data sets (e.g. HES &amp; ONS via NHS Digital) **</p> <p>Postcode used to validate address in AFD Refiner software (or manually if not available in AFD Refiner).</p> <p>Postcode is used to identify patients resident within a health authority area to provide information to commissioners.</p> <p>Address and postcode are also used for the devolved nations' reports, in which we report on children resident in the different countries.</p> <p>Also used to calculate distance between home and the</p>

Data Categories	Is this field used?					Justifications
	England	Wales	Scotland	Northern Ireland (NI)	Republic of Ireland (RoI)	
						unit of admission and assign deprivation score as part of health inequality analyses.
Date of birth	Y	Y	Y	Y	Y	Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *  Required for planned linkage to other routine data sets (e.g. HES & ONS via NHS Digital) **
Date of death	Y	Y	Y	Y	Y	To allow survival and mortality analyses to be performed.  Used to check if the child was admitted after their death, an admission like this is excluded from the SMR analysis.  Also used to clean the dataset before the production of the Annual Report, as we check for inconsistencies between discharge date and date of death.  Also planned comparison with date of death in other routine datasets (e.g. ONS from NHS Digital) to ensure accurate data received
Sex	Y	Y	Y	Y	Y	Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *  Required for planned linkage to other routine data sets (e.g. HES & ONS via NHS Digital) **  Used in various statistical models for analysis of the data as sex is a known confounder in clinical research.
General Identifier e.g. Hospital No	Y	Y	Y	Submitted in hashed format in absence of H&C number	Submitted in hashed format	Required for assigning admission, referral and transport events to an individual patient identifier within the database using a probabilistic matching algorithm (see below) *  Local identifiers such as case note number are used for local cross referencing and validation.
<b>Sensitive Personal Data</b>						
Physical / Mental Health or Condition	Y	Y	Y	Y	Y	These data are collected to provide the data to fulfil the aims and objectives of the project
Racial / Ethnic Origin	Y	Y	Y	N	Y	To allow assessment of outcomes according to ethnic origin – this has identified differences in outcomes which are being investigated

\* A probabilistic matching algorithm is used for the following elements to assign admission, referral and transport events to an individual patient identifier within the database:



Use of these identifiers maximises distinction between siblings and multiple births and minimises non-matches and mismatches.

Events need to be assigned to an individual patient in order to:

- identify emergency readmissions (an outcome measure)
- identify long term / repeated use of NHS services by individuals
- assess the number of referral / transport refusals for individual patients

The use of a pseudo-identifier to enable event assignment to an individual patient is not feasible or practical in the paediatric intensive care setting as the care pathway is highly complex with patients transferred between district general hospitals, specialist transport and retrieval teams and PICUs across the country (and across national borders) often in circumstances of emergency or urgent care need. As such the consistent and accurate communication of a PICANet identifier between all these different care teams would be unworkable and would not provide robust linkage.

\*\* These are the key identifiers for undertaking electronic data linkage with routine datasets to examine longer term outcomes including survival, subsequent health service usage and morbidity. Without these identifiers there will be missed linkages and erroneous linkages [Hagger-Johnson G, Harron K, Fleming T, et al Data linkage errors in hospital administrative data when applying a pseudonymisation algorithm to paediatric intensive care records *BMJ Open* 2015;5:e008118. doi: 10.1136/bmjopen-2015-008118]