Understanding Practice in Clinical Audit and Registries tool: UPCARE-tool

A protocol to describe the key features of clinical audits and registries

1.1. FAQ

Who should complete the tool?

This tool is designed to be completed by individuals and organisations planning and implementing clinical audits and registries. It has been specifically designed for national clinical audits and registries commissioned by the Healthcare Quality Improvement Programme (HQIP; Part of the National Health Service in England) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP), but can be adapted and used by audits and registries in other settings.

What is the tool for?

The tool is a protocol for audits and registries. It has been designed to provide a “one-stop” summary of the key information about how clinical audits and registries have been designed and carried out. It is expected that this will be published openly for anyone to view, and help users of audit/registry data and audit/registry participants understand the methods, evaluate the quality and robustness of the data, and find information and data that is most relevant to them. For national clinical audits and registries commissioned by HQIP, the intention is that publishing this information openly will reduce the requirement for reporting ad hoc and contract monitoring data and information to HQIP and other national agencies.

What type of information is contained within UPCARE?

It is intended that the responses to the tool are factual and written concisely. Where possible, documents can be embedded and hyperlinks provided if information is published elsewhere. This document is intended to be a complete account of the information for the audit or registry. Please be vigilant about keeping any links included in the document up to date so readers can access full information about the audit or registry.

This tool is not intended to be used to formally “score” the quality of the responses. The design of this tool has been inspired by reporting checklists used for clinical guidelines (e.g. AGREE[1]) and in reporting research studies (e.g. STROBE[2], SQUIRE[3]).

Who is the intended audience for the tool?

The information contained within the UPCARE tool will enable audit and registry stakeholders to access in one place and in a standard format key information about the audit/registry and evaluate the integrity and robustness of the audit.

Examples of audit/registry stakeholders include:

- Patients / Carers / Public / Patient representative organisations
- Clinicians / Allied health professionals / Healthcare providers / Multi-disciplinary teams / Primary, secondary and tertiary care providers
- National agencies
- Commissioners
- Healthcare regulators

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[1] AGREE stands for the Appraisal of Guidelines for Research & Evaluation. See https://www.agreetrust.org/about-the-agree-enterprise/introduction-to-agree-ii/, last accessed 24 April 2018.

[2] STROBE stands for Strengthening the Reporting of Observational Studies in Epidemiology. See https://www.strobe-statement.org/index.php?id=strobe-home, last accessed 24 April 2018.

[3] SQUIRE stands for Standards for Quality Improvement Reporting Excellence. See http://www.squire-statement.org/, last accessed 24 April 2018.

FAQ (cont'd)

How should the responses be written?

Please try and write responses clearly as this will help to make the tool accessible and useful. Some tips and suggestions for writing clearly include:

- avoiding technical jargon where possible
- using short paragraphs and bullet points
- using the "active" voice rather than passive
- keeping sentences short

Where information is published openly elsewhere please provide links and references rather than duplicating information that is already available

When and how often should I complete the tool?

The tool is intended to provide accurate and up to date information about the audit/registry, and so can be updated whenever and however frequently it is relevant to do so. For national clinical audits and registries commissioned by HQIP it is intended that the tool is updated annually, although audits can update the tool more frequently if they wish to.

Each version of the tool should include a date of publication and version number.

Where should the completed UPCARE report be published?

The completed tool should be published online e.g. on the website for the audit or registry.

How was UPCARE designed?

HQIP commission, manage and develop the NCAPOP (National Clinical Audit and Patient Outcomes Programme) under contract from NHS England and devolved nations. The work was led by HQIP who set up a Methodological Advisory Group (MAG) consisting of methodological, statistical and quality improvement experts. Meeting were held on a six monthly basis and the structure and content of the eight quality domains and their key items were agreed by the MAG. The tool was piloted by 5 programmes within the NCAPOP and re-edited in light of comments received. Other comments received by MAG members was also considered as part of the re-editing process. The final version of the UPCARE tool was signed off by the HQIP MAG and will be reviewed annually.

IPR and copyright

Contents

Domain 1: Organisational information

1.2. The name of the programme

Paediatric Intensive Care Audit Network (PICANet)

1.3. The name of the organisation carrying out the programme

Collaboration between The University of Leeds and The University of Leicester.

1.4. Main website for the programme

www.picanet.org.uk

1.5. Date of publication and version number of the tool on your website

v1.0
02/10/2019

Domain 2: Aims and objectives

2.1. Overall aim

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[4] 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.

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.

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.

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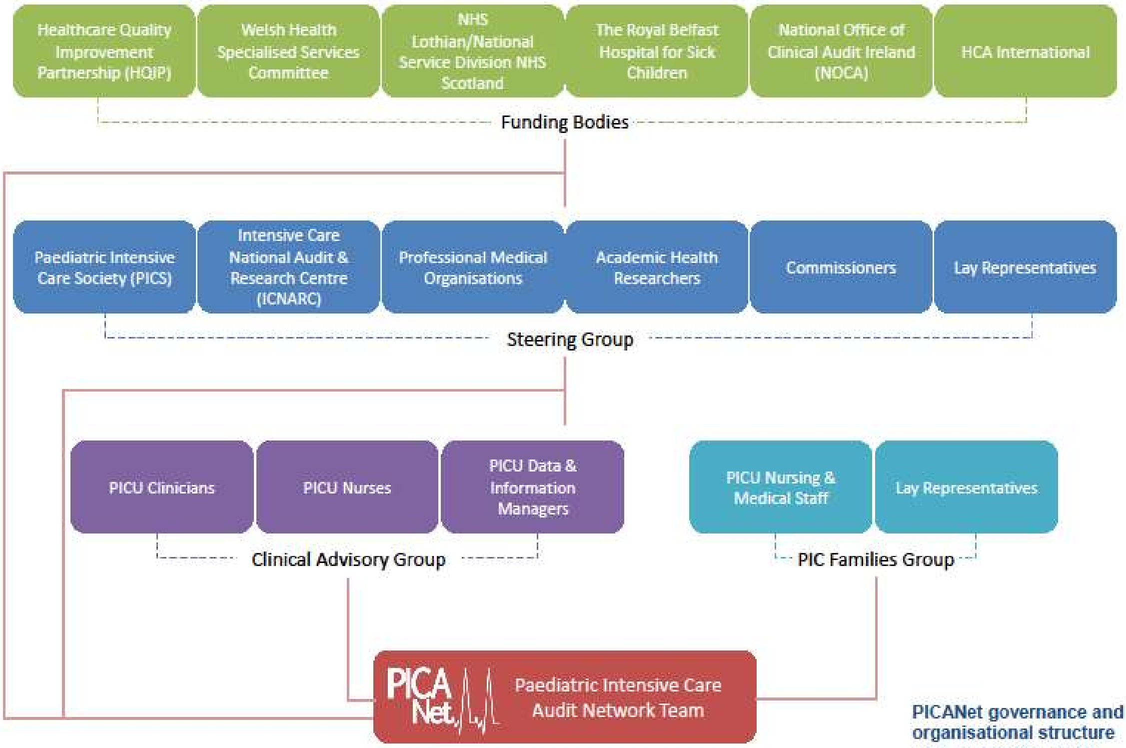
[4] As defined in Time to Move On (RCPCH, 2014)

2.2. Quality improvement objectives

The key metrics have been developed with quality improvement in mind. Specific quality improvement objectives are being developed in discussion with our Clinical Advisory Group, HQIP's Quality Improvement Lead and Get It Right First Time Lead for Paediatric Critical Care.

Domain 3: Governance and programme delivery

3.1. Organogram



PICANet governance and organisational structure v1.0, September 2016

3.2. Organisations involved in delivering the programme

Delivery of the Programme

Delivery of the programme is managed as a collaboration between the University of Leeds and the University of Leicester. The University of Leeds are responsible for the secure hosting of the PICANet Web database and take a lead on governance arrangements, managing data requests and analysis of the Admissions dataset. The University of Leicester provide clinical input to the team, are responsible for performing unit and transport team validation visits and take a lead on analysis of the Referral, Transport and Staffing data.

Governance / Steering of the Programme

Intensive Care National Audit and Research Centre (ICNARC)
The Intensive Care National Audit and Research Centre (ICNARC) run national clinical audits of the quality of care within adult intensive care units. ICNARC is represented on the PICANet Steering Group.
https://www.icnarc.org/

Paediatric Intensive Care Society (PICS)
The Paediatric Intensive Care Society (PICS) is the main professional society representing the UK paediatric intensive care community. PICANet works closely with PICS and audits practice against a number of PICS standards. The PICS President and PICS Study Group Chair are members of the PICANet Steering Group. http://picsociety.uk/

NHS England (Commissioners)
NHS England commissions paediatric critical care within England and also commissions the National Clinical Audit and Patient Outcomes Programme (NCAPOP) via HQIP. NHS England is represented on the PICANet Steering Group. https://www.england.nhs.uk/

Funders

Healthcare Quality Improvement Partnership (HQIP)
PICANet is commissioned for care providers within England by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit & Patient Outcomes Programme (NCAPOP). HQIP is represented on the Steering Group. www.hqip.org.uk

National Office of Clinical Audit (NOCA)

PICANet is commissioned for care providers within Ireland by the National Office of Clinical Audit (NOCA). www.noca.ie

The Royal Belfast Hospital for Sick Children

PICANet is commissioned for care providers within Northern Ireland by The Royal Belfast Hospital for Sick Children. The Royal Belfast Hospital for Sick Children are represented on the Steering Group and Clinical Advisory Group. www.belfasttrust.hscni.net/hospitals/ChildrensHospital.htm

Welsh Health Specialised Services Committee

PICANet is commissioned for care providers within Wales by the Welsh Health Specialised Services Committee. www.whssc.wales.nhs.uk/home

NHS Lothian/National Service Division NHS Scotland

PICANet is commissioned for care providers within Scotland by NHS Lothian/National Service Division NHS Scotland.

HCA Healthcare

PICANet is commissioned for a number of private care providers within England by HCA Healthcare. www.hcahealthcare.co.uk

3.3. Governance arrangements

The PICANet 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, 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/)

3.4. Declarations and Conflicts of interest

A policy for Declarations and Conflicts of interest is under development and will be published by PICANet along with a DOI/COI register on the PICANet website once available.

Domain 4: Information security, governance and ethics

4.1. The legal basis of the data collection

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, the Republic of Ireland and Latvia 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 to identify the same person but episodes of care for the same patient treated elsewhere cannot be linked.

Posters and information leaflets (for parents/carers and for children) are displayed in intensive care units and details of how personal identifiers are processed are outlined in our Privacy Notice and Fair Processing Statement.
These documents are all available on the PICANet website and are also available in Welsh.
www.picanet.org.uk/patients-and-families-information/

Patients, parents and carers have the option to request that the child's personal identifiers are removed from the database (this is outlined in the information leaflets, posters and in the PICANet Privacy Notice and Fair Processing Statement).

The project has had Research Ethics Committee (REC) approval as a Research Database since July 2005 (ref 18/EM/0267). Under this approval, research can be carried out either by the PICANet Database Research Team or by sharing de-identified data with other researchers (subject to a data access approval process).

4.2. Information governance and information security

The Information Governance Toolkit score achieved for the University of Leeds SEED server on 28/03/2018 was 71% (satisfactory). This indicates that the programme can be trusted to handle personal information securely. The link is https://www.igt.hscic.gov.uk/AssessmentReportCriteria.aspx?tk=435056258819735&lnv=3&cb=5de10b21-e1c6-45d7-a930-2a63fbf5211f&sViewOrgId=46385&sDesc=8E218+-+SEED

Domain 5: Stakeholder engagement

5.1. Approaches to involving stakeholders

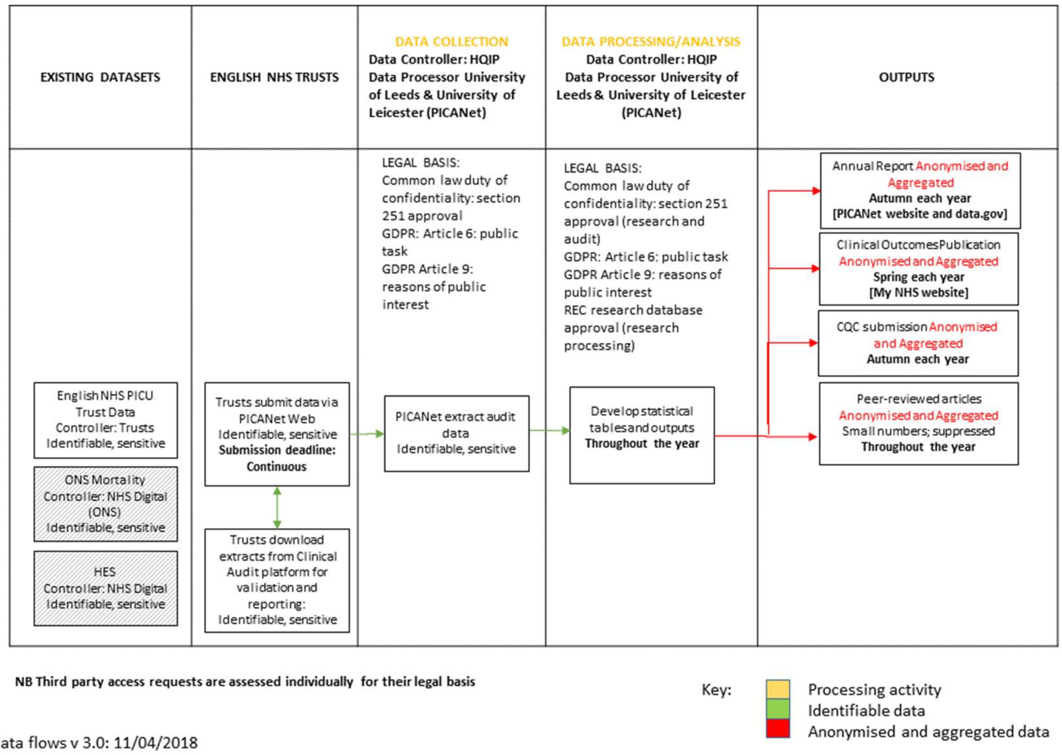
All stakeholders were originally involved in designing the programme and defining the aims and objectives.

Clinicians, nurses and audit staff are involved in collecting data and via the Clinical Advisory Group who help to select quality metrics and contribute to the data analysis and interpretation.

Patients and carers are involved via the Parent and Families Group and also via representation on the Steering Group defining aims and objectives for the programme.

Domain 6: Methods

6.1. Data flow diagrams



NB Third party access requests are assessed individually for their legal basis

PICANet data flows v 3.0: 11/04/2018

6.2. The population sampled for data collection

The database collects data on all children and young people accepted for referral, transported or admitted to designated paediatric intensive care units (PICUs) providing paediatric Level 3 Critical Care (as defined by the Royal College of Paediatrics and Child Health).

6.3. Geographical coverage of data collection

Data is collected from all:

- designated Paediatric Intensive Care Units (PICUs) providing Level 3 Critical Care (as defined by the Royal College of Paediatrics and Child Health)
- and Specialist Paediatric Critical Care Transport Services

in the UK, Ireland and Latvia (PICU only)

6.4. Dataset for data collection

There are three core patient level datasets:

- Referral
- Transport
- Admission

These collect data relating to patient demographics; referral, transport and admission details; diagnosis; interventions received and outcomes.

Customised data collections are also carried out from time to time which collect additional clinical data items specific to an area of care or in response to local or national policy requirements.

The data definition manuals can be found here:
https://www.picanet.org.uk/data-collection/data-manuals-and-guidance/

Staffing data is also collected on an annual basis via a staffing survey.

The dataset has been published on data.gov.uk since 2009.

6.5. Methods of data collection and sources of data

Data is collected via a secure web-based application designed specifically for PICANet (known as PICANet Web), either directly or via an upload facility for PIC teams that have their own in-house database systems

6.6. Time period of data collection

Prospective data collection started in 2002 and is continuously ongoing

6.7. Time lag between data collection and feedback

Submission of data to PICANet:
The PICS Standard for submission of Admission data to PICANet is as follows (L3-702):
'The service should collect and submit Paediatric Intensive Care Audit Network (PICANet) data for submission to PICANet as soon as possible and no later than three months after discharge from the PCC unit.'

The PICS Standard for submission of Referral and Transport data to PICANet is as follows (T-701):
'Paediatric Intensive Care Audit Network transport dataset for submission to PICANet as soon as possible and no later than three months after the transfer.'

Feedback
Once submitted to PICANet, units and transport teams can download their own data and run reports to support local audit immediately.

The first draft of the audit-wide benchmarked Annual Report outputs are prepared and submitted to audit commissioners in August of each year within four and a half months of the data becoming available (end of March each year). The feedback and review process is predicted to take up to a further 5 months from this point.

6.8. Quality measures included in feedback

Current **key** quality metrics:

- Outcome metrics:
    - In-PICU risk adjusted mortality
    - Emergency re-admissions within 48 hours
- Process metrics:
    - Transport mobilisation time
- Organisational / structure metrics
    - PICU nurse staffing establishment data

These metrics are represented at the unit or transport team level (as appropriate).

6.9. Evidence base for quality measures

The evidence base for the quality metrics is as follows:

- Outcome metrics:
    - In-PICU risk adjusted mortality

      The risk adjustment model used to determine risk-adjusted mortality (Paediatric Index of Mortality) has been externally validated (DOI: 10.1097/PCC.0b013e31829760cf)

    - Emergency re-admissions within 48 hours

      Clinical consensus within Clinical Advisory Group and Steering Group and designed to measure NHS England Specialised Services Quality Dashboard

- Process metrics:
    - Transport mobilisation time

      Clinical consensus within Clinical Advisory Group and Steering Group and designed to measure NHS England Specialised Services Quality Dashboard

- Organisational / structure metrics
    - PICU nurse staffing establishment data

      PICS Standard L3-207

6.10. Case ascertainment

Every PICU receives a validation visit from the PICANet research team on a rolling programme. At these visits the numbers of admissions locally are compared with the numbers held on the PICANet database (known as the ascertainment check) and any discrepancies are followed up by the PICU. This information is used to estimate the case ascertainment for admission events across the audit. In the 15 PICUs visited in 2017, we found that almost all admissions were reported to PICANet and our case ascertainment was estimated to be 99.4%.

6.11. Data analysis

The outlier policy for PICANet is published on the PICANet website:
https://www.picanet.org.uk/wp-content/uploads/sites/25/2018/05/PICANet_Policy_on_Units_lying_outside_the_control_limits-5_oct2015.pdf

Each section of the Tables and Figures published each year as part of the Annual Report is prefaced by a detailed description of the tables and definitions and analysis methods used (including relevant peer reviewed publications).

6.12. Data linkage

No linkage is currently performed.

6.13. Validation and data quality

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.

Data cleaning takes place on the frozen dataset prior to analysis to minimise the number of validation errors present at the time of final database lock and validates address details and clinical coding prior to analysis.

Case ascertainment and data quality is reported in each Annual Report.

The risk adjustment model used to determine risk-adjusted mortality (Paediatric Index of Mortality) has been externally validated (DOI: 10.1097/PCC.0b013e31829760cf)

Domain 7: Outputs

7.1. The intended users or audience for the outputs

The audit designs and produces outputs intended for:

- Clinical teams
- Specialist commissioners
- Trust/hospital boards
- Clinical commissioning groups

Summary report and tables and figures

- The Care Quality Commission (direct submission of data as part of National Clinical Audit Benchmarking)
- Patients and carers (summary report and My NHS data)
- General public (summary report My NHS data and publication on data.gov)

7.2. Editorial independence

As an independently commissioned programme, the contents of the outputs are written by the PICANet Principal Investigators Prof Liz Draper and Dr Richard Feltbower in conjunction with the PICANet Statistician and quality assured via the validation and governance processes described in previous sections.

7.3 The modalities of feedback and outputs

The audit provides feedback and outputs in the following formats:

- Clinical teams - Summary report and tables and figures including key metrics and benchmarking data where appropriate; real time data & reports & data downloads available; Annual Meeting for clinical teams presenting key findings and recommendations

- Specialist commissioners
- Trust/hospital boards
- Clinical commissioning groups

Summary report and tables and figures including key metrics and benchmarking data where appropriate

- The Care Quality Commission - direct submission of key metrics as part of National Clinical Audit Benchmarking
- Patients and carers - an ‘Easy Access’ summary report and data relating to key metrics on My NHS
- General public - an ‘Easy Access’ summary report, data relating to key metrics on My NHS data and publication on data.gov

7.4 Recommendations

The audit made 7 recommendations for PICUs, specialist critical care transport teams, commissioners and the Paediatric Intensive Care Society in the 2018 Annual Report. The link to the report is https://www.picanet.org.uk/wp-content/uploads/sites/25/2018/11/PICANet-2018-annual-report-summary-v1.1.pdf

7.5 Comparators and benchmarking

The audit provides comparative performance data for Paediatric Intensive Care Units (PICUs) and Specialist Paediatric Critical Care Transport Services. Each hospital has its performance measured against:

- Other units / transports teams across the UK and Republic of Ireland
- Paediatric Intensive Care Standards
- NHS England Specialised Services Quality Dashboard targets

Some summary data is presented at a National level.

7.6 Motivating and planning quality improvement

The audit supports participants in QI by:

- Providing key QI recommendations for action within the summary report
- Hosting Annual Meetings to discuss the audit’s key recommendations
- Providing online reporting facilities in real-time
- Supporting local audits with customisable local audit facilities
- Circulating RSPRT plots on a quarterly basis to encourage real time monitoring of mortality
- Providing guidance on interpretation of funnel plots and RSPRT plots