



November 2015 Annual Report

SUMMARY REPORT

Paediatric Intensive Care Audit Network





data collection period January 2012 – **D**ecember 2014















KEY

Α		Cambridge University Hospitals NHS Foundation Trust
B *		Brighton & Sussex University Hospitals NHS Trust
С		Cardiff & Vale University Health Board
D		Central Manchester University Hospitals NHS Foundation Trust
E		Great Ormond Street Hospital for Children NHS Trust
	E1	PICU/NICU
	E2	CCCU
F		Guy's & St. Thomas' NHS Foundation Trust (Organisation F includes data on journeys carried out by STRS)
G		Hull & East Yorkshire Hospitals NHS Trust
Н		King's College Hospital NHS Trust
1		Leeds Teaching Hospitals NHS Trust
К		Newcastle upon Tyne Hospitals NHS Foundation Trust
	K1/K3	Great North Children's Hospital
	К2	Newcastle Freeman Hospital
L		University Hospitals of North Midlands NHS Trust
Μ		Queens Medical Centre Nottingham University Hospitals NHS Trust
Ν		Oxford University Hospitals NHS Trust
0		Royal Brompton & Harefield NHS Foundation Trust
Р		Royal Liverpool Children's NHS Trust
Q		Sheffield Children's NHS Foundation Trust
R		Southampton University Hospitals NHS Trust
S		South Tees Hospitals NHS Trust
Т		St. George's Healthcare NHS Trust
U		Imperial College Healthcare NHS Trust (SMH)
V		Birmingham Children's Hospital NHS Trust
W		University Hospitals Bristol NHS Foundation Trust
Х		University Hospitals of Leicester NHS Trust
	X1	Leicester Glenfield Hospital
	X2	Leicester Royal Infirmary
Y		NHS Lothian – University Hospitals Division
Z		Barts and the London NHS Trust
ZA		NHS Greater Glasgow and Clyde – Women and Children's Division
ZB		The Royal Group of Hospitals and Dental Hospitals HSS Trust
ZC		Our Lady's Hospital for Sick Children, Dublin
ZD		The Children's University Hospital, Dublin
ZE		Harley Street Clinic (non-NHS)
ZF		The Portland Hospital for Women and Children (non-NHS)
CATS		Children's Acute Transport Service
Embrace	1	Yorkshire & Humber Infant & Children's Service
KIDS		Kids Intensive Care & Decision Support
NWTS		North West and North Wales P.T.S
SORT		Southampton and Oxford Retrieval Team
STRS		South Thames Retrieval Service (Journeys carried out presented as Organisation F)

* Brighton is no longer designated as a PICU and so will not be included in future annual reports

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 PICANet
 Telephone: 0113 343 8125

 School of Medicine
 E-mail: picanet@leeds.ac.uk

 Room 8.49, Worsley Building
 University Of Leeds

 Leeds, LS2 9JT
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For the Tables and Figures and Appendices to this report

PLEASE VISIT:

WWW.PICANet.ORG.UK

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ACKNOWLEDGEMENTS

The ongoing success of this international clinical audit is dependent on the hard work and commitment of a large number of individuals working within the paediatric intensive care community. We are very grateful to all the audit clerks, secretaries, nurses and doctors who support and contribute to the Paediatric Intensive Care Audit Network (PICANet) from their own paediatric intensive care units (PICUs).

PICANet was established in collaboration with the Paediatric Intensive Care Society (PICS) and their active support continues to be a key component of our successful progress. The PICANet Steering Group (SG) has patient, academic, clinical, government and NHS members all of whom are thanked for their continuing assistance and advice. Members of the Clinical Advisory Group (CAG) provide a formal interface between PICANet and clinical care teams and their valuable support and contribution is gratefully acknowledged.

We are also grateful for the support and commitment given by members of the PIC Families Group.

The PICANet Audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). 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, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCA Programme, comprising of more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The PICANet Audit is funded by NHS England, the Welsh Government, 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.

FOREWORD

Data and information are vital to inform choices, make difficult decisions (both personal and clinical) and to enable the mechanisms of government to decide how to spend tax payers' money. Data and information relate both to processes and outcomes and in healthcare a lot of effort has been put into getting processes right to deliver health care and increasingly professionals, politicians and the public are interested in outcomes.

In the pursuit of excellence in healthcare it is important to ensure 3 key "ingredients" are in place as follows:

- 1. Service providers need to have the right skills and knowledge for the healthcare provided
- 2. The correct systems and processes need to be in place to enable the right care and treatment to be effectively delivered
- 3. The culture of the service must be right and in particular be patient centred

In the 21st century whatever healthcare is provided you must be able to:

- Measure what you do
- Compare the performance with peers
- Identify how this performance can be improved

The rich data and information that exists within the PICANet 2015 Annual Report, as well as the whole 11 year database, provides the paediatric critical care community, academics, commissioners and public of Britain and Northern Ireland with "hard facts" that can be used intelligently to support the pursuit of excellence. We can ensure that within the PICUs of UK and Ireland that continual improvement is part of the culture and for the sake of our patients and their families that we deliver the best care possible with the resources available.

The PIC community has made great strides in advancing care over the last 20 years. NHS England and the Secretary of State for Health have been pushing the development of 7 day services over the last couple of years. PIC provision has been on a 7 day basis for a long time, though some of the data in this report shows that there are still improvements to be made on staffing for Sundays.

The PICANet reports have published data identifying centre for a number of years and this approach supports scrutiny and encourages openness. If we reflect back to the 1997 report A Framework for the Future, we can see although significant advances have been made on the 7 key features of PIC at the time, for some, much more is needed (there is still a lack of evidence on standards that provide the best outcomes for critically ill children). As mortality becomes an increasingly infrequent outcome (crude mortality 3.7%) it is vital to identify other meaningful and useful outcomes to measure and monitor.

When looking at the whole data set it is clear that there is significant variation in what units provide in terms of the different risk bands of children treated. The percentage in the lowest mortality risk band of <1% ranges from 20-70% and the percentage receiving invasive ventilation from 16-87%. Together this makes it difficult to compare units, however all services can look at these variations and ask fundamental questions about the service they provide and how this compares to their peers.

The development of the referral and retrieval data sets is to be welcomed and as this body of data grows, becomes more complete and is refined it should be able to support both service improvement and commissioning of services for the future.

Some of the data from the latest November Staffing Survey makes sobering reading and should be an area for attention. In 2014 there were 383 funded intensive care beds, 73 funded HDU beds and the PICS Standard on nursing numbers per bed (Standard 164 – 7.01 WTE/bed) was only met by 14.3% of units (n=5). This figure was 28.6% (n=10) when using the 2001 Standard (6.4 WTE/bed). There is a particular challenge within London where on the spot survey on a Sunday up to 25% of the nursing staff were bank or agency nurses and this was significantly different to outside London (p<0.001). This is clearly an area that needs careful consideration and some innovative thinking to improve the situation.

Finally I commend the recommendations on page 9 and hope that the wider paediatric intensive care community will engage in addressing them.



Dr Michael Marsh

Medical Director of Specialised Commissioning for NHS London

Chair of PICANet Steering Group

EXECUTIVE SUMMARY

- In 2014 only 5 (15%) PICUs met the nursing establishment levels currently recommended by the Paediatric Intensive Care Society.
- Use of agency and bank nursing staff to ensure adequate staffing levels was higher during the weekend than weekdays and was highest at midnight on Sunday when 15% of nurses on duty in NHS hospitals in London were agency staff and a further 11% were bank nurses.
- Advanced Practice Practitioners / Advanced Nurse Practitioners now form an essential part of the medical staffing establishment for nearly one third of PICUs (30%).
- Invasive ventilation rates continue to show significant variation (16%-87%) by geographical region. and reflect differences in the different patient case-mix for admissions and the unit configuration for the delivery of Paediatric Critical Care.
- **125,306 bed days were delivered in 2014** continuing the year on year increase which appears to reflect increased activity in some units. The majority of bed days are required by children <1 year of age (57%) reflecting the higher number of admissions in this age group (47%). Just over a quarter of patients have a length of stay of less than 24 hours and a further third stay between one and three days. Nearly nineteen percent of patients remain on the same PICU for seven or more days.
- Readmission to PICU within 48 hours is accepted as an important quality indicator of PICU care. Crude rates of emergency readmissions to the same PICU within 48 hours (required for the NHS England PIC data dashboard) are presented by health organisation. In 2012-2014 the average emergency readmission rate was 1.8%, varying between 0% and 5% between organisations.
- The prevalence of admission to PICU based on the underlying population has remained similar across the three year period with an **overall rate of admission of 146 per 100,000 children annually,** there is substantial variation by age group with older children having a much lower prevalence (1,034 per 100,000 for children <1 year to 61 per 100,000 in children aged 11-15 years).

- Further development in the reporting of referral and transport data has led to the production of new data tables, 80% of recorded referrals are reported as being successfully accepted by a PICU. Of 13,732 transport events 11,802 (86%) were non-elective admissions to a PICU destination. For 93% of journeys no critical incidents were reported. The team leader was a Consultant or ST4-8 grade staff member for the majority of journeys (85%).
- The number of admissions recorded in PICANet has increased slightly compared to last year's report. There has been no annual increase in admissions over the 3 year period.
- Deaths on paediatric intensive care units continue to be very rare: over 96% of children were discharged alive in 2012-2014. Risk-adjusted performance of all participating health organisations fell within acceptable limits in each individual year and when aggregated across the three year period.

RECOMMENDATIONS

- **1.** Commissioners should work closely with PICUs to ensure adequate staffing levels in accordance with professional standards.
- **2.** Nurse Managers should investigate innovative ways of utilising current nurse establishment staff to reduce the dependence of units on Agency and Bank staff and to encourage staff recruitment and retention.
- **3.** Commissions should review the PICANet data concerning increased critical care activity and the geographical variation in invasive ventilation rates across PICUs to inform their planning of critical care services for children.
- **4.** All PICUs and specialist PIC transport services should provide information about all referrals and refusals for admission to PIC, including their use of transport services, in order to inform future commissioning, knowledge of demand for services and to assess quality of service provision.
- **5.** Units should ensure complete and timely ascertainment of data submission to PICANet given the year on year increase in PIC admissions and seasonal variation in PIC requirement. This information is essential to facilitate appropriate resource planning and commissioning.
- **6.** PICANet should continue to work with PICUs and the Clinical Advisory Group to develop new morbidity outcome indicators for Paediatric Intensive Care as in-PICU mortality rates remain low (<5%) for all units and show little variation between units over time.

BACKGROUND

PICANet was established in 2001 with funding from the Department of Health and started collecting data from English and Welsh Paediatric Intensive Care Units in November 2002. The PICUs at the Royal Hospital for Sick Children, Edinburgh and the Royal Hospital for Sick Children, Glasgow started submitting data in December 2004 and March 2007 respectively. The Royal Belfast Hospital for Sick Children joined in April 2008 and Our Lady's Children's Hospital, Crumlin and the Children's University Hospital, Temple Street, both based in Dublin, have submitted anonymised data to PICANet since 2010. 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.

A full list of participating PICUs can be found in Appendix A of the online annual report section of the PICANet website.

GOVERNANCE

PICANet continues to receive support from the NHS Health Research Authority Confidentiality Advisory Group (formerly the NIGB) to collect personally identifiable data on infants and children admitted to paediatric intensive care without consent.

(http://www.hra.nhs.uk/documents/2015/09/piag-register-7.xls).

Ethics approval has been granted by the Trent Medical Research Ethics Committee, ref. 05/MRE04/17 +5.

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. We also have a PIC Families Group to consider the impact of admission to intensive care on children and their families. Appendices B, C and D provide a full list of CAG, SG and PIC Families group members. Additional support from the clinical community is provided through the UK Paediatric Intensive Care Society.

COMMISSIONING

The following organisations commission paediatric intensive care In the UK:

- England: NHS England Specialised Services
- Wales: Specialist Health Service Commission for Wales (SHSCW)
- Scotland: National Services Division of NHS National Services Scotland
- Northern Ireland: Health and Social Care Board

In the Republic of Ireland, Our Lady's Children's Hospital, Crumlin is governed by a Board of Directors and is a company limited by guarantee. Temple Street Children's University Hospital (TSCUH) is incorporated as a private limited company. Both receive funding from the Health Services Executive, charitable and private sources.

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, accident and emergency 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 report is produced each autumn 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 so that coverage is now for the whole of the UK and the Republic of Ireland. There are 34 PICUs and 6 specialist transport organisations currently submitting data to PICANet.

Data are submitted by individual PICUs prospectively, using our secure web-based data collection application with real-time online validation reporting, systematic monthly validation review by our research nurse and regular on-site 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 personal details of each child including their name, age, date of birth, NHS number, address and ethnic group; it also records where children are admitted from, their 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 dat*a for all children transported to a PICU from their original admitting hospital or who are transported but are not admitted to a PICU includes patient details as well as information about their presenting physiology. Details about the composition of the transport team, journey times, any interventions carried out and critical incidents are also recorded.

Additional data collection takes place to understand more about staffing on PICU and patient and family experiences:

Staffing data is collected each year in November to monitor staffing levels within PICUs as well as the PICS standards relating to staffing requirements.

Parent/Carer satisfaction data is collected on an ad hoc basis as part of the work programme of the PICU families group. During 2015 these data have been collected using the EMPATHIC 30 questionnaire developed by Dutch colleagues to facilitate international comparisons and the results of this work will be presented in the next annual report.

Case ascertainment, data quality and validation

We estimate that ascertainment is 99.9% complete for PICU admissions: PICANet Web allows PICU staff to obtain reports on their own data to check monthly admissions totals. In addition during validation visits by the PICANet research nurse a cross check is carried out against records held on PICU (such as admission books, or in-house data collection systems) and PICANet Web. These on-site validation visits are a core element of our data quality assurance process.

Data is validated on-line 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 has 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. We have provided baseline data for the two largest clinical trials in paediatric intensive care (CHiP (Control of Hyperglycaemia in Paediatric Intensive Care) and CATCH (CATheter infections in Children)), PICANet data is currently being used to provide data for the development of further trials and will also provide the baseline data required for trial subjects.

The NHS Service Specification for Paediatric Critical Care for 2015 has made extensive use of PICANet data as its evidence base, through published reports and *ad hoc* data requests. Detailed information obtained from PICANet annual reports and other publications was used extensively by the National Services Division in Scotland to inform the re-commissioning of Paediatric Intensive Care in Scotland.

PICANet data has been used as the gold standard in evaluating data returned by NHS Trusts to the NHS HSCIC Casemix Service for the development of the Paediatric Critical Care Minimum Dataset used to support the definition of Health Resource Groups. This dataset gives much more detail about the level of care delivered on a daily basis, and has been used by NHS England to inform policy on Clinical Networks about the delivery of children's critical care, providing information about the wide variation in the use of PIC beds by children requiring level 2 critical care across the country to identify areas with poor coverage. They were also cited in a recent report by a multidisciplinary working group including the Royal College of Paediatrics and Child Health exploring HDU care [1]. A further recent NHS England request has asked for information from PICANet about the impact of the lack of heart donation on children requiring heart transplant, admitted to Paediatric Cardiac Centres.

Professional and Quality standards audited by PICANet

The Paediatric Intensive Care Society (PICS) has developed a set of professional standards to make sure the quality of care provided by organisations involved in every aspect of intensive care is high. These standards are used in practice in all NHS organisations across the UK. The present standards [2] cover the whole patient pathway from the initial referral to paediatric intensive care, specialist transport and then inpatient care. PICANet has been an integrated part of the revisions of the PICS standards since their inception. Currently we audit 28 PICS Standards for the care of critically ill children using both the core PICANet data-set and the data collected via the staffing and PIC families surveys (Table 1).

PICS Standards		
118	The Retrieval Service should have written guidelines covering arrangements for transfer of parents. Wherever possible and appropriate, parents should be given the option to accompany their child during the transfer. Where this is not possible or appropriate, other arrangements should be made to transfer parents.	
122	The Retrieval Service should audit and monitor requests for retrieval to which it is not able to respond.	
123	The retrieval team should arrive at the referring unit within three hours of the decision to retrieve the child.	
124	Wherever possible, a child should undergo one retrieval journey only.	

Table 1: Paediatric Intensive Care Society Standards audited by PICANet in the 2015 Annual Report

127	The Retrieval Service should be submitting the required dataset to the Paediatric Intensive Care Audit Network (PICANet) within three months of the retrieval.
144	The following support services should be available; Interfaith support, Social workers, Interpreters, Bereavement support, Patient advice & advocacy, Family Psychological support, Staff psychological support. (Availability is not defined but should be appropriate to the case mix and needs of the patient)
157	For every 8 to 10 beds there should be at least one consultant available to the unit at all times.
158	During normal working hours one medical trainee (or equivalent grade doctor) should not normally be allocated more than five patients.
159	Outside normal working hours, for every eight PICU beds there should be at least one ST4 or above grade doctor available to the unit at all times.
164	The unit's nursing establishment and nursing rosters should be appropriate to the anticipated number and dependency of patients. Staffing levels should be based on the ratios in Appendix 13. Appendix 13:- the minimum number of qualified nurses required to staff 1 critical care bed is, at least 7.01 (WTE).
169	Each unit should have a discharge coordinator responsible for managing the discharge of children with complex care needs.
170	Daily sessional support should be available to the Paediatric Intensive Care Unit from pharmacy, physiotherapy and dietetic staff with competences in the care of critically ill children who have time in their job plans allocated for their work on the unit.
180	Average occupancy on the unit should not exceed 80%. The unit should be monitoring occupancy and there should be evidence of escalation within the Hospital and involvement of Health Boards/Commissioners if occupancy exceeds 80% for more than two successive months.
181	The unit should be submitting the required dataset to the Paediatric Intensive Care Audit Network (PICANet) within three months of discharge.
Appendix 13	Levels of Care & Patient Dependency, Paediatric Intensive Care Society (Clinically Based). Level 1 requires nurse to patient Ratio of 0.5:1. Level 2 requires 1:1. Level 3 requires 1.5:1. Level 4 requires 2:1.

NHS England has developed a Quality Dashboard programme for specialised services to provide assurance on the quality of care by collecting new information about outcomes from healthcare providers [3]. One of the dashboards is specifically for paediatric intensive care and PICANet provides data which can be used to calculate several of the indicators required (Table 2). We are discussing the amendment of the core PICANet dataset to allow for all paediatric intensive care data dashboard measures to be collected by PICANet to ensure standardisation of data collection between units.

	Dashboard Measure	Description & Provenance
PIC01	Risk adjusted mortality	PICANet is a clinical data base used by most / all PICU providers. PICANet produce a risk adjusted SMR that is accepted by Trusts.
PICO2	Refusal rate for emergency admissions	Number of emergency admissions refused from within the defined catchment population served
PICO4	Emergency readmissions to PICU within 48 hours	Emergency readmissions to PICU within 48 hours of a previous discharge / transfer from PICU
PIC05a	Bed occupancy	PICU bed occupancy rates
PIC08	Unplanned extubation	Rate of unplanned extubation of patients/100 ventilated days
PIC10	% of data submissions to PICANet within 3 months of discharge	PICANet expects provider information to be complete and accurate 3 months after patient discharge
PIC13	% of refused requests for retrieval of a patient within defined catchment	Ability to deliver a comprehensive retrieval service
PIC14	Mobilisation of PIC retrieval team	Number of retrievals performed within the agreed mobilisation time

Table 2: NHS Specialised Services Quality Dashboard Measures audited by PICANet

The NHS England Commissioning for Quality and Innovation (CQUIN) payment framework links a proportion of English healthcare providers' income to the achievement of local quality improvement goals, and both of the proposed National Paediatric Critical Care (PCC) CQUINs (prevention of unplanned readmissions to PIC within 48 hours and transfers out of normal catchment/network to PICU) are collected by PICANet [4].

Analytical techniques

Statistical techniques used include using logistic regression to recalibrate the mortality risk adjustment model based on a rolling 3-year data window; the calculation of crude and risk-adjusted SMRs and 95% confidence intervals; the construction of crude and risk-adjusted funnel plots of SMRs; local provision of Risk Adjusted Resetting Sequential Probability Ratio Test (RA-RSPRT) plots to assess real-time performance related to in-PICU mortality. Cox-proportional hazards models and Kaplan-Meir graphs will be used to assess survival trends using the mortality data obtained from the NHS Health and Social Care Information Centre to assess longer term survival. More sophisticated statistical techniques such as random effects logistic regression, propensity score matching and latent class analysis have been proposed to enable this rich dataset to be explored with greater subtlety.

Small number policy

Publication of PICANet data is subject to scrutiny for 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

When unusual performance is detected following routine or bespoke analysis which suggests that a PICU is an outlier, PICANet follow the established procedure outlined in our outlier policy (http://www.picanet.org.uk/Documentation/Policies/PICANet_Policy_on_Units_lying_outside_the_co ntrol_limits%205_oct2015.pdf), which relates specifically to assessment of risk-adjusted mortality. We also follow the more detailed guidance on outliers subsequently developed by HQIP published in 2011. On two specific occasions, PICUs have been identified as outliers with excess risk-adjusted mortality. In each case this was attributable to data quality issues and when corrected, the outliers fell within normal limits. Both PICUs contributed an article in a previous PICANet annual report detailing their experiences and lessons learnt from the process.

Links with the clinical community, patients and their families

The PICANet PICU Families Group currently has four Lay Representatives who are the parents of children who are currently or have previously received paediatric intensive care. In addition we have a standing Lay Representative on our Steering Group and work closely with the charity Well Child. Our Lay Representatives have worked closely with PICANet to develop the Annual Lay Report. To date all communications we have had from patients/parents have been to support PICANet and its work and to request further information.

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

DATA ANALYSIS – AN OVERVIEW

Full detailed analysis of all the PICANet data is provided in the accompanying Tables and Figures document. An overview is given below of some of the key analyses from the annual report are presented, where relevant the Paediatric Intensive Care Society Standard [2] or NHS England Data Dashboard item [5] relating to the data are presented (for further details on standards refer to the methods section).

Admissions

Between 2012 and 2014 59,642 admissions for children under the age of 16 years were recorded in the PICANet dataset; 19,760 children being admitted in 2014. Of those, nearly half (27,949, 47%) were under one year of age and a third of those children were less than one month old at admission (9382, 34%). Males made up a slightly higher percentage of admissions than females (33,791; 57% vs. 25,843; 43%).

There is marked variation in case-mix between organisations measured by risk of mortality on admission using the Paediatric Index of Mortality, (PIM2) (a scoring system to estimate severity of a child's condition) (Figure 1, see index at front of report to see which organisation is represented by each letter) with most organisations having a range of admissions falling in the lowest (<1%) risk of mortality group, between 70% and 20%. Much of this variation is explained by the geographical location of PICUs and whether onsite high dependency care services are available, as some children with a lower PIM score may only be receiving HDU level care. In some cases PICUs also contain HDU beds, in other hospitals these units are in a separate area of the hospital therefore, information on the children cared for in these separate areas is not submitted to PICANet.



Figure 1: Paediatric Index of Mortality (PIM2) expected risk of mortality group by health organisation, 2012-2014

* Unit G only receives a small number of admissions and therefore PIM score values have a different distribution to other units.

There is seasonal variation in the number of admissions to PICUs with higher admissions seen in the winter months of November to January. This is mostly explained by the peak in respiratory admissions during this period especially in those under one year of age. Overall, over half of admissions are classified as either cardiovascular (17,572, 30%) or respiratory (16,749, 28%) with a significant minority having a neurological primary diagnosis (6,222, 10%). Other common diagnoses (with over 1,000 admissions each) are sepsis (1,185) and status epilepticus (1,143). Diagnosis patterns change with age (Figure 2), with cardiovascular the most common reason for admission in under 1s (39%), respiratory in 1-4 (31%) and 5-10 year olds (24%) and musculoskeletal in those aged 11-15 (20%).





As England has the largest population of 0-15 years olds they also represent the country of residence for the most admissions recorded over 2012-2014 (44,849; 75.2%).

As in previous years, over half of the admissions to PICU are unplanned with significant variation by organisation. Diagnostic group varied by admission type (Figure 3). The majority (41%) of non-surgical unplanned admissions were respiratory.



Figure 3: Percentage of admissions from each diagnostic group by admission type, 2012-2014

Interventions

Two thirds of children received invasive ventilation at some point during their admission in 2012-2014, this varied by unit from 16% to 87%. 'Fifty three' percent of children admitted to PICU received invasive ventilation only, with 6% receiving non-invasive ventilation only and 13% receiving both during their admission. After ventilation, vasoactive drugs are the most commonly used intervention (33%).

Data concerning admissions requiring prolonged invasive ventilation (PIV) over the last ten years of PICANet (more than 21 days in one admission) were presented at the 2015 annual meeting of the Royal College of Paediatrics and Child Health. Of the 99,818 admissions receiving invasive ventilation it was found that 2,980 (3.0%) required PIV. As a proportion of all invasive ventilation, PIV has increased slightly over the previous decade from 3.1% in 2004 to 3.4% in 2013. Children receiving PIV account for over a quarter (26.5%) of all invasive ventilation bed days even though they are only a small percentage of all admissions. This population is being investigated in more detail to understand the underlying trends and characteristics of these children including their rates of readmission.

Bed activity and length of stay

In the three year period of this report, over 386,000 bed days of paediatric intensive care were delivered by PICUs contributing data to PICANet, over half of which were to children under 1 year of age. Just over a quarter of patients have a length of stay of less than 24 hours and a further third stay between one and three days. Nearly nineteen percent of patients remain on the same PICU for seven or more days; this is slightly increased from 17% in 2009-2011. Bed activity is measured in the PICANet Annual Report in several ways including total bed days, length of stay and bed census measures. There was a 1.9% annual increase in overall reported bed days over the 3 year period.

Outcomes

Mortality is a primary outcome and is risk-adjusted to allow inter-organisation comparisons. The riskadjustment takes into account differences in the severity of illness of children admitted to different PICUs to allow a fair comparison. This is allowed for using the Paediatric Index of Mortality (PIM) [6] which was previously updated to PIM2 [7], the version used in the current report. A third version has now been published - PIM3 [8]. PICANet has collaborated with the Australian and New Zealand Paediatric Intensive Care Audit group in the development of PIM3 to ensure it is relevant to the UK PICU population.

Each year for each annual report PIM is re-calibrated using the data from the previous three calendar years and crude and standardised morality ratios are calculated. The SMR uses the risk adjusted data to compare the number of deaths in a specific time period with the number predicted by the PIM score. Crude mortality is currently 3.7% with slightly higher rates amongst those under one (4.5%) and with variation between 0.1% and 6.8% across the different PICUs in 2014, predominantly due to variations in case-mix. Once adjustment for case-mix has taken place all units are operating within the expected limits in regard to standardised mortality ratio, quantified as part of Data Dashboard item PIC01.

As new versions of PIM are released, the PICANet dataset is updated and data collection forms are adapted to collect the new data items e.g. for PIM3 a new indicator for 'bone marrow transplant recipient' was required and introduced to the dataset in mid-2014.

The majority of children who survive are discharged to either a HDU or general paediatric ward in the same (82%) or another (12%) hospital with the remainder going to their normal residence, a hospice or an unknown destination.

Funnel plots are used to compare the average emergency readmission rate across the three years between units. In 2012-2014 the average emergency readmission rate was 1.8%, varying between 0% and 5% between organisations, this variation may be due to the local provision of HDU, and warrants further investigation. This is similar to the average rate (1.7%) in last year's report and is audited as part of Data Dashboard item PIC04.

Vital status at 30 days post-PICU discharge is still unknown for nearly half of all children admitted in 2012-2014 (44%); this is mainly due to the ongoing difficulty of tracing this information by units as many children will have been discharged from the admitting hospital by this time. Individual children who have been admitted to PICU have been flagged with the Health and Social Care Information Centre (HSC IC) so that any deaths occurring after discharge from PICU can be identified. Data from the HSC IC is currently being analysed to enable the calculation of longer term mortality.

Individual children

Four out of five children admitted to PICU in 2012-2014 had a single admission, multiple admissions were most common in children with multisystem (29%) and cardiovascular (26%) diagnoses on their first admission and least common in those with trauma (6%).

Prevalence of admission varies by age and sex, being lowest in females aged 5-10 years at 49/100,000 per year and highest in males aged <1 years at 1227/100,000 per year - a twenty-fold difference. Prevalence is lowest in Wales and highest in London (60% higher).

Children in adult ICUs

In some cases children are admitted to adult ICUs, for example if the nearest PICU is a long distance away or so the child can be stabilised before transfer to a PICU. Data on children cared for in adult ICUs is presented and was provided by the Intensive Care Audit and National Research Centre (ICNARC). Nearly 1,800 admissions of children to adult ICUs were recorded during the reporting period, slightly more females than males were admitted (53% vs. 47%) and 36% were in the 11-15 years old age group. When examining the primary diagnosis the highest proportions were in the respiratory (39%) and neurological (30%) groups.

Daily intervention data: the Paediatric Critical Care Minimum Dataset (PCCMDS)

Data on daily interventions is collected to provide information about the level of care a child is receiving on PICU each day of their stay, this includes information on ventilation given, drugs delivered, and whether other therapies are given e.g. renal replacement, ECMO. These were initially developed for the calculation of which Healthcare Resource Group (HRG) that day of treatment could be allocated to for Payment by Results (PbR) [9]. This year a new HRG group has been defined (XB09Z - Enhanced Care) at a lower level of care than the seven groups that are already used making eight in total, this means that days of care that previously weren't included in the PCCMDS are now included [10].

The PCCMDS is collected for 32 of the 34 PICUs for PICANet providing information concerning 327,925 (85%) of the 386,144 total days of admissions from 2012-2014. Sixty percent of activity days were classified in one of the intensive care categories, with 7% in the highest level of advanced care. This means a further 40% are classified as high dependency or enhanced care, a majority of these days will be 'step-up' and 'step-down' care for children who may have also received intensive care during their stay.

Referral and transport

PICANet referral and transport data collection was introduced in 2011. This has created two separate datasets which are complementary to the admissions data; one relating to referrals to PICUs and the other transports to PICU and other journeys carried out by paediatric intensive care specialist teams and PICU based teams. In this annual report eleven tables are presented; one relating to referrals and ten providing detailed information about the transport data collected. Over the period 2012 to 2014 19,523 referrals and 13,732 transport events were reported to PICANet. A specific supplementary section has been developed in the tables and figures section to report on this wealth of data. Several PICS Standards (Standards 118, 122, 123 and 124) and Data Dashboard items (PIC02, PIC13, PIC14) are linked to transport and referral related data. Over the period 2012 to 2014, 9.4% of referral cases were recorded as a refusal though this may be an underestimate as not all refusals were entered into the PICANet database.

In the vast majority (97.7%) of transport events recorded the patient was transported (transport of a child may not take place or journeys may not be completed if their clinical condition changes or if they die before or during a journey) and this was higher when only considering journeys to PICU (100%). Journey time data is now available and will be developed as more information on catchment

areas and agreed mobilisation time is elicited. In 15% of mobilised, non-elective journeys to PICU it took longer than 3 hours for the retrieval team to get to the bedside and this gives a benchmark for a comparison for future years. In 6% of journeys patient journey time was longer than two hours.

The data show parents were present on 62.5% of journeys, for 13.3% the parents chose not to accompany the child, for 7.8% the parents weren't present, for 9.3% they were not permitted to accompany and the outcome was unknown for 7.1% of journeys.

From data collected as part of the admission dataset 31% of admissions were reported as retrieved/transferred. A large number of specialist team retrievals (42%) were for respiratory diagnoses, the percentage was lower (27%) for non-specialist teams.

Data quality and completeness

The completeness of the PICANet dataset is a major strength and monitoring data quality and the evaluation of the timeliness of data collection are important aspects of PICANet's role; measures are quantified within the PIC Data Dashboard (Item PIC10) and the PICS standards (127, 181). PICS Standard 181 states data must be submitted to PICANet within 3 months of discharge for each admission, the data suggest there is large variation between organisations in the percentage of records where this is attained (mean: 56%, range: 0%-99%).

Staffing

Information was collected on numbers of nursing and medical staff employed on units during a specified week in November 2014 with details recorded at four specific 'snapshot' time periods (a weekday and a weekend at noon and midnight) as well as information about other professionals working on PICU. Complete data was returned by all PICANet units.

There were a total of 383 funded intensive care beds and 73 funded high dependency beds reported by the units in the 2014 survey. High dependency care beds are included in those critical care units where PICANet data are submitted for both intensive care and high dependency patients, and staffing is provided by the same paediatric intensive care nursing and medical establishment.

Nursing staff

PICS standard 164 details the qualified nursing establishment levels required. In November 2014 Figure 4 showed that 14.3% (n=5) of the UK PICUs met the standard of at least 7.01 Whole Time Equivalent (WTE) qualified nurses required to staff one critical care bed. A total of 28.6 % (n=10) units met the previously defined PICS standard (2001) of 6.4 WTE per bed. This compares to November 2013 when 5 units reached the target of 7.01 WTE per bed and 13 were equal to or above 6.4 WTE per bed.



Figure 4: Number of clinically qualified staff in post (WTE) per bed, by health organisation, Nov 2012-2014

Figure 5: Total number of whole time equivalent qualified nurses in post, 2012-2014



Figure 5 shows that the total number of whole time equivalent nurses in post has increased from 2308.1 in 2012 to 2581.9 in 2013 and was then reduced to 2493.4 in 2014. Following a reported increase in the numbers of band 5 and band 6 nurses in 2013 there has been a reported decrease in 2014 from 572.8 to 541.8. The majority of nurses employed were band 5 (67% in 2014). There is little variation in the proportion of whole time equivalent staff in post who were band 5 nurses (66% in 2012 to 67% in 2014) and band 6 nurses (21% in 2012 to 23% in 2014). 85% of band 5 nurses were children's trained and 29% had a paediatric intensive care qualification in 2014; 91% of band 6 nurses were children's trained and 92% had a paediatric intensive care qualification in 2014, these proportions have varied little in the past three years. However, discussions with staff on PICUs have shown an increasing tendency to recruit band 5 nurses directly to paediatric intensive care without post qualification ward experience; this impacts on the nursing team increasing pressure on

experienced nursing staff who are required to support and mentor inexperienced juniors and in turn affecting staff morale and retention of the workforce.

Table 1: Proportion of units meeting the PICS Standard defined levels of care and patient dependency (Appendix 13)

Snapshot tim	e period	% Meeting Standard
Wednesday	Noon	64.7
Weanesday	Midnight	50.0
Sunday	Noon	55.9
Sunday	Midnight	56.3

For each snapshot time period, Table 1 shows the proportion of units meeting the PICS standard levels of care and patient dependency defined in Appendix 13; where Level 1 requires nurse to patient Ratio of 0.5:1, Level 2 requires 1:1, Level 3 requires 1.5:1 and Level 4 requires 2:1. Two thirds of units met the nurse to patient ratio at 12 noon on a weekday (64.7%). At other times around half of the units met this standard.

Nursing staff – bank and agency

Figure 6: Percentage of bank and agency nursing staff working on PICU for the four snapshot time periods (noon and midnight Wednesday and Sunday, week commencing 17th November 2014)



Figure 6 shows the proportion of nursing staff that were agency and bank staff on duty during the four different snapshots recorded as part of the staffing survey. Analysis of the snapshot staffing data shows a statistically significant difference (p<0.001) between London and elsewhere in each time period with up to 5% of nursing staff from bank or agency in all units reporting to PICANet compared to up to 25% in the London units.

The Kings Fund report, published in April 2015 indicated that they did not have a "comprehensive picture of the full extent of the temporary clinical workforce delivering NHS-commissioned care"; the PICANet data helps to provide a picture for paediatric intensive care. It is important to remember that PICANet collects data at four specified times during November when Paediatric Intensive Care Units may be facing increasing admissions due to winter pressures [11].

Agency use was higher during the weekend than weekdays and was highest at midnight on Sunday when 15% (n=16 of 107) of the total number of nurses on duty in NHS hospitals in London were agency staff and a further 11% (n=13) were bank nurses. In Wales, Scotland, Northern Ireland and the Republic of Ireland there was no use of agency or bank staff at midday on the Wednesday.

The ten-fold increase in use of agency staff in London compared to the rest of England may be particular to the reported time period; it may indicate a solution to coping with increasing demand for PIC admission during the winter months and/or an increased dependency and acuity of patients cared for by the PICUs at this time. It reflects a situation where the PICUs have been unable to roster sufficient nursing staff to provide the levels of care required for their patients on that day, which may include the need to cover sickness or absence of core nursing staff. Another factor influencing the recruitment and retention of establishment staff may be competition for staff in London where there are several PICUs and the availability of agency work, an issue that has been raised across the wider NHS.

In February 2015 the Royal College of Nursing reported on the use of agency nursing staff and the "spiralling agency bill" in England, recording a year on-year increase in the NHS spend on agency nursing staff in a sample of provider NHS trusts in England, including acute trusts. The RCN research suggests that the increase in the use of agency staff follows unsuccessful attempts to increase nurse staffing in units across all sectors of the NHS due to cuts in nurse training places, difficulties in retention and recruitment due to low staff morale and short term workforce cuts [12].

Nurse leaders recognise the importance of investing in longer term solutions [13] such as selfrostering, flexible working for staff who may have caring responsibilities, or annualised hours; enabling workers with caring responsibilities for partners, children or other family members to remain or re-enter the workforce and perhaps to allow nurses with children to take an extended summer vacation, supporting the workforce during the busy winter season, a practice that has been used by at least one Trust previously.

Medical staff

A new addition to medical staff reporting this year is the inclusion of Advanced Practice Practitioners/ Advanced Nurse Practitioners (APPs) in the medical establishment graph (Figure 7). The number of APPs shown includes the proportion of the funded hours allocated to the medical staffing rota. This recognises the inclusion of APPs as an essential part of the medical staffing establishment and roster in ten units and shows how medical staffing varies between PICUs. The development of the role of APPs in units may be due to a number of factors including increasing acuity of patients receiving care in PICU, the flow of middle grade doctors who, due to changes in medical education, training and working time regulations, may be less experienced on arrival on PICU than their counterparts a decade ago and, also changes in nurse staffing. Increasingly the shortage of skilled PIC nurses has led to the appointment of newly qualified band 5 nurses to specialist units; these junior nurses have a greater initial requirement for support whilst caring for the sick on PICU and APPs may be part of the wider team providing access to a senior nurse at all times.



Figure 7: Number of Medical Staff by Position (WTE) by Organisation, Nov 2014

Table 2: Proportion of units meeting PICS medical staffing standards at specified times

Standard	Snapshot ti	me period	% of units meeting standard
157	Wednesday	Noon	91.2
Consultant availability at all times	weanesday	Midnight	69.7
	Sunday	Noon	66.7
	Sunday	Midnight	69.7
158 Medical trainee allocation during normal working hours	Wednesday	Noon	70.6
159	Wednesday	Midnight	61.8
ST4 or above availability outside normal working hours	ove availability outside normal working hours		76.5
	Sunday	Midnight	67.6

Data recorded at four specific snapshot time periods (a weekday and a weekend at noon and midnight) during a specified week in November 2014 showed that the majority, 91.2% (n=31 of 34) of units meet Standard 157 with at least one consultant available for every 8-10 beds at noon on Wednesday (Table 2).

With the exception of noon on Sunday, all units (n=12) with less than or equal to 10 beds met standard 157 at the specified times, the exception was one non-NHS unit. All units with more than 10 beds (n=22) have at least one consultant available to the unit at all times but only 47.6% met standard 157 at all specified times, providing at least one consultant for every 8-10 PICU beds.

PICS standard 158 requiring that during normal working hours one medical trainee or equivalent grade doctor should not normally be allocated more than five patients, was met by nearly three

quarters of units (72.7%) with more than 10 beds and by two thirds (66.7%) of units with less than or equal to 10 beds.

PICS standard 159 which requires that outside normal working hours, for every eight PICU beds there should be at least one ST4 or above grade doctor available to the unit at all times was met more often by smaller units with less than or equal to 10 beds than by larger units with more than 10 beds. 45.4% of larger units met the target at midnight on Wednesday, 72.7% at noon on Sunday and 59.1% at midnight on Sunday. The equivalent figures for units with 10 or less beds were 91.6% at midnight on Wednesday, 83.3% at noon on Sunday and 83.3% at midnight on Sunday.

The proportion of units meeting the above standards may reflect differences in use of medical trainees and other staff such as Advanced Nurse and PICU Practitioners in units.

Other professionals

Table 3: Proportion of units meeting PICS standards relating to support for critically ill children and their families.

	Available Support	% Meeting Standard	
Standard	Staff and Services	Less than or equal to 10 beds (n=13)	More than 10 beds (n=21)
144	Interfaith support	92.3	100.0
	Social workers	69.2	90.5
	Interpreters	100.0	100.0
	Bereavement support	76.9	85.7
	Patient advice & advocacy	84.6	95.2
	Family Psychological support	69.2	100.0
	Staff psychological support	69.2	100.0
169	Discharge coordinator in post	23.1	23.8
170	Pharmacy	92.3	100.0
	Physiotherapy	100.0	100.0
	Dietician	84.6	100.0

Table 3 shows the proportion of units with less than or equal to 10 beds and the proportion of units with more than 10 beds who have dedicated time from the support services and key support staff listed in Standards 144 and 170 and from the discharge coordinator.

All units have dedicated time of a physiotherapist, all but one (a unit with 10 or less beds) have dedicated time of a pharmacist and all but two (both with 10 or less beds) have dedicated time of a dietician, providing daily sessional support to the units and therefore meeting Standard 170.

Eighty-one percent of units with greater than 10 beds and 46% with 10 or less beds met PICS Standard 144 having all the listed support services for families available. In some trusts additional support may be provided by external agencies such as social work support provided to the child and family by area social services teams. Two units admit patients electively from overseas and additional support is provided to the family by the embassy.

Less than a quarter of all units (n=8) reported having a discharge coordinator in post. However, within other trusts there may be other models employed to manage the discharge of children with complex care needs, including a named nurse/team from PICU who are given responsibility for discharge planning, a hospital wide discharge liaison team to support staff with discharge planning, or discharge planning services may be located as part of a wider network of multi-agency staff caring for the child and family i.e. a specialist nurse providing support and care for children who require long term ventilation.

The availability of additional support on PICUs enhances the provision of a multi-disciplinary approach to the management of children with increasingly complex and long-term conditions and the care of the PIC family.

Conclusion

PICANet provides a rich dataset which can be used to evaluate organisational performance against measurable standards. The dataset is continually reviewed and developed leading to the collection of new data items and new datasets such as those relating to referral and transport. The recently developed ability for customised data collection allows PICANet to respond to audits which are clinically relevant but where information may not be fully captured through the core dataset or where additional data collection is needed at short notice e.g. if extra information is needed during a specific disease outbreak or public health emergency. PICANet is actively engaging and collaborating with key stakeholders including clinicians, commissioners and families to collect relevant and accurate information for the purposes of audit.

NEW DEVELOPMENTS & FUTURE WORK

Updating and improving the data collected

The information PICANet collects has changed over time and updates are needed to collect the most relevant information to patient care.

One recent change has been to collect more information on ventilation of children in intensive care:

- High flow oxygen is now being used with increasing frequency in PICU but little is known about actual flow rates and how it is used in practice. Recent changes to the PICANet admission dataset allows recording of maximum daily flow in I/min to provide the necessary benchmark data to inform the use of this new technology. This will be reported in our next annual report.
- In August 2014 the PICANet dataset was updated allowing the collection of a new outcome: unplanned extubation to support the collection of Data Dashboard item PIC08.

All units were required to begin collecting this information from January 2015 onwards and the data will be presented in next year's annual report to give baseline figures for the use of high flow oxygen and the levels of unplanned extubation in PICU.

PICANet are working with the PICS Acute Transport Group on a process to standardise the reporting of referral event data to improve data quality as it was indicated that units have not all reported refusals in the same way. Over the next year this will improve the completeness of the dataset as previously not all refusals were being recorded by all organisations.

PICANet is collaborating with the Clinical Advisory Group to develop a new staffing data collection tool which will collect the number of direct clinical care (DCC) programmed activities attributable to paediatric intensive care. Data will be collected in November 2015 with the refined questionnaire and will be presented in the next annual report.

Learning more about long term outcomes

Little is currently known about the outcomes of children after they are discharged from PICU, as currently follow up data is difficult for some units to collect themselves. It is important to understand how intensive care stay is related to a child's future health as it may represent an underlying condition worsening or a severe episode of illness which will impact on a child for the rest of their lives. PICANet receives data directly from the NHS Health and Social Care Information Centre (HSCIC) on the date and cause of death for children who have died and who were previously admitted to paediatric intensive care. We will look further at children to see how age at admission, deprivation and underlying conditions affect long term outcome.

Customised data collection

In the last twelve months customised data collection has been developed by PICANet and this is currently being utilised by two audit projects:

PICANet evaluation of Post cardiac Arrest Care in Kids (NET-PACK2)

NET-PACK2 is a customised data collection of post cardiac arrest management. The clinical lead for this audit is Dr Barney Scholefield (Consultant Paediatric Intensivist, University Hospital Birmingham). By collecting simple resuscitation variables and early proposed post cardiac arrest temperature management plans for PIC admissions following cardiac arrest, the aim of the audit is to validate a previously developed prediction model for hospital survival after out-of hospital cardiac arrest. The validated prediction model should enable 1) more accurate clinical prediction, at PICU admission, of patients' eventual survival outcome, and 2) stratification of patients in future out-of hospital cardiac arrest.

In October 2015, the International Liaison Committee On Resuscitation (ILCOR - <u>http://www.ilcor.org/consensus-2010/timeline/</u>) published guidelines on the resuscitation of children following cardiac arrest. PICANet will be able to audit the effects of new guidance on clinical practice (such as the use of hypothermia) using the NET-PACK2 customised data collection module.

PICANet renal replacement therapy audit

A customised data collection tool is being piloted for a new renal replacement therapy dataset relating to paediatric patients who receive Continuous Renal Replacement Therapy (CRRT) in PICUs in the UK and Ireland. Clinical support for this audit is being provided by Dr Claire Westrope (Consultant PICU/ECMO, University Hospitals of Leicester NHS Trust) and the Paediatric Intensive Care Society Study Group (PICS SG) Renal Group. While it is clear that the use of CRRT in critically ill children is increasing, very little is known about outcomes, modality, timing of initiation and a host of other parameters. This pilot audit will provide baseline information on current practice that has not been available up until now.

Supporting the development of new and updated standards

The Paediatric Intensive Care Society is currently updating their Standards to ensure they are relevant and up to date; PICANet is collaborating in the development of updated PICS standards.

Through the NHS England Clinical Reference Group PICANet is involved in the refinement of the Data Dashboard (<u>http://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e07/</u>). Online reporting is being developed for units to allow them to be able to report as many dashboard items as possible from the PICANet dataset, including the referral and transport data. Additional data items are being gathered and new methods of displaying the metrics are being developed to support units and make sure the latest figures are available to be reported to commissioners. We have now added a new table to the annual report to quantify the timely completeness of data submitted to PICANet which is required for both PICS Standard 181 and Data Dashboard item PIC10.

Providing units with reporting tools to improve access to information and reporting of activity

PICANet provides reporting tools to PICUs so they can access their data and create online reports, this helps them measure the levels of care they are delivering and identify areas where additional capacity might be needed as well as carry out routine reporting on a day to day basis. This information can be

used to report PICU activity to others including hospital managers, commissioning groups and other stakeholders. Ongoing work is being carried out to extend the available reports and provide additional reports for the referral and transport datasets.

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INVITED PAPERS

The PICANet dataset has become the most authoritative source of information on paediatric intensive care activity and outcomes in the UK and the Republic of Ireland.

The invited articles in this report describe the utility of PICANet data for driving quality improvement through research and clinical trials as well as providing examples of how information from PICANet has supported commissioning and service development in the devolved nations of the UK.

We are very grateful to the authors for their contributions.

PICANet HEALTHCARE AUDIT AND RESEARCH: A TRIUMPHANT PAST AND PRESENT, BUT WHAT ABOUT THE FUTURE?

Past

A generation has passed since the mid-to-late 1980s when Helen Price and Duncan Matthew – Senior Registrar and Consultant in the Paediatric Intensive Care Unit (PICU) at Great Ormond Street Hospital for Children – started studying the use of severity scoring systems to enable auditing of performance [1]. The study was modest with comparisons made in only 151 PICU patients, but the information was detailed and came out of a United Kingdom (UK) centre of excellence. Ten years later, 1994–1995, Gale Pearson and colleagues from the Trent Health Authority and the state of Victoria, Australia, used a risk-adjusted severity-of-illness model (based on information gathered at the time of admission to the PICU) in their landmark study of PICU mortality in these two regions [2]. The findings and extrapolations to the whole of the UK, suggested that substantial reductions in mortality could be achieved, if every child who needed endotracheal intubation in a PICU in England for more than 12 to 24 hours was admitted to one of 12 large specialist PICUs. In 2001, the Paediatric Intensive Care Audit Network (PICANet) was established with funding from the Department of Health. Since then, PICANet has obtained information on all PICU activity within the UK and the Republic of Ireland; this database of some 200,000 admissions to 33 PICUs contains high-quality, reliable information on population demographics, clinical and outcome data, and comparative data using a risk-adjusted severity-ofillness model.

Present

One triumph of the PICANet dataset is that it has engendered a wealth of clinical study over the last 10 years, with much of this work falling into four main categories of healthcare audit and research (see Table 1). The first one involves description of epidemiology and prediction model building, which aims to fit a model for future predictions that can be used to assess clinical performance [3-13]. These publications include differences between admissions to various types of units: geographic and national differences; disease, ethnicity, and deprivation patterns and PICU size; the effect of physician training and experience level; and, 24-hour physician cover. The second involves assessment of the system of PICU care within the UK, and has the potential to inform healthcare policy [14-18]. These studies investigate simple and easily obtainable parameters. By using a limited dataset of variables, however, such studies are sometimes criticised for lacking novelty or depth. The third involves examination of the patient pathway [19-22]. There are two approaches here: one is to perform data mining in response to a specific research question, and the other is to adapt a research question to the limits of the database. Sometimes these approaches are used simultaneously. The fourth type supports the development and execution of randomised controlled trials (RCT) which is, after all, the definitive method for finding out new knowledge about treatment effectiveness [23-26]. The PICANet dataset has informed the preparation phase of trial feasibility by quantifying potential numbers of cases meeting RCT inclusion criteria. For example, in the Control of Hyperglycaemia in Paediatrics (CHiP) trial the PICANet database combined its information with the unique trial case report form and

allowed efficient sharing of data and parameters already collected within one system to be combined with the other.

Type of studies	Clinical research population or problem	Type of question	References
Epidemiology	 TBI ³ All UK children ^{4,9} Critical illness ⁴ Respiratory failure ^{4,5} Acute diabetes ⁶ ADEM ⁷ Anaphylaxis ⁸ Blood stream infection ¹³ Tracheostomy ⁹ 	 What ³⁻⁹ How much ^{3,4,8,9} Influence of ethnicity Influence of deprivation ^{4,5} Modelling ¹⁰⁻¹² Risk-adjustment ^{11,12} 	3–13
System of care	 TBI access for neurosurgery ^{14,17} Organ donation ¹⁵ Retrieval teams ¹⁶ Out-of-hours work ¹⁸ 	• What and when ¹⁴⁻¹⁸	14–18
Patient pathway	 TBI management ¹⁹ Palliative care and place of death ^{20,21} Blood stream infection ^{13,22} 	• What and when ^{13, 19-22}	13, 19–22
Supporting RCTs	 TBI ²³ CHiP ²⁴⁻²⁶ 	 Feasibility ²³ Data support ²⁴⁻²⁶ 	23–26

Table 1: Types of PICANet clinical audit and research studies

Key: ADEM, acute disseminated encephalomyelitis; CHiP, control of hyperglycaemic in paediatrics; TBI, traumatic brain injury; UK, United Kingdom.

Future

As the PICANet dataset grows what are we to expect from the healthcare audit and research community? Can we conceive new audit research ideas with the database? One avenue of work is to continue down the same track we have been down (circa 2002 - 2015) with an agenda that focuses on important unanswered questions about care and outcomes in the PICU combining audit and research. The issue for the next generation of work product (circa 2015 - 2045), however, is whether to continue with more of the same, and address only questions that are adapted to the limits of the database. Alternatively, should we prepare for the possibility that we have reached a 'tipping point' where we need a better and more relevant solution to answer healthcare questions pertaining to PICU practice and management?

As clinicians we are often left to our own education and experience to help apply general principles of risk stratification and risk modification in assessing and auditing our performance with patients. This process is clearly open to bias. Consider the fact that in an individual clinical encounter a prediction about prognosis is usually arrived at using two approaches in combination. The clinician may draw upon evidence from the medical literature to formulate an initial estimate of risk. Second, this estimate may then be adjusted based on the practitioner's judgment, taking account of prior cases in one's practice and any experience of outliers. As such, this approach is open to bias from our level of

experience, recall, the most "recent case", publication bias, and errors of fixation. One solution to this issue of outcome prognostication and the consequent choices one makes about interventions is better retrieval and handling of ever-growing amounts of information available to us, and improved system-wide cross-talk between large scale healthcare datasets. To some extent PICANet analyses of blood stream infection [13, 22] in the PICU is one example of this new "big data" revolution occurring in healthcare [27, 28]. However, there may be yet another idea that we should consider – a more specific or personalised approach that considers patient similarity rather than solely assessing severity of illness assessment [29, 30]. If you like, thinking about homogeneity rather than heterogeneity.

Severity of illness scores were developed using large-scale data collected from many countries. This traditional approach using up to 10,000 patients performs well for assessing 'average' PICU patient populations, but case-mix has been a major challenge when comparing performance between individual PICUs. A new idea, which arises from having access to datasets with over 100,000 patients and an electronic medical record (EMR), is the thought that with bigger datasets the likelihood of recognising in real time past and present patients that are similar is increased. That is, we begin to have the opportunity to let past similar patients inform our current index patient [30]. In my own institution in Boston we have an EMR and see over 2,500 PICU admissions per year, which creates the possibility of developing personalised and local versions of severity/similarity of illness assessment with many other centres also using an EMR.

Taken together, my assessment is that we can look forward to a new era of PICANet healthcare audit and research that builds on the impressive foundation of severity scoring and the 2002 – 2015 dataset, and moves towards database integration [13, 22], embracing the "big data" revolution [27, 28], and local EMR-based personalised PICU similarity metrics [29, 30].

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CONTRIBUTION FROM:

Robert C Tasker

Professor of Neurology & Anaesthesia, Harvard Medical School; Chair in Neurocritical Care & Senior Associate Staff Physician, Department of Neurology, Department of Anesthesiology, Perioperative and Pain Medicine, Division of Critical Care Medicine, Boston Children's Hospital, USA

REFERRAL AND TRANSPORT DATASET

"Data! Data! Data!" he cried impatiently, "I can't make bricks without clay!"

Sherlock Holmes: The Adventure of the Copper Beeches

The PICANet referral and transport dataset first went live in 2012, and has since been updated in August 2014. This is a unique dataset – although there are other voluntary initiatives to collect neonatal/paediatric transport data, [1] there is currently no other system in the world collecting comprehensive audit data on emergency referrals and PICU transports at a national level. As a resource, therefore, the PICANet referral and transport dataset is invaluable for future national comparative audit and benchmarking of transport services as well as local audit/quality improvement, in much the same way that benchmarking of PICUs using the PICANet admissions dataset has now become an established standard.

Background

Just over half of all emergency admissions to paediatric intensive care units (PICUs) in the United Kingdom are for sick children who first present at their local hospital and require stabilisation and transport to a hospital with a PICU. Over 6000 very sick children were transported to PICU in 2014, 77% by specialist paediatric intensive care transport teams (Figure 1). While these children are some of the sickest admitted to PICU (with a crude mortality rate of 8%), there is clear evidence that the use of specialist retrieval teams improves patient survival [2].



Figure 1: Retrieval team type by age group, 2014

Teams are defined in the following ways:

• **Own team** identifies the treating unit's own transport team or the specialist paediatric intensive care (PIC) transport team to which the unit is contracted, collected the child from the referring hospital.

• Other specialist PIC team identifies that another specialist PIC transport team transferred the child to the treating unit.

• **Specialist non-PIC team** identifies that another transport team, not a specialist PIC transport team (e.g. A&E, theatres or neonatal team), transported the child to the treating unit.

• Non-specialist team identifies that a non-PIC, non-specialist team transported the child to the treating unit (e.g. ward staff).

The original PICANet dataset contained detailed information on case mix, resource use and outcome on children admitted to PICU. It was soon recognised that detailed information regarding emergency referrals to PICU and the use of specialist PICU retrieval teams was crucial in order to provide a comprehensive view of a critically ill child's pathway from referral through to discharge.

Referral dataset

The aim of the Referral dataset is to collect systematic national data on the outcome of emergency referrals to PICU from another hospital. It is well recognised that children often need to be referred to multiple PICUs to find a bed, particularly at times of high demand such as in winter. By collecting a standard dataset on emergency referrals received by all PICUs, and identifying refused emergency admissions, a comprehensive view of the emergency referral pathway can be generated.

Example of expected output:

Refusal rate for emergency PICU referrals from another hospital.

Unit refusal rate is on the national PICU Quality dashboard (PIC02), and could be derived from PICANet referral data.

Transport dataset

The aim of the Transport Dataset is to collect detailed and systematic national data on care provided during transport to PICU. It is well recognised that there are regional variations in the availability of a retrieval team (particularly at times of high demand such as in winter), in the timeliness of a specialist team reaching the patient's bedside, and the interventions performed during transport. By collecting a standard dataset on emergency transports, national data can be used for audit and benchmarking.

Examples of expected output:

A. Refused retrieval requests from a defined catchment area (PIC13 on the national PICU Quality dashboard)

B. Timely mobilisation of a PICU retrieval team (example data from the annual report - Figures 2 & 3) (PIC14 on the national PICU Quality dashboard)



Figure 2: Mobilisation time by organisation, 2014*

*Organisations with small numbers of journeys may have skewed patient journey times



Figure 3: Percentage of retrievals with mobilisation time less than 1 hour by organisation, 2014*

*The red horizontal indicates the mean percentage of retrievals with mobilisation time up to 1 hour, for all organisations.

Future use

Together, the two datasets (referral and transport) provide an invaluable resource to comprehensively examine the PICU care provided to sick children before they reach a PICU. In conjunction with the admissions dataset, PICANet will greatly facilitate national audit and benchmarking of services, leading to further improvements in the outcome of critically ill children in the United Kingdom.

You need clay to make bricks, and bricks to build a house...

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CONTRIBUTION FROM:

Padmanabhan Ramnarayan

Consultant in paediatric intensive care and retrieval at the Children's Acute Transport Service at Great Ormond Street Hospital, London.

The Control of Hyperglycaemia in Paediatric intensive care (CHiP) Trial

PICANet was involved in the very early stages of the planning of the *Control of Hyperglycaemia in Paediatric intensive care trial* [1]. Roger Parslow was a member of the trial development group which became, once funding was secured, the trial management group. When designing the study, PICANet data was interrogated to establish the size of the populations likely to meet trial entry criteria, from which we were able to estimate the likely accrual of research subjects and therefore the length of recruitment required for the study.

The trial was funded by the NIHR Health Technology Assessment programme. At the date of publication, it was the largest interventional clinical trial in the field of paediatric intensive care. The trial assessed the effectiveness of insulin infusion in strictly controlling hyperglycaemia in critically ill children compared to conventional management. Children meeting certain trial entry criteria were randomly assigned to either so-called *tight glycaemic control* or conventional management, recruiting 1369 patients from 14 English centres. The key finding of the study was that children managed with tight glycaemic control (except for those undergoing cardiac surgery) left hospital sooner with associated reduction in healthcare costs [2,3].

PICANet was also very important in assisting with data collection. Data required by the CHiP trial which was already routinely collected as part of the PICANet data set was not collected in duplicate when completing the CHiP trial data form. The data was acquired later by the trial data coordinating centre by mapping using the PICANet unique identifier. This enabled a 'work light' data form with only those data fields not included in the PICANet submission being collected independently.

The immense wealth of data in the UK PICANet database is of great value to researchers planning clinical trials or evaluations. The ability to interrogate the database to determine numbers of patients fulfilling proposed entry criteria may lead researchers to modify their objectives based on the 'reality' of the number of subjects likely to be available for recruitment. Researchers are usually optimists, so the ability to establish the reality of likely recruitment based on an independently acquired dataset enables researchers to decide objectively whether or not their research is feasible given the likely number of subjects available in the time-frame for which funding is available.

Finally, PICANet collects NHS numbers. This potentially offers a means of following up the later PICU admission history of research subjects an important asset when planning medium and long-term follow-up.

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CONTRIBUTION FROM:

Duncan Macrae

Chief Investigator of The CHiP trial and Director of PICU at the Royal Brompton Hospital.

MONITORING QUALITY OF CARE THROUGH LINKAGE OF PICANet DATA: CVC CARE BUNDLES AND TRENDS IN BLOODSTREAM INFECTION IN UK PAEDIATRIC INTENSIVE CARE UNITS 2003-2012

Introduction

Paediatric intensive care units (PICUs) have one of the highest reported rates of hospital-acquired Bloodstream Infection (BSI) of any clinical specialty [1]. An estimated 70% of BSI in PICU is caused by central venous catheters (CVCs), an important focus for a number of quality improvement initiatives [2, 3]. Following a Comprehensive Spending Review in 2007 in the UK, the Department of Health invested £270 million a year to support infection prevention and control, including the updated Saving Lives CVC care bundle [3, 4]. However, there is a lack of evidence on the impact of these strategies, with monitoring mostly limited to process measures that were collated only locally.

We used linkage between clinical information from PICANet and the national laboratory surveillance database coordinated by Public Health England to compare trends before and after the reported implementation of infection control strategies. Our study is the first to combine national data on BSI trends with reported changes in PICU practice. Further details of the study have been published elsewhere [5].

Methods

Linked data was available for 20 PICUs (102,999 admissions for children <16 years) between March 2003 and December 2012, comprising clinical information and positive isolates from blood culture [6-8]. Previous validation suggests that 80-95% of clinically significant BSI in children is included in the linked data [9, 10]. We were interested in BSI occurring during a PICU admission and therefore only included samples taken 2 days after admission to 2 days following discharge. Approximate dates for implementation of CVC care bundles designed to reduce CVC-related BSI in PICU (mainly based on Saving Lives or Matching Michigan initiatives [2, 3]) were obtained by a survey of PICU practice.

The rate of BSI was defined as the number of BSI per 1000 bed-days. Multi-level Poisson regression was used to model the rate of BSI over time, allowing for clustering of admissions within PICUs. Rates were adjusted for significant admission characteristics associated with BSI (p<0.05).

The expected trend, had there been no implementation of CVC care bundles, was produced from model predictions. This trend was extrapolated for 24 months post-implementation, to derive the expected rate had there been no intervention. The expected trend was then compared with the observed trend 24-months post-implementation. For the most recent period (2011-2012), by which time CVC care bundles had been implemented, a funnel plot was used to examine the variation among PICUs in risk-adjusted rates [11].

Results

Of the 102,999 admissions in the study period, 2045 (2.0%) experienced at least one BSI. The overall rate of BSI was 5.11 (95% CI 4.90-5.31) per 1000 bed-days. Quarter-year of admission, younger age, vasoactive agent, renal support, primary diagnosis of infection on admission and non-invasive ventilation were independently significantly associated with BSI. Risk-adjusted rates of BSI were falling by an average of 13.2% (95% CI 11.8-14.6%) per year (from 8.96; 95% CI 7.72-10.20 in 2003 to 2.87; 95% CI 2.40-3.35 in 2012). This corresponded to an absolute rate reduction of 68% over the ten year period.

Dates of infection control strategies were available for 14 PICUs. Adjusted rates decreased significantly more rapidly following implementation of CVC care bundles: 13.4%; 95% CI 10.3-16.4 per year post-implementation, compared with 8.0%; 95% CI 6.3-9.7% per year pre-implementation. The observed rate of BSI fell 25.5% in the 24 months following implementation of CVC care bundles (Figure 1). The observed BSI rate was 15.1% lower than would have been expected had pre-implementation trends continued at the same rate. Although there was significant variation in the risk-adjusted rate of BSI for the 18 PICUs with available data in 2011-2012 (Figure 2), the majority of PICUs fell within the expected range of the national rate.

Discussion

Our population-based study of PICUs in England and Wales quantifies a steady decline in BSI rates over time. Use of linked PICANet data allowed us to identify that in UK PICUs, rates of BSI were already falling before the implementation of infection control strategies, but that these interventions were associated with a significant additional reduction in BSI.

This study was only possible through the linkage of national data on PICU admissions and infection surveillance, which offered an efficient and cost-effective method for exploiting existing data with comprehensive coverage over an extended study period. Linkage of national administrative data sources provides an opportunity to monitor quality of care through enhanced surveillance of BSI trends in PICU. Standardised recording of unit-level interventions could help increase understanding of variations in practice, and to identify interventions that lead to improvements in outcomes. Monitoring quality of care by measuring variation in BSI outcomes in PICU could then help sustain improvements in practice [12, 13].

Figure 1: Trends in rates of bloodstream infection (BSI) per 1000 bed-days for pre- and post-implementation of infection control strategies. Data is centred at date of implementation (0 months since bundle implementation). By 24-months post-implementation, rates were 15% lower than would have been expected if pre-implementation rates had continued with the same trend. Symbols = observed rates by 30-days; solid lines = smoothed adjusted rates; dashed line = predicted rate if trend in pre-implementation period had continued.



Figure 2: Caterpillar and funnel plot showing risk-adjusted rates of BSI in 18 PICUs in England and Wales 2011-2012. Confidence intervals for PICUs with highest and lowest rates in the caterpillar plot do not overlap, showing shows significant variation in risk-adjusted rates of BSI between PICUs. The majority of PICUs fall within the 95% funnel plot limits, showing that most PICUs had rates within an expected distance from the national average.



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CONTRIBUTION FROM:

Katie Harron

Research Fellow of Statistics, London School of Hygiene and Tropical Medicine.

GENERALISING FINDINGS FROM THE : CATHETER INFECTIONS IN CHILDREN (CATCH) TRIAL TO PRACTICE IN NHS PICUS

Background

Bloodstream infection (BSI) is an important cause of adverse clinical outcome and cost to the National Health Service (NHS) in the UK. Paediatric intensive care units (PICUs) have one of the highest reported rates of hospital-acquired BSI of any clinical specialty and BSI in PICU is associated with increased morbidity and mortality [1-4].

Nine systematic reviews, two cost-effectiveness analyses, and at least 48 randomised controlled trials (RCTS; 11,586 patients) demonstrate substantial benefits of impregnated compared with standard central venous catheters (CVCs) for catheter-related BSI (CR-BSI) in adults [5-9].

Despite the wealth of trials, large reductions in the risk of infection observed in adults, and the fact that impregnated CVCs have been in use for over 25 years, standard CVCs are still used for the majority of children in British PICUs [10, 11]. There is a lack of child-specific evidence for impregnated CVCs and they are not recommended for children in UK or US guidance. From a policy perspective, there could be significant gains for children's health and healthcare costs if impregnated CVCs could be confirmed to reduce rates of BSI. However, any estimate of benefits of adopting impregnated CVCs for BSI need to take into account the context of declining rates of BSI in PICUs as infection control improves.

To determine changes in the baseline rate of BSI in children given standard CVCs, we conducted generalisability and cost impact study alongside the CATCH trial - a large pragmatic, randomised controlled trial that compared antibiotic impregnated and heparin bonded CVCs with standard CVCs in 14 PICUs (results not yet published). Our aim was to inform purchasing of CVCs across NHS PICUs by assessing the generalisability and the cost-impact of adopting impregnated CVCs for all children who need them.

Methods

We determined the generalisability of the CATCH findings to the baseline risk of BSI in children with a CVC across all PICUs in England. We used a data linkage study to evaluate rates of BSI in all children, based on detailed information from PICANet and national laboratory surveillance data coordinated by Public Health England [12-15]. We restricted analyses to children expected to require a CVC in PICU. CVC use is not routinely captured for all admissions in PICANet, so we estimated the probability of CVC use for all admissions based on a subset of individual-level audit data from two PICUs where CVC used was recorded. CATCH participants with consent to link with PICU admission data were also identified within PICANet [14].

Within the linked dataset, rates of BSI per 1000 bed-days were modelled using multi-level Poisson regression. For comparisons between units and over time, rates were adjusted for significant patient risk-factors (p<0.05). We compared BSI rates and admission characteristics for CATCH participants and non-participating admissions during the trial period.

The baseline risk was defined as the number of BSI per 1000 bed-days in children using standard CVCs in 2012. We estimated the BSI rate using antibiotic CVCs by applying the rate-ratio from the trial to the baseline BSI rate, assuming that irrespective of baseline risk, the relative effect of impregnated CVCs would be the same in all children. The number of BSI averted using antibiotic CVCs was estimated by applying the respective BSI rates to the total number of bed-days in 2012. We estimated the number of admissions requiring CVCs from responses to a PICU survey on the percentage of emergency and elective admissions receiving CVCs in 2012 [11].

We determined the budget and cost-impacts of adopting antibiotic-impregnated CVCs by synthesising the following evidence: i) the estimated risk of BSI using standard CVCs (derived from the data linkage study) ii) the number of BSI potentially averted by using antibiotic-impregnated CVCs (based on the relative treatment effect in the trial) iii) the additional costs associated with purchasing impregnated CVCs for all children expected to require a CVC (numbers of CVCs based on PICU survey data) and iv) the value of the healthcare resources associated with each BSI (from the trial economic analysis).

Outputs

- The results of the generalisability and cost impact study will be published later this year.
- The project has allowed analyses of variation in BSI according to type and timing of causative organism, patient characteristics, paediatric intensive care unit and over time in England and Wales. These analyses have provided valuable evidence on the impact of investment in infection control strategies at a national level [16-19].
- Lastly, the linked PICANet BSI infection surveillance dataset provides a resource that researchers can apply to use [12, 13, 20]. The linked data include diagnostic and procedure codes, patient risk-factors, outcomes, characteristics and demographics, timing and number of BSI for PICUs accounting for >70% of admissions (n=102,971) to PICUs in England and Wales between 2003 and 2012. This data provides the information required for risk-adjusted monitoring of bloodstream infection (BSI) at a national level, although the data do not include BSI before 48 hours after PICU admission. Data are available to researchers subject to approvals (contact: picanet@leeds.ac.uk).

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CONTRIBUTION FROM:

Katie Harron on behalf of the CATCH investigators

Research Fellow of Statistics, London School of Hygiene and Tropical Medicine.

USING PICANet DATA NATIONALLY TO IMPROVE QUALITY OF CARE

Scotland:

National Services Division, commissions the delivery of Paediatric Intensive Care in Scotland from the Royal Hospital for Sick Children in Edinburgh and Glasgow. Both units contribute to the PICANet database and over recent years it has proved to be a very useful source of data for analysis and comparison purposes.

Scotland has two PICUs, one in Glasgow and one in Edinburgh, who have both routinely reported data to PICANet since 2005 for Edinburgh and 2007 for Glasgow. Reporting on both Scottish units from 2008, when the first full calendar year of data was collected from both units there has been a similar number of total admissions annually (Figure 1).



Figure 1: Annual admissions from Scottish PICUs by year, 2008-2014

Median length of stay has also remained relatively similar across the years with a median stay of 1.6 days (Figure 2).

Figure 2: Median length of stay from Scottish PICUs by year, 2008-2014



In 2012, the PICANet team provided data from the Scottish units to support a review of PICU capacity in Scotland. Data allowed for the analysis of activity within the units and provided a breakdown of services delivered across both sites. It also highlighted staffing levels and wider comparisons across all PIC providers. The data also played a pivotal role in helping determine future intensive care capacity in Scotland. As a result of the analysis and review, an expansion in the number of intensive care beds was advocated and endorsed by funding bodies. This development has been adopted and will be phased in over the current and next financial year; with an expansion of up to 5 additional beds being delivered in 2015 / 16.

In addition to the work on the review, the PICANet Annual Reports, both full and Scottish, provide an overview of activity across all participating centres and a benchmark against which units can be compared. We will continue to support the collection and analysis of PIC data by PICANet as a comprehensive and well established structure to aid the delivery of paediatric intensive care across the UK.



The new Royal Hospital for Children Glasgow

The Royal Hospital for Children Glasgow including the PICU has recently moved to new premises and Edinburgh's site is being redeveloped with building beginning this year, with the hospital due to be ready in 2017. Using PICANet data in the future it will be possible to monitor the impact these changes in infrastructure may have in improving patient care.

Wales:

Wales has one PICU at University Hospital of Wales, Cardiff which has been submitting data to PICANet from the beginning of the audit in 2003 with a total of 3,681 admissions being submitted (Figure 3). During the same period a total of 6,618 admissions were recorded for children resident in Wales across all PICUs including Cardiff.



Figure 3: Number of admissions by year to Cardiff PICU, 2003-2014

In the current reporting period over 95% of children admitted to Cardiff PICU are resident in Wales, whereas 49% of the 1,708 admissions of children resident in Wales are admitted to other units in England, mainly Liverpool Alder Hey (18%) and Bristol (21%) (Figure 4).



Figure 4: PICU admission by organisation for children resident in Wales, 2012-2014

The retrieval figures created by PICANet were used to help Bristol and Cardiff develop the combined retrieval service. Sixty-one percent of children residing in Wales were admitted through retrieval and there was variation depending on destination unit (Figure 5).





The PICANet Annual Report is taken to the Wales Patient Safety Collaborative as assurance the mortality rates, for units Welsh children are admitted to, are within the control limits. The funnel plot for 2012-2014 shown below highlights the units where one or more child resident in Wales was admitted (Figure 6).



Figure 6: Funnel plots of adjusted standardised mortality ratios (SMRs) highlighting units where one or more child resident in Wales was admitted, 2012-2014

Wales and its Paediatric Intensive Care Unit in Cardiff have participated in PICANet data collection since its inception. The Welsh Assembly Government via its Specialist Health Commissioners was very keen to support the PICANet project, and it has continued to hold the data gathered in high regard.

PICANet data has been very useful in several respects for Wales, and for the unit in which I work. The PICU in Cardiff opened in 2000, and although generally well received by the district general hospitals for which it provided a service, there was some lingering controversy over its viability given that it was a relatively small PICU. There were some concerns that seven bed PICUs may not produce outcomes as good as larger PICUs, but the data gathered by PICANet continues to be good evidence that these concerns are unfounded. The publication annually of risk-adjusted mortality has been invaluable in assuring the DGHs that we provide a safe service, and reassures the staff working in the PICU that we perform well in terms of mortality, as all other units in the United Kingdom. More recently, there has been a project to reshape the provision of acute paediatric care in south and mid Wales. The so-called South Wales Plan arose out of recognition that there were too many acute in-patient units in this area compared to other parts of the United Kingdom, and that these services were not sustainable. As it would have been expected, these proposed changes to the configuration of services elicited considerable anxiety among the public, politicians and health professionals. The project, however, brought together senior clinicians, managers and patient representative groups who worked to arrive at an informed plan over a two to three year period. The PICANet data was a very important source of information regarding epidemiology of paediatric critical illness in South and Mid Wales, and in particular the fact that PICANet produces a report for the whole of Wales made comprehensive data available to the team formulating the South Wales Plan. It was published in early 2014, although, again, not unexpectedly its implementation continues to throw up significant challenges. One area that has never been challenged during this process is that paediatric intensive care should continue to be provided in Cardiff for the population of south and mid Wales and the robust PICANet dataset has been paramount in establishing that position.

Over the same time period in Cardiff, phase 2 of the new children's hospital for Wales has been planned and built, and this included a new paediatric critical care unit. Again the projections in respect of critically ill patients is very important in ensuring the unit was the correct size, and was very valuable in helping plan a new model for the retrieval service to patients in south and mid Wales. The neighbouring units in Cardiff and Bristol have worked together to launch a new combined paediatric intensive care retrieval service on a regional basis covering the south west of England and south and mid Wales starting in September 2015. The commissioning process for this was informed by data provided by PICANet on both sides of the border.

The most striking feature for me of the PICANet dataset is its reliability and accuracy. There are few other data used in the areas described above which offer the same degree of assurance, and this has been recognised by many others involved in those projects. A common feature of discussions around much health service data is a questioning of its accuracy, and recognition that there may not be clear definitions for each data item, meaning there is variation in how data is recorded. Even when definitions exist, it is not often possible to ensure that they are being obeyed by those responsible for collecting the data. The yearly data validation visits are fundamental in providing the assurance that PICANet data is clearly defined and consistently collected. PICANet remains a standard setter for the quality and reliability of data that we should be seeking to collect in child health services and wider health services as a whole.

Northern Ireland:

The Royal Belfast Hospital for Sick Children (RBHSC), the only PICU in Northern Ireland began reporting to PICANet in April 2008. Up until the end of 2014 the unit has recorded 3,048 admissions of which just over half were for male children (55%) and most were for children less than one year of age (45%); which are similar figures to the rest of PICANet. The majority of the admissions were for respiratory diagnoses (32%) and crude mortality has remained relatively stable at 4% over the seven

years. Using PIM2 with the original published coefficients case-mix across the years has also remained relatively similar (Figure 7).





PICU bed numbers expanded from 8 to 12 in January 2014 and this is reflected in an increase in admissions and bed days reported to PICANet (Table 1). PICANet data was used as part of a case to demonstrate over-occupancy and therefore need for expansion.

Year	Number of Admissions	Number of bed days
2009	487	2,371
2010	450	2,528
2011	445	2,630
2012	451	3,074
2013	441	2,841
2014	516	3,707

Table 1: Number of admissions and bed days as reported in PCCMDS data, 2009-2014*

* 2008 not included as data only available for a partial year

A new transport service NISTaR (NI Specialist Transport and Retrieval) has also been expanded. This is the joint paediatric and neonatal transfer service for Northern Ireland. The service is made up of paediatric and neonatal teams, including a dedicated ambulance and crew. Appointment of a paediatric transport coordinator will allow data collection for the PICANet transport and referral dataset.

The Northern Ireland Paediatric Quality Improvement Collaborative are currently using PIM2 data to compare the acuity of illness from all referring units to ensure that care is standardised across the region, part of the aim of this and related work is to allow the development of a regional early warning score system.

In March 2015 PICANet data was requested to allow the unit to carry out a bronchiolitis review due to significant morbidity associated with bronchiolitis in the unit in Winter 2014, figures were used for internal audit and analysis and to facilitate planning and resources for next winter. Essentially the data showed a short spell with a marked increase in severity of illness of patients with bronchiolitis leading to demand on equipment (Nitric Oxide and Oscillators) that we were just able to supply. By using PICANet data it was possible to explore how to future proof the unit to look at what equipment we have and can access if required. Figure 8 shows the number of admissions where the primary diagnosis was respiratory by calendar year quarter.

Figure 8: Percentage of admissions to Royal Belfast Hospital for Sick Children that were respiratory primary diagnoses by calendar year quarter, 2008-2014



The unit's membership of PICANet has increased its national profile which is also maintained by membership of wider organisations including: the Critical Care Network in Northern Ireland (CCaNNI) established in March 2007 "to improve access, experience and outcome for patients with potential or actual need for critical care by providing a service that is high quality, co-ordinated, timely and unrestricted by traditional clinical or organisational boundaries", there are currently 11 units in the Network, including paediatric critical care services, treating more than 5,000 Critical Care patients a

year, the unit also works closely with the Health and Social Care Board for Northern Ireland and the Northern Ireland Public Health Agency.

The unit is actively involved in several PICANet projects including the Families Survey, the renal replacement therapy audit and NET-PACK 2 customised data collections which began last year. These may not have been as easy to access without being a part of PICANet. Membership has allowed the unit to be involved in other projects including clinical trials as it established the unit as part of a wider network and allowed for routine electronic data collection in a standardised format to PICANet which means baseline data is easily available.

The unit has faced some difficulties in capturing data locally as no computerised records exist, meaning the unit is reliant on medical staff to capture data and a single administrator to record data onto PICANet web. To try and keep up-to-date an interested group of Consultants keep the forms under review and local chasing up takes place when they are not all entered. Northern Ireland doesn't operate a payment by results system as in other parts of the UK so less investment in infrastructure can make data collection and PICANet membership more difficult, but the unit has overcome these challenges. Dr Mark Terris (Consultant Anaesthetist, RBHSC) is also part of the PICANet Clinical Advisory and Steering Groups which helps the PICU be informed and involved in what is happening at a national level.

PICANet will also allow the recording of the impact of changes taking place to the unit such as the availability of new facilities after the announcement in October 2013 of a new £250million children's hospital for Belfast.

Republic of Ireland

Republic of Ireland has two units that started submitting data to PICANet in 2009. These are Dublin Our Lady's Children's Hospital, Crumlin and Dublin's Children's University Hospital Temple Street, with a total of 5,868 and 2,431 admissions being submitted respectively (Figure 9).



Our Lady's Children's Hospital, Crumlin

Figure 9: Number of admissions to both PICU units by year, 2009-2014



Dublin's Children's University Hospital Temple Street

In the years 2012-2014, 95.3% of children that were admitted to these two PICUs were resident in the Republic of Ireland. Of the 4,573 admissions of children resident in the Republic of Ireland 1.75% are to other units in England, mainly London Kings College Hospital (0.83%) and London Great Ormond Street Hospital (0.24%).



Figure 10: Percentage of admissions from different care areas in both hospitals by year, 2009-2014

The majority of children are admitted from theatre and recovery; this is similar to the pattern across PICANet (Figure 10).

The valuable repository of patient data provided by PICANet has allowed us to place a research focus on analgesia and sedation in PICU, end of life care, congenital diaphragmatic hernia, outcomes in post HSCT patients, as well as our unique neonatal and cardiac populations.

We deliver a monthly presentation of key quality performance indicators such as source of admission, length of PICU stay, length of mechanical ventilation, and casemix (particularly emergency admissions). This data is sourced from PICANet, and demonstrates comparability with other units with similar casemix, and has formed the basis for our quality improvement programme. Our local Annual Reports include data from PICANet including admissions, occupancy, casemix, staffing and SMR.

Aided by PICANet data; National Standards for Paediatric Critical Care have been devised. We are currently developing a Model of Care for Paediatric Critical Care across Ireland. PICANet data has also assisted in capacity modelling for expanding the National Congenital Cardiac Surgery and Extra corporeal life support (ECLS) programmes to provide an 'All-Ireland' service. We are currently using the dataset for workforce planning and patient level costing for the proposed new National Children's Hospital.

PICANet data has contributed in launching and implementing national guidelines for example 'The National Sepsis Guidelines', and formulating a pathway of care for paediatric patients presenting with sepsis, facilitating early PICU referral. The quality of the data has also facilitated the collaboration and recognition by the Joint Faculty of Intensive Care Medicine in Ireland for Paediatric Intensive Care Medicine (PICM) training.

PICANet data has illustrated to Health Service Executives and the Management Teams that our key quality indicators and outcome data are comparable to other large units with similar casemix across the UK. It has also emphasised the shortage of medical staffing when compared to similar units and allowed development of business cases to target future recruitment.

CONTRIBUTION FROM:

Mel Miller

Programme Manager, National Specialist and Screening Services Directorate (NSD), NHS National Services Scotland

Dominique Gray-Williams

Assistant Specialised Commissioner, Welsh Health Specialised Services Committee, NHS Wales

Allan Wardhaugh

Consultant Paediatric Intensivist, Clinical Director, Child Health, Cardiff and Vale University Health Board

Mark Terris

Consultant Anaesthetist, Belfast Health and Social Care Trust, Royal Belfast Hospital for Sick Children

Cathy McMahon

Consultant Intensivist, PICU, Our Lady's Children's Hospital, Crumlin, Dublin

Claire Magner

Clinical Audit and Research Nurse, PICU, Our Lady's Children's Hospital, Crumlin, Dublin

Erika Brereton

Data Manager, PICU, Our Lady's Children's Hospital, Crumlin, Dublin

GLOSSARY

Α		
	APP	Advanced Practice Practitioner
	AR	Annual Report
В		
	BSI	Blood Stream Infection
С		
	CAG	Clinical Advisory Group
	Cardiovascular	Relating to, or involving the heart and the blood vessels
	Cardiac Arrest	A cardiac arrest happens when your heart stops pumping blood around the body due to failure of the heart to contract effectively. If you have a cardiac arrest, you lose consciousness almost at once. A cardiac arrest is different from a heart attack, where blood flow to the muscle of the heart is impaired
	Case Mix	The term case mix refers to the type or mix of patients treated by a hospital
	Clinical Trial	Clinical trials are research studies that compare different treatments and treatment strategies
	CTS	Centralised Transport Service
D	Data Validation Dataset	The process of ensuring the quality and reliability of data for a study or audit by checking against dataset rules and definitions A set of standardised data fields collected for an audit or trial, allowing comparisons between sites to be made
	DGH	District General Hospital
	DH	Department of Health
E		
	EMR	Electronic Medical Record
	Event	A single instance of paediatric intensive care (PIC) activity, such as a referral, transport or admission
F	Funnel plots	Scatterplots of an outcome ratio (observed outcome divided by predicted outcome) against the number of eligible individuals. Used when observations for different critical care units/hospitals are based on varying sample sizes
Н	Health Organisation	Any unit or transport service involved in the provision of paediatric intensive care

	HFNCT	High Flow Nasal Cannula Therapy
	HQIP	Healthcare Quality Improvement Partnership
	HRG	Healthcare Resource Group
	HSCIC	Health & Social Care Information Centre
	Hyperglycaemia	The presence of an abnormally high concentration of glucose in the blood
I		
	ICNARC	Intensive Care National Audit & Research Centre
	IV	Invasive ventilation
L		
	LOS	Length of stay
Μ		
	Mean	The 'average' value (obtained by summing all values and dividing by the
	Madian	number of values)
	Mortality	Death rate
	Musculoskeletal	Relating to or involving the muscles and the skeleton
N		
	NHS	National Health Service
	NIHR	National Institute for Health Research
	NOCA	National Office of Clinical Audit Ireland
0		
	Outcome	Outcomes are measures of health, e.g. response to treatment,
		occurrence or recurrence of disease, a measure of well-being
Ρ	Patient identifiable	Patient identifiable data, such as NHS Number, are confidential.
	PbR	Payment by Results
	PCCMDS	Paediatric Critical Care Minimum Data Set
	PICANet	Paediatric Intensive Care Audit Network
	PICS	Paediatric Intensive Care Society
	PICU	Paediatric Intensive Care Unit
	PIM	Paediatric Index of Mortality
	Poisson distribution Principal Investigator	Probability distribution that characterises discrete events occurring independently of one another in time The lead person at a single site designated as taking responsibility within the research team for the conduct of the study

R		
	RCT	Randomised Controlled Trial
	Respiratory	Of, relating to, used in, or affecting respiration
S		
	Sepsis	The poisoned condition resulting from the presence of pathogens or their
		toxins
	SG	Steering Group
	SMR	Standardised Mortality Ratio
	Status Epilepticus	A condition in which repeated epileptic seizures occur without the
		patient gaining consciousness between them
Т		
	ТВІ	Traumatic Brain Injury
W		
	WTE	Whole Time Equivalent

UNIVERSITY OF LEEDS

Roger Parslow Sarah Fleming Melpo Kapetanstrataki Lee Norman Jodie Singh

PICANet School of Medicine University of Leeds 8.49 Worsley Building Leeds LS2 9JT

R.C.PARSLOW@LEEDS.AC.UK 0113 343 4856 UNIVERSITY OF LEICESTER

Elizabeth Draper Alun Evans Caroline Lamming Sarah McLoughlin Martin Perkins

PICANet DEPARTMENT OF HEALTH SCIENCES UNIVERSITY OF LEICESTER 22-28 PRINCESS ROAD WEST LEICESTER LE1 6TP

> MSN@LEICESTER.AC.UK 0116 252 5414

www.PICANet.org.uk PICANet@leeds.ac.uk

