

Annual Report of the Paediatric Intensive Care Audit Network

January 2008— December 2010
Summary Report



Elizabeth Draper
Rachel Hobson
Caroline Lamming
Phil McShane
Lee Norman
Roger Parslow
Sarah Skinner

Paediatric Intensive Care Audit Network
University of Leeds
University of Leicester

Key

A	Cambridge University Hospitals NHS Foundation Trust
B	Brighton & Sussex University Hospitals NHS Trust
C	Cardiff & Vale University Health Board
D	Central Manchester & Manchester Children's University Hospitals NHS Trust
E	Great Ormond Street Hospital for Children NHS Trust
F	Guy's & St. Thomas' NHS Foundation Trust
G	Hull & East Yorkshire Hospitals NHS Trust
H	King's College Hospital NHS Trust
I	Leeds Teaching Hospitals NHS Trust
J	The Lewisham Hospital NHS Trust (finished reporting in Aug 2010)
K	Newcastle upon Tyne Hospitals NHS Foundation Trust
K1	Newcastle General Hospital
K2	Newcastle Freeman Hospital
K3	Newcastle Royal Victoria Infirmary (In 2010 the General and Royal Victoria PICUs merged within the Great North Children's Hospital)
L	University Hospital of North Staffordshire NHS Trust
M	Queens Medical Centre Nottingham University Hospitals NHS Trust
N	Oxford Radcliffe Hospitals NHS Trust
O	Royal Brompton & Harefield NHS Foundation Trust
P	Royal Liverpool Children's NHS Trust
Q	Sheffield Children's NHS Foundation Trust
Q1	Sheffield Children's Hospital (NICU)
Q2	Sheffield Children's Hospital (PICU)
R	Southampton University Hospitals NHS Trust
S	South Tees Hospitals NHS Trust
T	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
X	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	The Harley Street Clinic (non-NHS)

Published in the UK by the Paediatric Intensive Care Audit Network (PICANet). This work is copyright. Apart from any use as permitted under the Copyright, Designs and Patents Act 1988, no part may be reproduced by any process without permission from PICANet.

Requests and enquiries concerning reproduction rights should be directed to PICANet at:

PICANet- Paediatric Epidemiology Group, Centre for Epidemiology and Biostatistics
The Leeds Institute of Genetics, Health and Therapeutics
Room 8.49, Worsley Building
University Of Leeds
Leeds, LS2 9JT
Telephone: 0113 343 8125
E-mail: picanet@leeds.ac.uk

In all cases PICANet must be acknowledged as the source when reproducing or quoting any part of this publication. Please use the following format when citing this report:

Paediatric Intensive Care Audit Network National Report 2008 - 2010 (published September 2011): Universities of Leeds and Leicester.



**Annual Report of the
Paediatric Intensive Care Audit Network
January 2008 – December 2010
Summary Report**

ISBN [Insert]

Contents

Key	2
Acknowledgements	7
Foreword	8
Executive summary	10
Recommendations.....	12
Lay summary	13
1. Background.....	15
2. Introduction.....	16
3. Mortality prediction: recalibration of PIM2	18
4. An unexpected elevated SMR value: Response from Leeds Teaching Hospitals NHS Trust .	21
5. Commentary	24
6. PICU Families Group	27
7. Asthma in PICU	28
8. ECMO in Paediatric Intensive Care in England and Wales	30
9. Staffing Survey.....	34
Nursing staff	34
Occupancy	38
10. Using PICANet data.....	42

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 PICU Families Group.

PICANet is funded by the National Clinical Audit & Patient Outcomes Programme, administered by Healthcare Quality Improvement Partnership (HQIP), Health Commission Wales Specialised Services, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, Our Lady's Children's Hospital Crumlin, the Children's University Hospital, Temple Street from Dublin, Ireland and The Harley Street Clinic.

The organisation and functioning of PICANet is dependent on IT programming and development from Martin Perkins (University of Leicester) and Tom Fleming (University of Leeds), who we thank for their essential contributions.

And finally, we would all like to express our warm thanks to Professor Tricia McKinney for her substantial contribution to setting up and running PICANet as principle investigator until her retirement in July 2010. Tricia's tenacity, attention to detail and ability to develop new ideas has driven PICANet forward over the years.

Foreword

I am delighted to introduce the Paediatric Intensive Care Audit Network report for 2008-2010. This is the product of well-established, respected and trusted collaboration between clinicians, researchers, and support staff. As PICANet moves into its 10th year, we have become familiar with the format, but the scale of the enterprise is increasingly impressive. This report captures 52,337 admissions into British and Irish paediatric intensive care units in 29 NHS Trusts (and 1 non-NHS institution). This resource is envied around the world.

Of course, these data would be of no value if they were not put to work. PICANet has specific aims. There have been important achievements in the last year against each of these:

- **To study the epidemiology of critical illness in children.**

Paediatric Index of Mortality 2 has been recalibrated to reflect improvements in PIC mortality in the UK and Ireland – in a much larger dataset than the original. Retrieval data is now included and was summarised in a major publication in the Lancet.

- **To monitor the outcomes of treatment episodes/to identify best clinical practice.**

The decline in crude mortality (5.5% in 2003-2004 vs. 4.2% 2008-2010) amongst critically ill children is encouraging. But as standards rise, so do expectations. Case-mix adjustment with the newly recalibrated PIM2 has identified a potential outlier in terms of an unexpectedly high standardised mortality ratio (SMR). Leeds Teaching Hospital NHS Trust's SMR for 2009, but not 2010, fell outside the revised funnel plot confidence limits. Regardless of the cause, the timing of this observation deserves

comment. Following recalibration of PIM2, the 2009 outcomes alone were identified as potential outliers 2 years after the events. So, at worst, we might have observed differences in the rate of improvement but not current outcomes.

In line with PICANet's policy and strong clinical governance, Leeds Teaching Hospital NHS Trust have reviewed the relevant deaths in detail and identified systematic problems in data quality and completeness as major contributing factors. Many readers will recall similar consequences of inadequate data collection from King's College Hospital, London in the 2010 report.

But only identifying potential outliers in an annual report is clearly not ideal. The challenge now is to devise a system that facilitates prompt data submission and provides real-time case-mix adjusted outcomes to units. The planned web-based interface should assist in this.

- **To monitor supply and demand/to facilitate healthcare planning.**

The hot topic in PIC in England and Wales in 2011 are the reviews of the safety and sustainability of Cardiac and Neurosurgical services. These may alter the configuration of Paediatric Intensive Care provision. PICANet data has been essential to these. There are many opinions on the proposals, but PICANet data is acknowledged as an objective resource that is trusted and respected by clinicians.

Finally, in my role in Paediatric Intensive Care Society Study Group (PICS-SG), I recognise the essential role PICANet has played in making clinical studies feasible. Multiple-centre randomised studies of Control of Hyperglycaemia in Paediatric Intensive Care (CHiP) and Catheter Infections in Children (CATCH) are well advanced and will be landmarks in our speciality.

We can, at last, envisage developing a meaningful evidence-base in paediatric intensive care medicine.

For all these reasons, PICANet is an indispensable part of our speciality and our

endeavours to improve the care for critically ill children.

Mark Peters
Chair of PICS-SG
MCRN APICC Clinical Study Group Chair

Executive summary

- 1) PICANet is one of the national clinical audits supported by the Health Quality Improvement Programme (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme. It provides a clinical audit of paediatric intensive care (PIC) activity in the UK and Ireland with the aim of improving patient outcomes by providing information on delivery of care to critically ill children and an evidence base for clinical governance.
- 2) With additional support provided by Health Commission Wales Specialised Services, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, Our Lady's Children's Hospital Crumlin, the Children's University Hospital, Temple Street from Dublin, Ireland and The Harley Street Clinic, London, PICANet has full coverage of the UK and Ireland.
- 3) PICANet is able to audit against standards produced by the UK Paediatric Intensive Care Society (PICS) for PIC including both clinical and patient/parent reported outcome measures.
- 4) Data quality is rigorously monitored through central validation procedures and regular site visits by the PICANet team.
- 5) The mortality risk adjustment tool, the Paediatric Index of Mortality 2 (PIM2) has been recalibrated for this report to compensate for global improvements in mortality that made the tool overestimate expected risk of mortality.
- 6) Data are presented on 52,337 paediatric intensive care admissions (aged under 16 years) and 1297 admissions 16 years and over to 29 NHS trusts/health authorities, over the three year period January 2008 to December 2010, data for 2010 is included from one non NHS unit and two units in Ireland.
- 7) Detailed tables present information nationally, by Strategic Health Authority/Health Board (SHA/HB), Primary Care Organisation (PCO) and named individual NHS trust. Data are available for downloading from the Web in spreadsheet format.
- 8) Children under 1 year make up 48% of all admissions with more boys (58%) compared to girls (42%). A large proportion of admissions (58%) are unplanned.
- 9) Over three quarters (77%) of retrievals are carried out by specialist paediatric intensive care transport teams.
- 10) Invasive ventilation procedures are recorded for 66% of admissions. This varied from 6% to 89% of patients by NHS Trust in 2010. Invasive ventilation rates also vary by geographical region (based on residential address at admission) reflecting the different patient case mix admitted to PICUs.
- 11) A total of 308,513 bed days were delivered between 2008 and 2010. The increase in 2010 reflects additional data from Ireland and Harley Street. Just under one third of patients have a length of stay of less than 24 hours and a further third stay between one and three days. Sixteen percent of patients remain within one PIC for seven or more days.

- 12) It is extremely rare for a child to die in paediatric intensive care and nearly 96% of children were discharged alive in 2008-2010. The death rate has reduced from 4.5% in 2008 to 3.8% in 2010.
- 13) Risk-adjusted performance of all Trusts except one fell within acceptable limits in each individual year and aggregated across the three year period using the recalibrated mortality risk adjustment tool.
- 14) One NHS Trust had higher than expected mortality outside the upper control limits in 2009 and aggregated over 2008-2010. This Trust has provided a report of their review of data and medical case notes in accordance with PICANet policy guidelines.
- 15) Only 23.5% of Trusts employ the recommended minimum number of qualified nurses required to staff one critical care bed of at least 7.01 WTE (PICS Standard 164) despite a 9.5% increase in qualified nursing staff in England and Wales.
- 16) The mortality rate for ventilated children with asthma admitted to PICUs in England and Wales is higher than expected based on international data.
- 17) The survival of children receiving Extracorporeal Membrane Oxygenation (ECMO) outside of the 3 main ECMO centres and 2 designated 'surge' centres, varies considerably between PICUs offering this treatment.

Recommendations

- 1) All UK NHS Trusts and other health organisations should ensure adequate resources are made available to PICUs submitting data to PICANet to enable timely, complete and accurate information to be submitted. (PICS Standard 181)
- 2) PICANet should work towards a technical solution that enables PICUs to monitor their performance in real time to enable pro-active follow-up of their activity and outcomes.
- 3) All PICUs should aim to submit the activity data that comprises the Paediatric Critical Care Minimum Dataset to allow more detailed comparisons of activity and level of care delivered.
- 4) All PICUs and specialist PICU transport organisations should aim to be submitting referral and transport data to PICANet by March 2012. (PICS Standard 127)
- 5) More lay members should be recruited to the PICANet Steering Group and PICANet should ensure there is adequate participation from parent/patient representatives on the PICU Families Group.
- 6) PICANet should work with other government, health, social care and education organisations and seek additional resources to analyse linked data, in order to gain a better understanding of the impact of admission to paediatric intensive care on children and their families.
- 7) Mortality risk-adjustment should continue to be recalibrated each year, based on a rolling 3 year data window, to ensure effective comparison of PICU performance.
- 8) A prospective national audit of children admitted to PICU with status asthmaticus should be performed to facilitate the development of alternative disease modifying therapeutic strategies for this condition.
- 9) A review of the use of Extracorporeal Membrane Oxygenation outside designated centres should be performed.
- 10) The PICANet dataset should continue to be utilised by the clinical community, commissioners, academics and health services professionals to provide the evidence base for improved performance in paediatric intensive care.

Lay summary

PICANet is an international clinical audit that collects information on children receiving intensive care in Britain and Ireland. Clinical audit provides a way of measuring the quality of care received by patients by reviewing what happens to patients during and after their care, and examining how the services that deliver that care are set up.

PICANet collects data to help doctors and nurses to plan how to ensure that the best quality care is given to children in Paediatric Intensive Care Units. These data also help PICANet to describe what external and social factors affect the admission of critically ill children to paediatric intensive care.

PICANet works with the teams of doctors and nurses who care for children in Paediatric Intensive Care Units. We have also established a PICU Families Group and are reviewing the facilities and information available to families admitted to PICU.

Every year PICANet publish a report including information on the numbers of children who receive care and the type of treatment they receive in each unit. No individual child can ever be identified. This year, the report highlights the following:

- Over 52,000 children aged between 0 and 15 years received care in a Paediatric Intensive Care Unit in England, Wales, Scotland, Northern Ireland and Ireland in the three years 2008 - 2010.
- Over 60% of children admitted to the 31 Hospital Trusts and hospitals sending data to PICANet are admitted for intensive care as a result of unplanned emergencies.
- Children are generally transported to hospital by specially trained teams of doctors and nurses.
- Nearly half the children are under 1 year of age (48%) and more boys (58%) than girls are admitted for intensive care.
- Two thirds of children admitted to paediatric intensive care receive help with their breathing via a tube connected to a machine called a ventilator, although the numbers vary by hospital.
- Most children stay in paediatric intensive care for 2 days or less. Their stay in hospital may vary from under one hour to over a week. It is extremely rare for children to die in paediatric intensive care and over 95% leave this type of specialist care alive. The death rate has fallen in recent years.
- One of the hospitals taking part in PICANet had a death rate which was higher than expected after taking account of how ill the children they treat were. The hospital took this matter very seriously. Included is a report of their review of the data they sent to PICANet and of the medical notes of the children who died.

There are standards for the care of critically ill children published by the Paediatric Intensive Care Society, the professional society of doctors and nurses who work in paediatric intensive care. PICANet is working with this society to measure these standards.

- Children in England and Wales who are admitted to paediatric intensive care with asthma, and need a machine to help them breathe, seem to be at more risk of dying than elsewhere in the world.

PICANet makes a number of recommendations for improving the Paediatric Intensive Care service. In 2011 these include:

- 1) PICANet should enable doctors, nurses, patients and their families to have access to basic information about their PICU on the internet.
- 2) More parents and representatives of patients should be recruited to the PICANet Steering Group and the PICU Families Group.
- 3) PICANet should work with other government, health, social care and education organisations to gain a better understanding of the impact of admission to paediatric intensive care on children and their families.
- 4) PICANet should support a study of children who are admitted to paediatric intensive care with asthma to help find better treatments.

1. Background

PICANet was established in 2002, with funding from the Department of Health (DOH) to step up and manage a national paediatric intensive care database that would allow core data to be collected in a standardised way throughout all PICUs in England. Additional funding from Scotland, Wales, Northern Ireland, Ireland and a non-NHS PICU in London have enabled PICANet to establish international coverage of the UK and Ireland.

Since November 2002, all NHS PICUs within England and Wales outside the Pan Thames region have been collecting data on consecutive admissions to their units. The Pan Thames units began data collection in March 2003, the PICU at the Royal Hospital for Sick Children, Edinburgh in December 2004. The Royal Hospital for Sick Children, Glasgow in March 2007 and The Royal Belfast Hospital for Sick Children in April 2008. 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 for 2010 and are presented in this

year's annual report. The non-NHS Harley Street Clinic PICU started contributing data in September 2010 to allow them 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.

PICANet receives support and advice from a Clinical Advisory Group (CAG) consisting of doctors and nurses working within the speciality and a Steering Group (SG), comprising professionals from Health Services Research, the Royal Colleges of Paediatrics & Child Health, Nursing and Anaesthetics. We also have a PICU 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 PICU Families group members. Additional support from the clinical community is provided through the Paediatric Intensive Care Society.

2. Introduction

As PICANet enters its 10th year the annual report presents an international overview of paediatric intensive care with the inclusion of data from Our Lady's Children's Hospital, Crumlin and Dublin Children's University Hospital, Temple Street, both based in Dublin. We have also received data from the non-NHS Harley Street Clinic PICU in London.

This year, the format of the printed report has changed markedly. It was felt that a document featuring the large number of tables and figures also presented on the PICANet website was no longer necessary. Instead, we have produced this shorter report that summarises and comments on the main results and identifies key issues from the data. All of the data tables, appendices and descriptions of methods are available on the PICANet website (www.picanet.org.uk). This enables the public, patients, clinicians and commissioners to have free access to data on PICU activity and performance.

Trusts have agreed that analysis of the data collected as part of the Paediatric Critical Care Minimum Dataset (PCCMDS) should be de-anonymised this year to allow the level of care represented by the seven paediatric critical care Healthcare Resource Groups (HRGs) to be published.

It was also agreed that the calculation of risk-adjusted standardised mortality rates (SMRs) should be based on a revised version of the Paediatric Index of Mortality 2 (PIM2). The effect of this is to take into account the observed year on year reductions in mortality in the PICANet dataset. The effect of this recalibration is discussed in detail in section 3. For one Trust, the recalibration has resulted in their PICU falling above the upper control limits of the funnel plots in 2009 and in 2008-2010 combined, although their 2010 SMR is within the limits. In accordance with PICANet policy, the PICU and Trust concerned has been contacted and a

process of review has been instigated. The response of the Trust is described in section 4.

As in previous years, we have encountered delays in receiving data from some PICU units, this has unfortunately meant that we have not been able to meet publication deadlines set by HQIP. In every case it is clear that delays are caused by resource or IT issues in the PICUs concerned. There is a strong commitment to provide data to PICANet from the PICU staff but not always adequate resources to help them get the data to us in good time. Good quality audit relies on accurate, timely data, we therefore strongly recommend that Trusts allocate sufficient resources to enable data collection and transmission to PICANet without placing an additional burden on already busy PICU staff.

In those PICUs with good support, this is reflected in the quality and timeliness of submission of their data. In some cases, a record of good quality submissions has been compromised by key personnel leaving.

We hope that implementation of the PICANet web data entry and reporting system will improve data quality as it will allow users to obtain central validation reports on demand and to download standard and customised reports on their own data. The system has been piloted over the summer of 2011 and will be rolled out 'live' in Autumn 2011.

Future developments in the web system will include the ability to add in local/regional/or national modules or custom fields to collect additional data for clinical audit, research or clinical trials; and to access patient flows across administrative boundaries.

This year we are pleased to include two articles written by members of the PIC clinical community, both based on PICANet data: the first describes the prevalence of acute asthma admissions to PICUs in

England and Wales over a six year period. The article highlights the apparently high mortality in those admitted with asthma who are ventilated and suggests that there is a need for a more detailed prospective audit to investigate the possibility of new or alternative therapeutic strategies in this patient group. The second article describes the use of extra-corporeal membrane oxygenation (ECMO) in England and Wales between 2005 and 2010 in and out of designated ECMO centres.

Both articles highlight the utility and uniqueness of the PICANet dataset. We hope that the continued accrual of high quality data and the addition of the transport and referral dataset will result in better understanding of paediatric intensive care practices across the UK and Ireland.

3. Mortality prediction: recalibration of PIM2

Background

Every year PICANet has reported the Standardised Mortality Ratio (SMR) for all PICUs. This SMR compares the observed and expected mortality in each PICU. Since 2006, PICANet has estimated expected mortality using the Paediatric Index of Mortality 2 (PIM2) which is based on medical history, interventions and physiological measurements taken from time of first contact with a PICU doctor up to the first hour after admission. These factors were originally selected as good predictors of subsequent mortality and the PIM2 score is used to predict expected mortality for a PICU by adding the PIM2 scores calculated for each admission.

As well as tabulating the SMRs by Trust, PICANet presents them graphically using funnel plots. These plot SMR against number of admissions for each Trust with upper and lower control limits. Trusts

falling above the upper control limits are deemed to have an excess mortality that warrants investigation.

Over the last few years, it has become apparent that PIM2 has been over-predicting mortality as the majority of PICUs have an SMR of less than one (figures 47b-50b in previous reports). In-PICU mortality has decreased year on year and it now stands at 4.2% compared with 5.5% in 2003-2004.

Figure 1 shows changes in observed and predicted mortality (using PIM2) and risk adjusted SMRs with 95% confidence interval since 2006. It is clear that although this improvement in mortality is very welcome, PIM2 no longer predicts mortality correctly and thus cannot be used as a measure of PICU performance in relation to mortality.

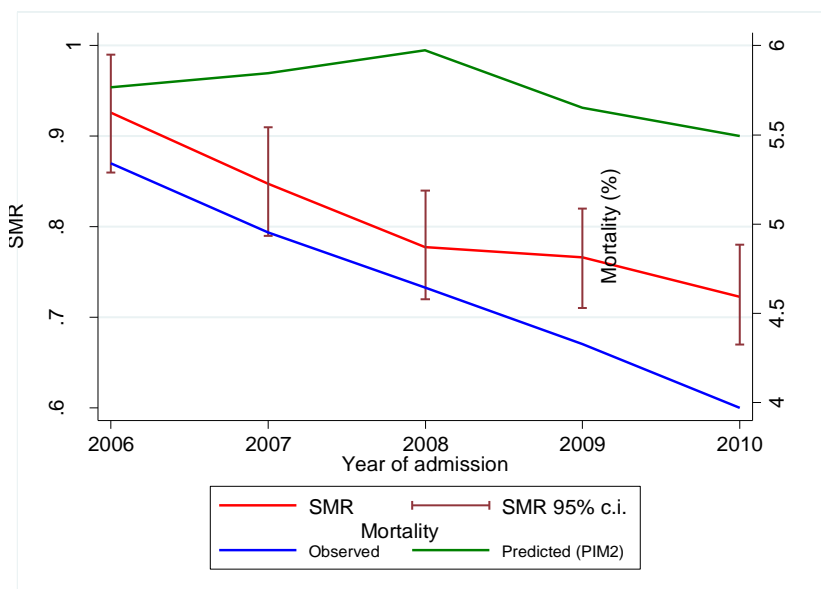


Figure 1 Observed and predicted mortality and overall SMR by year

PICANet also uses PIM2 to produce Resetting Risk Adjusted –Sequential Probability Ratio Test (R-RSPRT) charts for individual units and again these have become less sensitive to a worsening of performance.

Recalibration

We have recalibrated PIM2, using the original published factors, deriving new coefficients based on the data from this report (2008-10). All the PIM2 variables

were entered into a logistic regression model and the resultant coefficients combined to produce a new recalibrated PIM2 score denoted PIM2r. The coefficients derived, as log-odds ratios, are shown in *Table 1* below together with the published PIM2 coefficients for comparison. All are highly statistically significant except for the cardiac bypass variable, which no longer exerts a significant independent influence. The calculation of expected probability of mortality follows the same formula for PIM2, simply replacing the coefficients in the equation.

Standard statistical methods were used to assess the performance of the recalibrated model in the 2008-2010 data: the area under the ROC curve was 0.84, comparable to that reported for PIM2; however the fit was not perfect, with a significant Hosmer-Lemeshow statistic ($\chi^2=24.6$, 8 degrees of freedom, $P=0.002$) and in particular over-prediction in the lower deciles of risk. Its mean is more than 1% lower than PIM2 (4.1% vs. 5.4%).

Factor	PIM2r Coefficient	se	z	p	PIM2 Coefficient
Pupils unreactive	3.7758	0.1535	24.5925	<0.00001	3.0791
Elective admission	-0.6041	0.0913	-6.6134	<0.0001	-0.9282
Mechanical ventilation	0.9084	0.0763	11.8978	<0.00001	1.3352
Cardiac bypass	-0.0493	0.1311	-0.3759	0.706986	0.7507
Recovery from surgery	-0.9100	0.1056	-8.6174	<0.00001	-1.9526
High risk diagnosis	1.3639	0.0557	24.4814	<0.00001	1.6829
Low risk diagnosis	-1.4365	0.1332	-10.7834	<0.00001	-1.577
FiO2/PaO2 ratio	0.2765	0.0308	8.9891	<0.00001	0.2888
Absolute base excess	0.0724	0.0041	17.7344	<0.00001	0.104
Absolute (Systolic BP -120)	0.0149	0.0012	12.9618	<0.00001	0.01395
Constant	-4.6422	0.0797	-58.2229	<0.00001	-4.884

Table 1 PIM2r coefficients derived from PICANet data 2008-2010 with original PIM2 coefficients for comparison

We used the recalibrated model to generate the SMRs shown in Tables and Figures 47-50. Figure 2 shows the result for 2010. It can be seen that units are spread more evenly above and below the line representing an SMR of 1.

In the main report, one PICU falls outside the upper control limits in 2009 and for 2008-2010 combined. Their response to this finding is discussed in section 4.

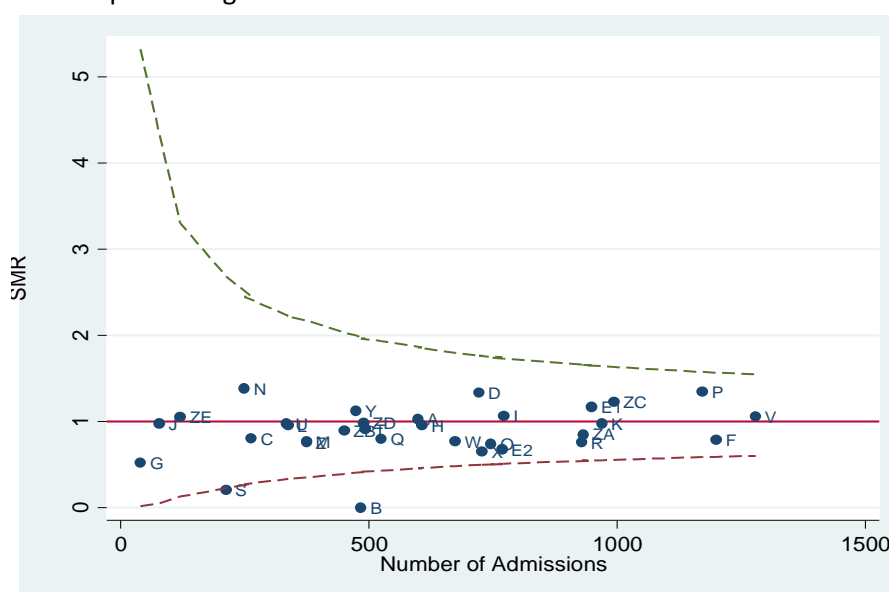


Figure 2 SMRs by Trust for 2010 using PIM2r recalibrated coefficients.

The effect of discharging to theatre

Some PICUs discharge children to theatre and then re-admit them generating a new PIM2 score, whilst others do not, instead counting it as one admission. This means that comparisons between these PICUs are not based on an expected probability of mortality generated at the same time point.

A PICU readmitting children from theatre will appear to have more admissions, and a lower mortality, than one which does not discharge in this situation.

Following discussions at the PICANet clinical advisory group it was agreed that the effect of discharging to theatre and readmitting from theatre on SMR should be investigated.

In a preliminary analysis, we identified children who were discharged and readmitted on the same day to the same PICU. There were 924 re-admissions out of 53,590 (1.7%). The proportion varied greatly between PICUs, from 0 – 7.5%. Treating these as a single admission proved to have very little effect on SMR overall; the largest change was an increase of 0.07.

Further more sophisticated analysis will be carried out to verify these preliminary findings.

The recalibrated coefficients given in *Table 1* should be used by units in the UK and

Ireland when calculating their own SMRs as they will give a more contemporary assessment of their performance.

Future recalibration and the development of PIM3

In future, PICANet will continue to recalibrate PIM2 using a three-year rolling data window to account for global changes in mortality.

In collaboration with ANZPICS, the Australian and New Zealand Paediatric Intensive Care Society, PICANet is involved in the development of a new international risk adjustment model, to be denoted PIM3. This work is currently being peer reviewed.

An international standard will allow comparison between countries although we do recommend that within countries, regular recalibration of mortality risk adjustment models is carried out.

As a postscript to this section, PICANet have been working with colleagues in the UK, France and Australia to assess the effectiveness of blood lactate levels as a predictor of mortality.

Lactate may be included in future risk adjustment models and has already been incorporated into the PICANet dataset.

4. An unexpected elevated SMR value: Response from Leeds Teaching Hospitals NHS Trust

PICANet has an established policy for dealing with PICUs whose risk-adjusted standardised mortality rate (SMR) falls outside the control limits of the funnel plots produced by individual years and aggregated over the three-year period of the PICANet national report. Falling outside the upper control limit suggests that the data represent an unexpected excess mortality. The PICU at the Leeds Teaching Hospitals Trust has participated in PICANet since its inception in 2002 and submits data promptly with minimal missing variables.

As indicated in the previous chapter the standardised mortality ratios for PICUs were calculated for 2008 to 2010 following the recalibration of PIM2 providing a more up to date and appropriate mortality risk adjustment model. Although, prior to recalibration, Leeds' standard mortality ratio fell within recognised control limits this was not the case following recalibration and Leeds became an outlier. In particular, the SMR for 2009 was clearly outside of control limits and although the SMR in 2010 fell close to unity the 2008 - 2010 combined SMR remained high due, in part, to the large affect of the 2009 data.

In response to this finding PICANet investigated the basic data quality from Leeds PICU and the patient case mix which had occurred over the three years in question. However, no specific issues were identified. PICANet alerted the team at Leeds who investigated data quality further concentrating specifically on patients admitted during 2009.

Two consultants, Tim Haywood, Clinical Lead and myself Catherine Penrose, reviewed all fifty seven patient deaths which occurred during 2009 including all case notes, all nursing observation charts (held on microfiche) and all PICANet data collection forms.

Each case was summarised and a new PICANet form completed for each patient. Any changes made to the data collection forms were itemised and summarised in detail. In total 28

out of the 57 deceased patients had data variables altered. The net result was that for the majority of patients their individual PIM2 score had been underestimated. The revised data set was then submitted to PICANet. Analysis of this new data revealed an increase in the predicted mortality when compared to the originally submitted data and hence the overall standard mortality ratio for Leeds was reduced. The revised SMR for 2009 and the combined SMR 2008 - 2010 now fall within the control limits of the funnel plots.

The patients' summaries revealed a number of issues in particular relating to those patients who were retrieved from outlying hospitals. It was striking that the initial data submitted for these patients did not use available retrieval data to calculate the PIM2 score in the majority of cases. More often than not this led to an underestimation of the predicted mortality for these patients. Despite formal training the junior doctors, who complete the PICANet forms, had repeatedly omitted documenting retrieval variables as per the PICANet Instruction Manual. Retrieved patients appear to have been a specific source of poor data quality. In sharp contrast, the data for patients who died, but who were not retrieved, showed a high level of accuracy. In addition we were concerned that data errors amongst retrieved patients who survived might also be adversely affecting the SMR and we endeavoured to address this concern.

During 2009 154 patients were retrieved into Leeds PICU. The data for a random sample of 18 retrieved patients who survived were reviewed. In all but one patient the retrieval data had not been used to calculate the PIM2 score. In common with the deceased patients the net result was that for the majority of patients there had been an underestimation of their predicted mortality. For a number of patients this was a very significant underestimation. Although not submitted for further PICANet analysis this small sample would also have lead to a further reduction in

the Unit's SMR. This sort of detailed patient review, although essential, is very time consuming and labour intensive. Time delays in retrieving notes from Medical Records and Consultant clinical commitment has made analysis of all 154 retrieved patients' notes impractical in the small amount of time we have been allotted. It would appear that if we were to extrapolate our findings to all retrieved patients we would show an overall underestimation of the predicted mortality for our patients due to the omission of retrieval data in our PIM2 calculations and hence our true SMR is even lower than the revised SMR reported. This review excluded children discharged alive and who were not retrieved. There is still the possibility that incorrect data from these patients could increase the unit's SMR. The unit will monitor all data closely in future.

Was 2009 really different to other years?

To us as clinicians 2009 did appear to be a 'rogue year' in many respects.

During 2009, in common with a number of other units in the UK, we admitted a number of children with H1N1 infection. This condition carried a high expected mortality and indeed we had four fatalities secondary to this. In 2009 we also had a higher than average number of out of hospital arrests - 8 in total. Seven of these patients were retrieved and all patients had a 'down time' (time without any recognisable cardiac output) in excess of 45 minutes. PICU admission for these patients was clearly futile but this represents the difficulty and reluctance of some to withdraw care in the District General Hospital setting. Education of our junior medical staff and of our paediatric colleagues, with regard to appropriate resuscitation duration, may go some way to address this issue. However, DGHs may still require advice and support to facilitate withdrawal of care outside of the PICU.

In addition, two patients were dead on arrival yet these patients remained in our

data set in the final analysis. Exclusion of these patients would further reduce our SMR.

I now know that discussion directly with the PICANet team can clarify a patient's eligibility and these patients should not have been included as we, as a PICU, could not affect the outcome.

In common with many paediatric units throughout the UK, 2009 represented challenging times with regard to junior medical staff. During one of these six month periods only 9 out of 14 junior doctor posts were filled yet there was no reduction in bed numbers or patient numbers during this time. As it is our junior doctors who are responsible for entering clinical data into the PICANet data collection forms may have negatively impacted on our data accuracy.

During 2008-2009 we did not have a validation visit from the PICANet team due to staffing issues. A validation visit in October 2010 identified that, for patients retrieved to the unit by a specialist regional transport service, the unit were not routinely recording the retrieved PIM2 values for the PICANet dataset. In 2009 'Embrace' was commissioned as a new regional transport service, retrievals no longer being performed by in house staff. This finding and additional differences between the data submitted and that extracted from hospital notes by PICANet were identified and reported to the unit.

With the introduction of the new PICANet referral and transport data collection PIM2 values will be automatically and clearly set out on the transport data collection form and will eliminate any future errors.

In summary, the reported excess mortality appears to have been due to data quality issues and, as indicated, the unit will monitor this closely in future. Indeed, this whole experience has been a salutary lesson for all of us here and has highlighted how the submission of incorrect, or misleading

data, can significantly affect the outcome measures we have come to rely on. As a clinician it has been an eye opener that changes to a relatively small number of patients can impact so heavily on the

outcome measures we have come to rely on and perhaps should be a lesson for us all.

Dr Catherine Penrose
Consultant in Paediatric Intensive Care
Leeds General Infirmary

5. Commentary

This commentary gives a very brief summary of the information contained in the data tables and figures as they appear in the spreadsheet section of the report available from www.picanet.org.uk.

Admissions

There were 52,337 admissions recorded in the PICANet dataset between 2008 and 2010, nearly half of whom (24,892) were under one year of age. It should be noted that year on year increases in admissions are primarily attributable to the inclusion of data from Ireland and more recently, the Harley Street Clinic. However, despite these additional units, the number of admissions over 16 years of age has remained the same.

As in previous years, over half the admissions to PICU are unplanned.

The winter peak in respiratory admissions in those under 1 year is still very pronounced. The PICANet team are preparing a report on the effect of H1N1 between 2009 and 2011, in collaboration with clinical colleagues.

The diagnostic case-mix has not changed overall and the most commonly returned diagnoses continue to be dominated by respiratory and cardiac conditions although head injury, sepsis and status epilepticus also figure in the top 20 diagnoses returned to PICANet.

Retrievals

The proportion of retrievals undertaken by non-specialist teams remains around 7.5%. It is anticipated that the proportion of children retrieved by 'other specialist team (PICU)' will increase as specialist retrievals services take over from PICU teams.

Interventions

The percentage of children receiving invasive ventilation varies between 6% and 89% in 2010, reflecting the differences between PICUs in diagnostic case-mix and admission criteria. Mapping this data by Nation/Strategic Health Authority (Figure 31a in the data tables spreadsheet) indicates higher levels of invasively ventilated children resident in Wales and the west of England. These differences may be explained by regional differences in the organisation of services for critically ill children, especially when the services serve geographically large areas.

Bed activity and length of stay

In the three year period of this report, over 308,000 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.

The bed census data (how many children are actually present in a PICU bed at ten minutes past midnight) clearly identify the winter admission peaks. The peak in December 2010 of 385 PICU beds occupied (compared with 338 in December 2009) partly reflects the additional data from Ireland. The 2009 figure was exceptionally high compared with the rest of the year and reflects the increasing winter pressures placed on PICUs.

Outcomes

The overall mortality rate in the PICANet dataset has continued to fall, with a three year average of 4.2% but just 3.8% in 2010. Mortality rates in PICUs varied between 0 and 7% in 2010.

The effect of revising the coefficients of PIM2 is clearly seen in the funnel plots of SMRs with the scatter of points representing the PICUs becoming more evenly distributed across the plots. The outlier in 2009 and in the combined 2008-2010 plot is discussed in detail in section 4.

There is still incomplete collection of 30-day follow-up with nearly 50% of data being returned as 'unknown'. This reflects the practical difficulties of tracing individuals who have moved out of a Trust or may have been discharged home. By flagging individuals who have been admitted to PICU with the Office for National Statistics, PICANet will be able to determine 30 day and longer mortality and also obtain information on cause and place of death.

Individual children

Nearly 39,000 individual children were admitted to a PICU contributing data to PICANet during 2008-2010. The majority (80%) only had one admission but for some children, admission to PICU happens more than once in 3 years. It should be noted that some children will have been admitted before and after the period covered by this report.

Prevalence for admission

Prevalence for admission has remained steady at around 141 admissions per 100,000 population overall. Regional differences exist, some of which may reflect admission policy and others the underlying demographics. An increase in births will inevitably lead to higher admission levels and these factors need to be included in the long-term planning of PICU services.

Children in adult ICUs

The marked increase in the number of children admitted to adult ICUs (see Table 62) is most probably due to increased reporting to ICNARC, the adult intensive care audit. There is very limited data available on these children and it is not possible to ascertain whether their needs

would have been better served by admission to a PICU. In some cases, these children would have only spent a short time in an adult ICU before being transferred to PICU, in others, their management on adult ICU would have been agreed between the adult and paediatric intensivists.

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

The data that make up the PCCMDS allow a more detailed analysis of the daily interventions in PICU on a patient by day basis. The aim of the PCCMDS was to produce data that could be used to calculate Healthcare Resource groups (HRGs) for Payment by Results (PbR). These data also describe the level of care based on interventions. This year we have identified each Trust that submitting this data to PICANet as we are confident the software that groups the data into HRGs has been sufficiently well validated. PICANet have been instrumental in helping the NHS Information Centre Casemix Service in testing the HRG Grouper and providing valuable information to the Paediatric Critical Care Expert Working Group as we have the most complete set of this data available in England and Wales.

Overall, contributing PICUs have approximately 50% of their activity classified as 'Intensive care basic' or 'Intensive care advanced'. Just over a third of their activity is classified as high dependency although this will include 'step-up' and 'step-down' care for children who will have received a higher level of care at some time in their PICU stay.

The relative proportions of the different levels of care vary markedly between Trusts. We recommend that Trusts ask PICANet for a breakdown of their PCCMDS data by patient by day (we will allocate an HRG for each day). These files are readily available and will be accessible via the new web-based data entry and reporting system. Currently 3 trusts do not submit PCCMDS data to PICANet.

The PCCMDS daily intervention data is a rich source of information on daily levels of care delivered by the PICU. Combined with bed occupancy data this provides an opportunity to examine the overall pressures on PICUs at different times of the year.

Data quality and validation visits

PICANet relies on good quality and timely data. Data quality is assessed in a number of ways.

Data entered via the PICANet software has a number of checks at the input stage and users are able to validate the details they are entering at any time. Once submitted to the PICANet server, the data are processed further and central validation reports are returned to the PICUs on a monthly basis or on request. Included with the monthly validation reports are the data submission and data quality tables that list how many admissions have been received by PICANet month by month, the last admission date, the last date that data was submitted, the number of errors and missing values that are in the data overall.

Validation visits are also carried out by PICANet staff to verify submitted data against hospital notes and check on admissions numbers. These validation visits are vitally important to maintain contact with PICU staff and to pick up on systematic errors that can creep into data, such as when new staff are recruited. The evidence presented in the data tables spreadsheet suggests that following validation visits quality improves.

The main concern about data quality still centres around the variables collected for the mortality risk adjustment model, PIM2 and the interventions received. These are important issues as Standardised Mortality Rates are calculated using PIM2, and intervention data is used to reflect the activity of the PICU.

The solution to these issues must be locally driven and, with the help of PICANet staff, we look forward to improvements in these areas.

Overall, checks carried out centrally reveal very high quality data. The ability to download reports based on a 'live' dataset will provide a strong incentive to PICUs to maintain this performance.

PICANet now receives valid NHS numbers for 90% of admissions facilitating data linkage with other healthcare data systems. The ultimate goal is to record an NHS number for every eligible child.

Summary

There is a huge amount of data in the PICANet report, relating to many aspects of PICU activity. All of the tables and figures are downloadable from the PICANet website for use in reports, presentations and publications. Please acknowledge PICANet if you do use them.

6. PICU Families Group

PICANet are working with the clinical community to consider and develop processes enabling families to be involved in determining quality standards of care within the PICU. Group membership comprises nurses and clinicians who are interested in the perspective of patient and public involvement in paediatric intensive care and participate in meetings as representatives of their PICU; a lay representative who has recent experience of PICU and PICANet team members (Appendix D).

The group first met in October 2009 and continues to meet three to four times per year. The agreed remit of the group is:-

- to develop a programme of work researching aspects of patient and public involvement within the paediatric intensive care service
- to ensure that parents and families are supported and provided with comprehensive information throughout the stay of their child in PIC
- to assess the long term impact and support requirements of children and families affected by a stay in PIC
- to facilitate the monitoring of the appropriate Standards of the Paediatric Intensive Care Society

A survey of the availability of services, facilities and support for families during their PICU stay has been developed and implemented. Questionnaires are completed with a member of the clinical staff during annual PICANet validation visits.

Currently the group are:

1. Developing a questionnaire asking families about the availability of services, facilities and support during their PICU stay, for comparison with the findings from the staff survey. This will also enable individual units to review themselves against comparable PICUs in the United Kingdom and Ireland.
2. Supporting the development of a collaborative study to establish the rate of post traumatic stress disorder in parents following the discharge of their child from PIC. This work aims to develop and test an intervention to improve the mental health of parents of children who have been treated in an intensive care setting.
3. Supporting the development of a questionnaire by the PICS National Retrieval Group to collect parental feedback.

PICANet are currently seeking up to four additional lay representatives to join the PICU Families Group and would also welcome suggestions for future projects.

7. Asthma in PICU

Background

Asthma is one of the most common diseases in childhood affecting over 1.4 million children aged under 16. Despite improvements in health care delivery its prevalence remains high. In 2002 there were 27 recorded deaths from childhood asthma in England and Wales. This report focuses asthma related deaths in patients admitted to Paediatric Intensive Care units (PICU) in England and Wales between 2005 and 2010. Scotland and Ireland were not included in the analysis as a full dataset was not available over the 6 year study period.

Methods

Cases were identified from the PICANet dataset by screening primary and secondary diagnostic codes for asthma related disease. 1640 admissions (1410 patients) were identified after exclusion of co-morbid conditions (cardiac, neurological, immune disorders, malignancy and chronic respiratory disorders such as tracheobronchomalacia, cystic fibrosis and chronic lung disease).

Results

The commonest diagnostic codes were asthma (38%), status asthmatics (26%), exacerbation of asthma (24%) and acute asthma (3.5%). In 2010, the proportion of asthma relative to total PICU admissions was highest in South East England (SE 4.2% of all PICU admissions) compared to North England (NE 1.4%) and South West England and Wales region (SW 1.0%).

Asthma related admissions increased by 67% (195 to 327 admissions) between 2005 and 2010 without a change in ventilation rate (44 to 37%,(Figure 3). Admissions were predominantly from SE 49.5%, NE 40.5% and only SW 10%. Median age was 71.5 months (IQR 36-132) of which 55% were male. The number of readmissions (n=127 patients) ranged from 1 to 25 (75th centile

= 3) with the median time to readmission of 4 months (IQR 1-12).

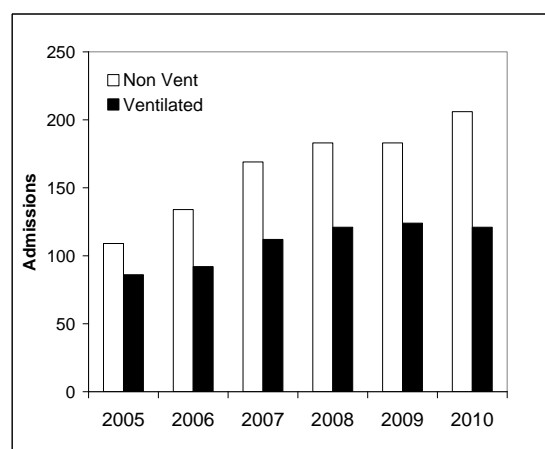


Figure 3 PICU asthma admissions between 2005 and 2010 for England and Wales

Almost half of the admissions (46%) required retrieval, the proportion being highest in SW (66.4%). Patients were ventilated for the majority of retrievals (81%), the proportion being lowest in NE (76%) and highest in SW (87%). These regional variations are likely to reflect differences in acute care and retrieval provision between District General Hospitals and PICUs.

Mechanical Ventilation

The ventilation rate was highest in SW at 62.8% vs. NE 43% & SE 32.8%. (Table 2) However, disease severity (using PIM2 predicted mortality) was also highest in this region (p=0.006). Interestingly PIM score was not different between these regions (p=0.14). PIM predicted mortality was 4 times that of PIM2 model (median 5.5% vs. 1.4% respectively) reflecting the adjustment for asthma as a low risk factor in the PIM2 model. Length of ventilation and length of PICU stay was 2 days (IQR 2 to 4) with no intraregional differences.

Deaths

There were 31 deaths over the 6 year period (n=5, 2, 6, 6, 7 and 5 for 2005 to 2010 respectively). Thirty of the deaths occurred on the 1st admission episode for

asthma and only 1 death occurred on the 2nd re-admission episode. Time to death was a median of 3 days (IQR 5-7) with maximum of 26 days (*Figure 4*).

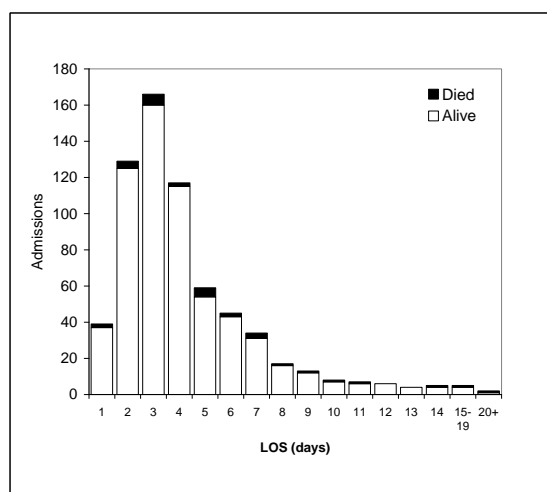


Figure 4 Histogram of length of stay (LOS) in mechanically ventilated asthma patients

The overall mortality rate for ventilated asthma was 4.7% with a PIM2 standardised mortality ratio of 1.34 (IQR 0.92 – 1.91). This death rate is higher than that reported in other paediatric studies where there is almost zero mortality or at worst 1.3% of ventilated cases.^{1 2 3 4}

The majority of deaths (64.4%) occurred in patients without fixed pupils prior to PICU admission suggesting that outcome could be improved by therapeutic interventions. It was beyond the scope of this report to analyse mode of death and to determine if therapeutic or ventilatory strategies had an influence on outcome. This differs from international reports demonstrating deaths

occurring exclusively in patients with fixed pupils prior to PICU admission.^{1 2}

Five patients required extracorporeal membrane oxygenation (80% survival). Non-survivors were older (129 months (IQR 84-159) vs. 78(32-134), $p=0.0001$). A logistic regression model incorporating PIM2, age, region and readmission status showed the only factor predicting death was PIM2 (OR 7.2, 95% CI 6.3 – 13.7, $p<0.0001$).

Conclusion

The mortality rate for ventilated children with asthma admitted to PICUs in England and Wales remains consistently high. A prospective national audit is merited and future research on alternative disease modifying therapeutic strategies in status asthmaticus is warranted. HQIP has recently commissioned a review of asthma deaths from the Royal College of Physicians, children are included in the review.

Andrew Nyman
Paediatric Intensive Care Registrar
Evelina Children's Hospital

Andrew Durward
Consultant in PICU
Evelina Children's Hospital

References

1. Triasih et al, Arch Dis Child 2011 doi:10.1136/adc.2010.205062
2. Sarnaik et al, Ped CCM 2004 5:133-138
3. Roberts et al, Crit Care Med 2002 30:581-585
4. Carroll et al, Pediatr Pulmonol 2007 42:914-919

Variable	North England	South East England	South West England & Wales	All
Mechanical Ventilation (%)	287 (43.1)	266 (32.8)	103 (62.8)	656 (40.0) $p<0.0001$
Ventilated and retrieved (%)	219 (76.3)	228 (85.7)	90 (87.3)	537 (81.8) <0.0001
Age in months	94 (39-148)	69 (32-123)	70 (26-123)	81 (33-136) $p=0.006$
PIM risk	5.4 (4.3-7.6)	5.3 (4.1-7.3)	5.9 (4.3-7.4)	5.5 (4.3-7.4) $p=0.14$
PIM2 risk	1.4 (0.9-2.3)	1.3 (0.9-2.2)	1.8 (1.1-2.5)	1.4 (0.9-2.5) $p=0.006$
Died (% of ventilated)	18 (6.2)	9 (3.4)	4 (3.9)	31 (4.7) $p=0.27$
Fixed pupils	5 (4 died)	2 (2 died)	3 (3 died)	10 (9 died)
CPR before PICU	24 (7 died)	17 (3 died)	7 (3 died)	48 (13 died)
ECMO	3 (1 died)	2	0	5

Table 2 Demographic variables for patients requiring mechanical ventilation (n=654)

Values as median (IQR). P-values are Fisher's exact or chi squared for categorical data or Kruskal-Wallis for continuous grouped data. PIM = Paediatric Index of Mortality.

8. ECMO in Paediatric Intensive Care in England and Wales

Background

Since the UK trial of neonatal respiratory extracorporeal membrane oxygenation (ECMO) in the early 1990s¹, respiratory ECMO for neonates and children has been a nationally commissioned service based at 3 hospitals in England and Wales², plus one centre in Scotland. However, since the time of the trial and the designation process in 1997, the role of extracorporeal support for children with cardiac disease, either post-operatively or as a bridge to heart transplant; has been increasing to the point that it has been argued that one cannot provide state of the art paediatric cardiac surgical services, without the backup of mechanical circulatory support.

Furthermore, the numbers of neonates receiving ECMO support has decreased with the greater adoption of innovations such as High Frequency Oscillatory Ventilation (HFOV) and inhaled Nitric Oxide (iNO); although it is not clear whether this change in practice has increased survival across the board, since it runs the risk of delaying ECMO referral for non responders. The most recent development especially in North America has been the proliferation of ECPR (extracorporeal cardiopulmonary resuscitation) where extracorporeal support is used as part of the treatment of cardiac arrest from all or any causes³. PICANet data shows that ECMO is being undertaken in

more English centres than the 3 designated ones, but no further details regarding the types of patients supported or their outcomes have been published.

Methods and results

All episodes of ECMO support in England and Wales in the 6-year period 2005-2010 were identified and diagnostic information and outcome. In this period there were 809 episodes of ECMO support reported to PICANet from 15 centres, including the 3 designated 'respiratory ECMO' centres. The vast majority of the workload was performed in these 3 centres (681 of 809 admissions; Great Ormond Street 269, Newcastle 128, Leicester 284). Underlying cardiac conditions predominated as the diagnostic grouping with the largest number of cases supported via ECMO.

The overall survival to PICU discharge for children supported on ECMO was 71.1% (234 deaths), although this may be something of an overestimate as in a small number of cases children may have been transferred from one centre to another on ECMO. Survival was slightly lower for 'cardiac ECMO' which was only undertaken in 10 of 11 cardiac surgical centres (231/382; 60.5%).

Diagnostic Group	Number of cases	Percentage survival to PICU discharge
Cardiac	383	60.5
Respiratory	288	86.1
Infectious Disease	44	63.6
Gastrointestinal	30	73.3
Others	64	70.3
Total	809	71.1

Table 3 Number of children supported on ECMO and percentage survival to PICU discharge by diagnostic group

It is also worth noting that the survival figures for infectious disease, including sepsis, are somewhat higher than the reported figures for meningococcal sepsis in the UK⁴, although PICANET data only contained 2 children with a primary diagnosis of meningococcaemia.

The number of admissions receiving ECMO per year between the 3 designated 'specialist ECMO' centres has been relatively constant whereas that in the other 7 cardiac surgical centres is probably increasing (*Table 3*).

Variation over time

Year	Number of children in 3 designated respiratory ECMO centres	Number of children in 7 non-designated cardiac surgical centres
2005	109	12
2006	117	16
2007	120	16
2008	113	22
2009	116	18
2010	106	27

Table 4 Numbers of children supported on ECMO in cardiac surgical centres by year

Variation by cardiac surgical centre

The units undertaking the most 'cardiac ECMO' were the 3 designated 'specialist ECMO' centres, 2 of which (Great Ormond Street and Newcastle) are also the designated paediatric heart transplantation units (*Table 4*). Leicester undertook a greater number of cardiac cases than Newcastle, even though it does not support patients awaiting or undergoing heart transplantation (*Table 5*). This either implies that the need for such support is greater

there or more likely that the threshold for using ECMO is lower due to confidence and experience with the technique. Survival rates show wide variation between centres probably for similar reasons. On that basis, these figures should be interpreted with caution and; it should be noted that further analysis is not possible as there is no risk adjustment available in terms of potential case selection for ECMO support in each centre.

Cardiac Surgical Centre	Number of children with primary cardiac diagnoses supported on ECMO	Percentage survival to PICU discharge
Great Ormond Street	117	64.1
Leicester	90	68.9
Newcastle	77	58.4
Royal Brompton	22	50.0 Range 15.4-100.0
Liverpool	19	
Birmingham	16	
Leeds	13	
Southampton	13	
Bristol	8	
Evelina	7	

Table 5 Number of children supported on ECMO and percentage survival to PICU discharge by cardiac surgical centre

Common underlying diagnoses requiring ECMO support

The most common primary diagnoses that required ECMO support remained the causes of neonatal pulmonary hypertension, including meconium aspiration syndrome and congenital diaphragmatic hernia (*Table 6*) Cardiomyopathy of various types was the second most common indication. All 10 cardiac surgical centres supported children with transposition of the great arteries (discordant ventriculoarterial connection/total great vessel transposition), although there was some variability in the

number of cases between units (Leicester 10 cases; 3 other units as few as just 2 cases each), whilst other common congenital cardiac diagnoses needing ECMO support included hypoplastic left heart and tetralogy of Fallot (*Table 6*). Unfortunately, accurately ascertaining the use of ECPR (extracorporeal cardiopulmonary resuscitation) in England & Wales is not possible from the PICANet data. Although 7 cases had a primary diagnosis of cardiac arrest.

Primary Diagnosis & Diagnostic Codes (Read Code)	Number of cases
Meconium aspiration syndrome (Q3110) Neonatal aspiration of meconium (Xa0tw)	165
Cardiomyopathy (G55..) Hypertrophic obstructive cardiomyopathy (G551.) Restrictive cardiomyopathy (G5541) Primary dilated cardiomyopathy (G5544) Cardiomyopathy NOS (G55z.) Cardiomyopathy in metabolic diseases classified elsewhere (Gyu5R) Congestive cardiomyopathy (XE0Uz)	56
Persistent pulmonary hypertension of the newborn (X2001)	46
Congenital diaphragmatic hernia (XE1MG) Diaphragmatic hernia (XE0ab)	39
Discordant ventriculoarterial connection (P51..) Total great vessel transposition (P510.)	37
Hypoplastic left heart syndrome (P67..)	25
Tetralogy of Fallot (P52..) Tetralogy of Fallot, unspecified (XE1KD)	19

Table 6 Seven most common primary diagnoses receiving ECMO support

Conclusion

In conclusion, it would seem that although the overall numbers of children supported by the use of Extracorporeal Membrane Oxygenation use is relatively steady in England and Wales, an increasing proportion of this workload is taking place outside of the 3 designated respiratory ECMO centres, in the 7 other cardiac surgical centres for children with underlying congenital cardiac diagnoses. This is most

likely occurring post-operatively and; it is potentially concerning that the survival figures for the various centres vary quite considerably.

Peter Davis
Consultant Paediatric Intensivist
Bristol Royal Hospital for Children.

Gale Pearson
Consultant Paediatric Intensivist
Birmingham Children's Hospital

References

1. UK Collaborative randomised trial of neonatal extracorporeal membrane oxygenation. UK Collaborative ECMO Trial Group. Lancet 1996; 348: 75-82
2. <http://www.specialisedservices.nhs.uk/service/extracorporeal-membrane-oxygenation-service-children-neonates-infants-with-severe-respiratory-failu>
3. Morris MC, Wernovsky G, Nadkarni VM. Survival outcomes after extracorporeal cardiopulmonary resuscitation instituted during active chest compressions following refractory in-hospital pediatric cardiac arrest. Pediatric Critical Care Medicine 2004; 5: 440-446
4. Luyt DK, Pridgeon J, Brown J, et al. Extracorporeal life support for children with meningococcal septicaemia. Acta Paediatr 2004; 93:1608-11
5. <http://www.specialisedservices.nhs.uk/service/heart-lung-transplant-service/search:true>

9. Staffing Survey

PICANet is committed to monitoring and analysing staffing levels within PICUs, and to monitoring the appropriate Standards of the Paediatric Intensive Care Society. Staffing data was collected in November 2010 and is presented here compared with previous data from 2005 and 2009. This data has been used to monitor the PIC Standards for the Care of Critically Ill Children (4th Edition); Version 2, June 2010. Information was collected on numbers of nursing staff and medical staff employed on units. Details were recorded at four specific 'snapshot' time periods (a weekday at noon and

midnight, and a weekend at noon and midnight). Data was also collected about other professionals working on PICU. All units participating in PICANet (thirty four units in 30 trusts) returned data following the circulation of questionnaires in 2010.

Nursing staff

Under the Agenda for Change established in 2004, NHS pay scales are by bands rather than grades. Three units continue to apply grades, for the purpose of this report grades A-C were mapped to bands 1-4, grades D-E to band 5, grade F to band 6, grade G to band 7 and grades H-I to band 8.

Table 7 Total number of qualified nurses in post and the proportion of specially trained children's nurses and nurses with intensive care qualification and additional life support training.

BAND	Number of qualified nurses in post	% of children's trained nurses	% with additional intensive care qualification	% with PLS ^a training	% with EPLS ^b / APLS ^c training
5	1977.0	73	24	41	9
6	781.0	78	77	55	42
7	308.5	96	93	55	68
8	38.0	95	89	61	55

a PLS Paediatric Life Support Training – includes Hospital Life Support Training

b APLS Advanced Paediatric Life Support Training

c EPLS European Paediatric Life Support training

Figure 5 Proportion of nursing staff (WTE) by band (December 2009 and November 2010)

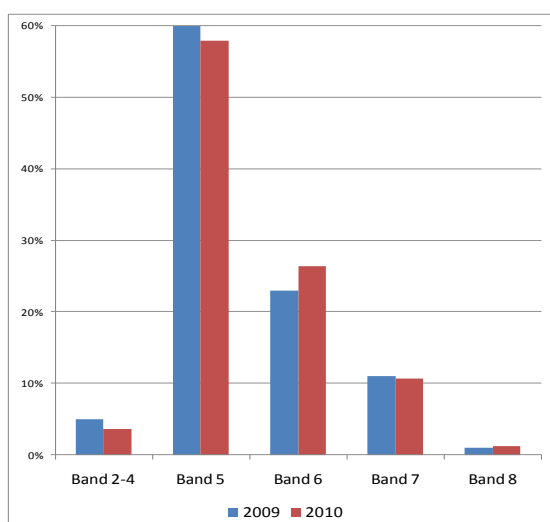


Figure 5 shows the proportion of nurse whole time equivalents by band in the same trusts in 2009 and 2010.

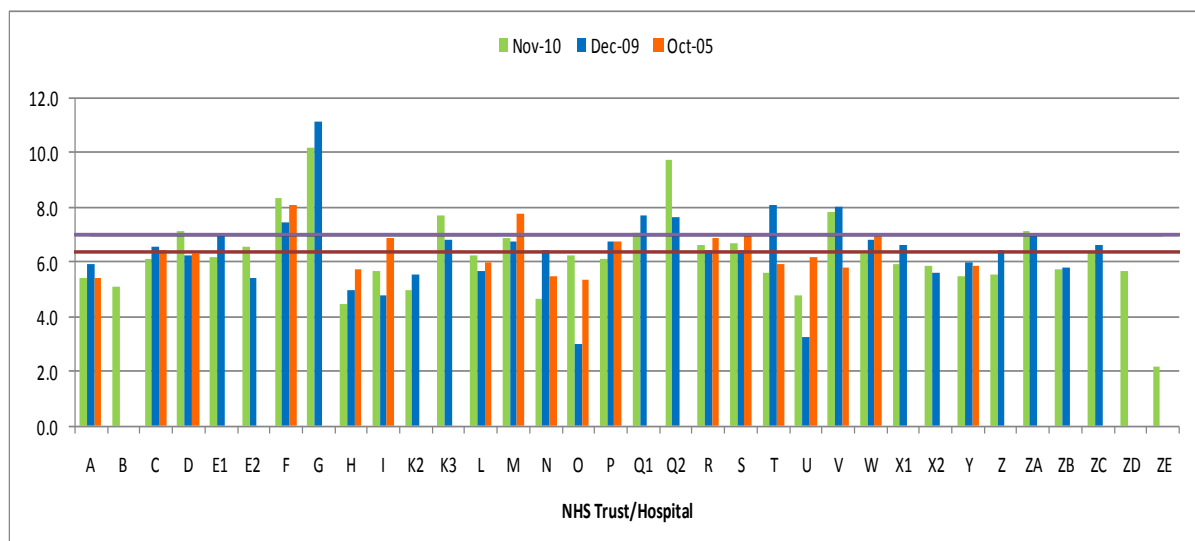
There has been little change over time with a small reduction in the proportion of band 5 WTE nurses employed on the units in 2010 compared with 2009 and a small increase in the proportion of band 6 and 8 WTE nurses.

Standard 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 which states:- **the minimum number of qualified nurses required to staff 1 critical care bed is, at least 7.01 whole time equivalents (WTE).**

minimum of 25% uplift to nursing establishments to cover annual leave, study leave and sick leave. Additional considerations are study leave, mandatory and statutory training, maternity, special leave and an allowance for a nurse in charge and/or runners. The final calculation takes the minimum WTE per bed to 7.01. This guideline is shown on the graph.

Previous standards endorsed the benchmark of 6.4 WTE per bed. The RCN recommends a

Figure 6 Number of clinically qualified nursing staff (WTE) in post per bed, by NHS trust (October 2005, December 2009 and November 2010)

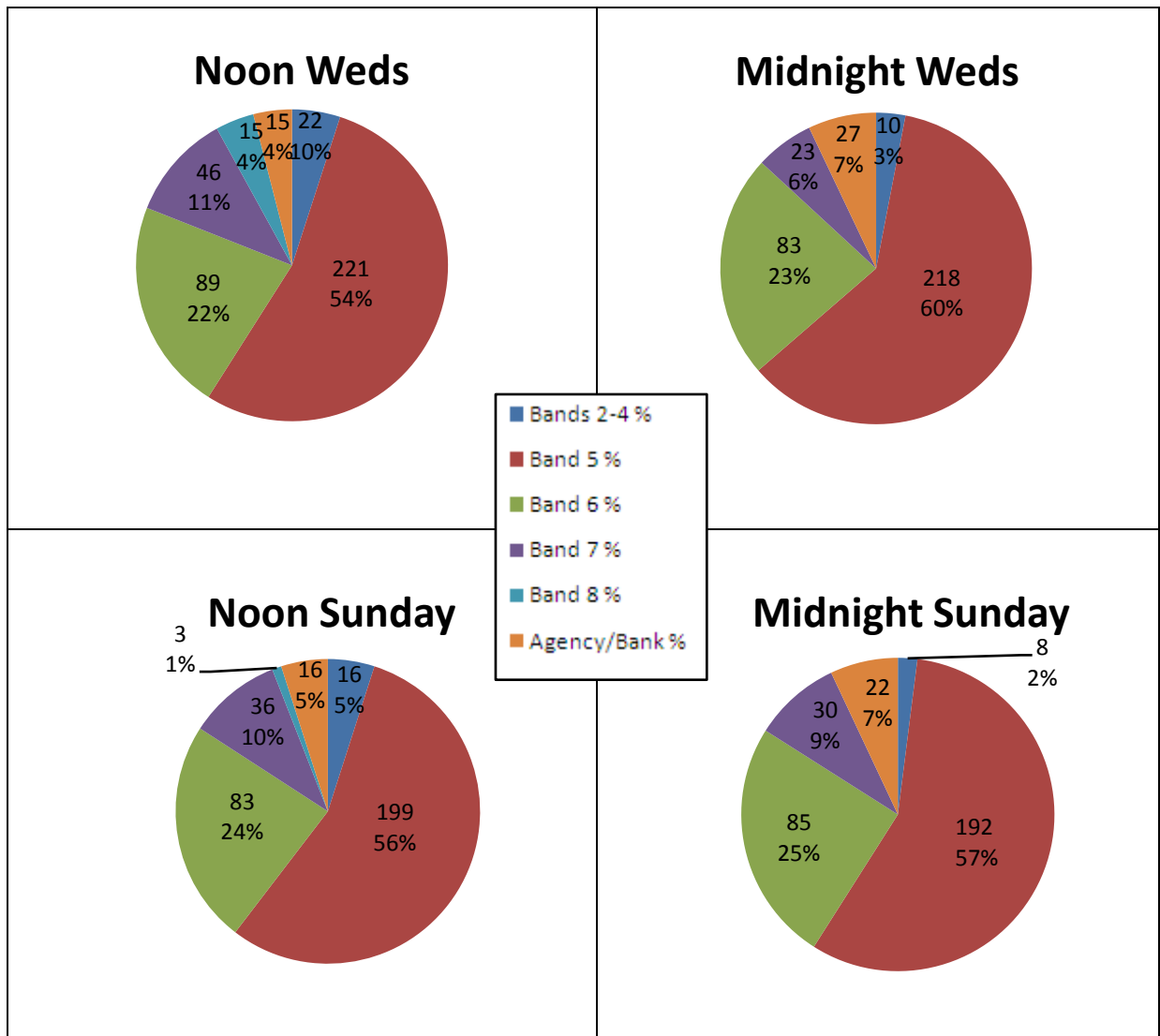


Unit B did not return nurse staffing data for 2005/2009
 For units E1&E2, K1, K2 & K3, Q1 & Q2 data in 2005 was only available by trust.
 Units K1 and K2 had a combined nurse staffing rota in 2009
 Units Z, ZA, ZB, ZC were not included in PICANet in 2005.
 Units ZD and ZE were not included in PICANet in 2005 and 2009
 Unit ZE has 40% nursing establishment complemented by agency/bank staff.

Figure 6 shows the total numbers of WTE clinically qualified nursing staff per funded bed. The number of beds is based on the figures returned by the units in October 2005, December 2009 and November 2010. Data for all qualified nursing staff and the number of funded beds on each unit are calculated from the data returned (nurse/patient ratio, intensive care 1:1, high dependency 0.5:1). These figures do not include non-clinical staff, such as educators

and retrieval co-ordinators not clinically active on PICU. The guideline of 7.01 minimum qualified nurses WTE per bed is indicated on the graph. Figure 3 shows that in November 2010 eight units meet Standard 164 indicated by the purple line, with a qualified nursing establishment of equal to or more than 7.01 WTE per bed. An additional five units meet the previous standard of 6.4 WTE per bed indicated by the red line.

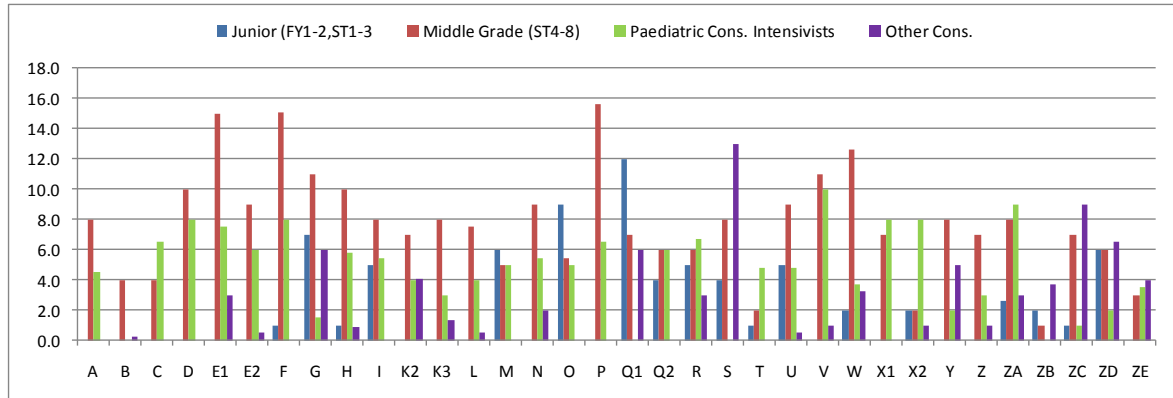
Figure 7 Proportion (percentage) of nursing staff by clinical and qualification status working on PICU for the four snapshot time periods (noon and midnight Wednesday and Sunday, week commencing 8th November 2010).



The snapshot surveys looked at the numbers of nursing staff working on a weekday (Wednesday) at midday and midnight and a weekend (Sunday) at midday and midnight. **Figure 7** shows the proportion of untrained and trained nurses by band (clinical and non-clinical) and agency nursing staff (bands 5-7) - at four different time periods in 2010. The highest proportion of band 8 nurses are on duty at noon on Wednesday, with

none on duty at midnight on Wednesday or Sunday. A larger proportion of agency/bank nurses are on duty at midnight on Wednesday and Sunday. The proportion of band 5 (Range 54-60%) and band 6 (Range 22-25%) nurses on duty is similar at all the snapshot times. There is a higher proportion of band 2-4 nurses on duty at noon on Wednesday and Sunday than at midnight on these days.

Figure 8 Numbers of medical staff (WTE) by position and NHS trust (November 2010)



Research pots have been recorded as 50% clinical hours

Unit G is a 10 bedded ICU with 2 designated PICU beds

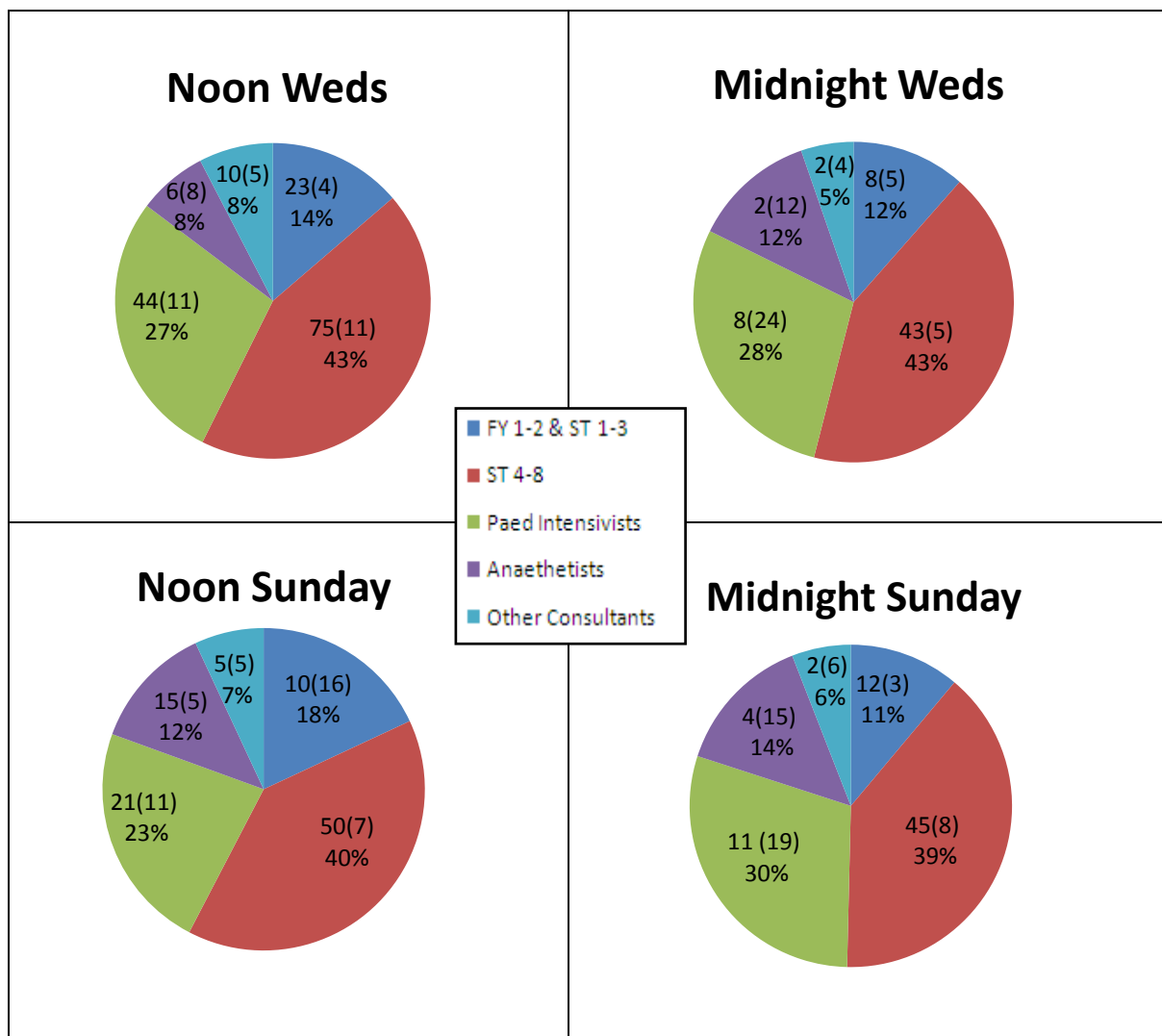
Unit T has 3 physician assistants

Units N, F, X1, X2, have on call support from Cons. Anaesthetists

Units X1 & X2 Paediatric Consultant Intensivists work across 2 sites in trust

Unit ZE has 3 ST 4-8 doctors contracted for employment and up to 8 additional middle grade locums employed on PICU.

Figure 9 Proportion (number) of medical staff by position working on PICU and on call for the four snapshot time periods noon and midnight Wednesday and Sunday, week commencing 8th November 2010).



For each snapshot time period the chart shows the proportion of medical staff of a specific grade on duty; with the number on call in brackets following.

The snapshot surveys looked at the numbers of medical staff working on a weekday (Wednesday) at midday and midnight and a weekend (Sunday) at midday and midnight. **Figure 5** shows the proportion of Junior, Middle Grade and Consultants (paediatric consultant intensivists, anaesthetists and others) at four different time periods in 2010.

The greatest proportion of Junior doctors (FY1-2, ST 1-3) 18% are on duty at noon on Sunday. The number of Paediatric Intensive Care Consultants on duty is highest at noon on Wednesday but the number as a proportion of the medical workforce is similar in all snap shot time periods (Range 23-30%).

Figure 10: Number of medical staff on duty and on call at the four snap shot time periods.

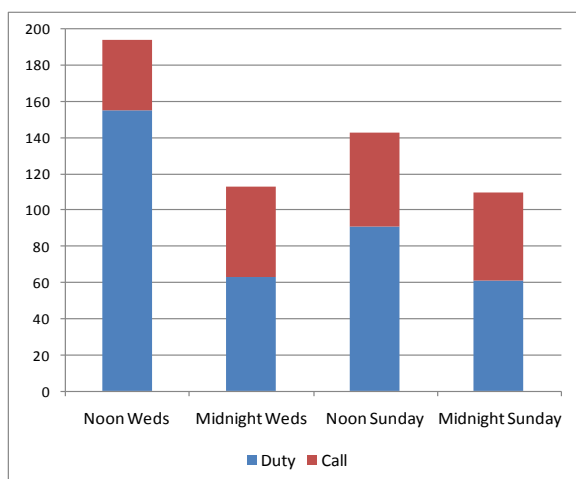


Figure 10 shows that the greatest numbers of medical staff are on duty at noon on Wednesday, followed by noon on the Sunday. A similar number are on duty at midnight on a weekday and weekend.

Standard 157 “For every 8 to 10 PICU beds there should be at least one consultant available to the unit at all times”.

All units with > 10 beds had at least one consultant available for every 8 to 10 beds at noon and midnight on Wednesday. Only 38% of these units had more than one consultant available at noon and 92% at midnight on Sunday.

For units with less than or equal to 10 beds, all had at least one consultant available at each of the four snap shot data collection time periods.

Occupancy

Figure 11: Total number of critical care beds and the number occupied at the four snapshot time periods.

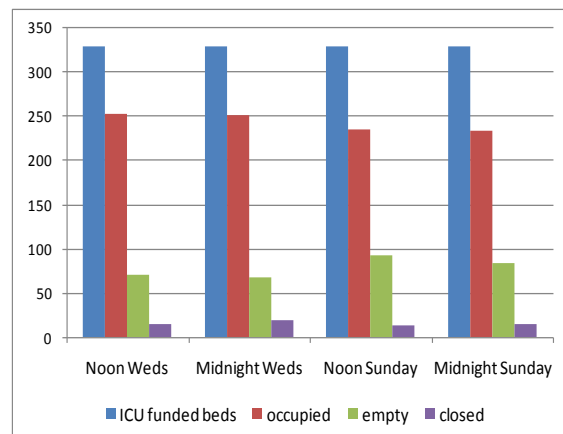
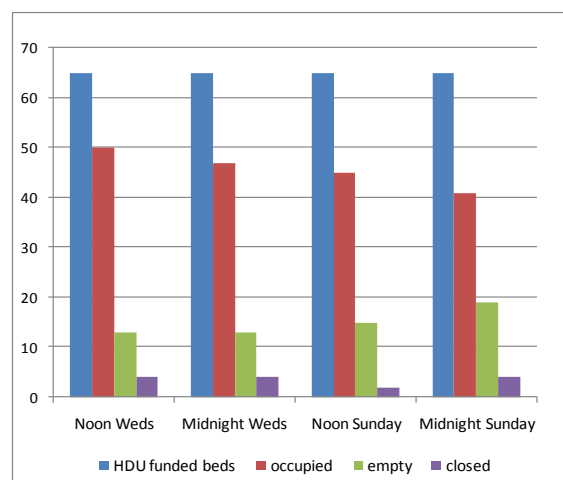


Figure 12: Total number of high dependency beds and the number occupied at the four snapshot time periods

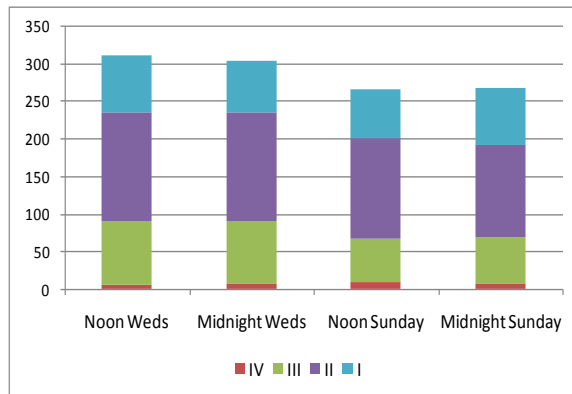


Trust L is funded to provide 13 care levels flexibly divided between critical and high dependency care.

Figures 11 and 12 show the numbers of critical care and high dependency beds occupied on the units on a weekday (Wednesday) at midday and midnight and a weekend (Sunday) at midday and midnight. The survey recorded the number of funded beds in the units, 330 intensive care and 65

high dependency beds were funded in November 2010. High dependency beds are included in those critical care units where PICANet data is submitted for both intensive care and high dependency patients.

Figure 13 Proportion of patients receiving Levels I, II, III and IV of care at the four snapshots hot time period



The greatest proportion of patients, mean 47.5% (Range 46-50%) were receiving level two care during each of the four snapshots times, noon and midnight Wednesday and Sunday. At any time over one fifth of PICUs are treating more than 20% of patients who only require high dependency care

Other professionals

Standard 170 "Daily sessional support should be available to the Paediatric Intensive Care unit from pharmacy, physiotherapy and dietetic staff with

competencies in the care of critically ill children who have time in their job plans allocated for their work on the unit".

Figure 14 Proportion of units with less than or equal to and more than 10 beds and the availability of other named professionals.

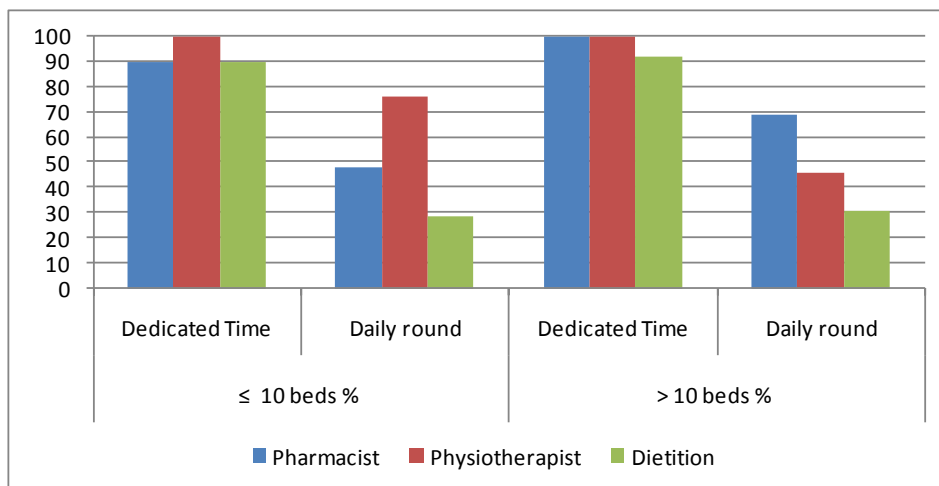


Figure 14 shows all the units have dedicated time from a physiotherapist and all the units with > 10 beds have dedicated time from a pharmacist; over 90% of all units have

dedicated time from a pharmacist, providing daily sessional support to the units and therefore meeting Standard 170.

Support for critically ill children and their families

Standard 144 “The following support services should be available:

- **Interfaith and spiritual support**
- **Social workers**
- **Interpreters**
- **Bereavement support**
- **Patient advice and Advocacy Services**
- **Psychological support for families and children”**

Availability is not defined but should be appropriate to the case mix and needs of the patient.

Figure 15 Proportion of PICUs with less than or equal to and more than 10 beds and the availability of specified support services.

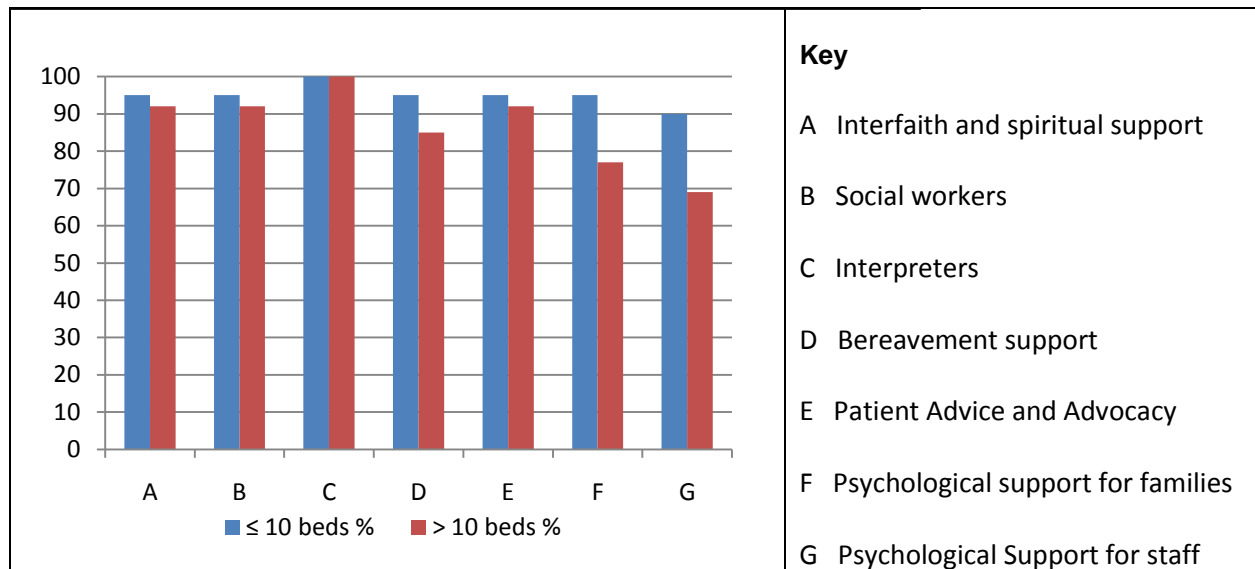


Figure 15 shows the proportion of the thirteen units with more than 10 beds and the proportion of twenty one units with equal to or less than 10 beds; in which the support services specified in Standard 144 are available. 100% of all units provide access to interpreting services. 95% of units with ≤ 10 beds provide interfaith and spiritual support, social workers, bereavement support, patient advice and advocacy and a service providing psychological support for families.

For units with > 10 beds 92% of units provide interfaith and social support, social workers and patient advice and advocacy, 85% provide bereavement support and 77% psychological support for families. One large unit admits patients electively from overseas and additional support is provided to the family by the embassy.

Summary

- In 2010 the response rates to the PICANet survey were 100%. This is the first time PICANet have achieved a 100% return
- The majority of nurses employed are band 5 (58% in 2010 compared with 60% in 2009). The small reduction in the proportion of band 5 nurses compares with an increase in the proportion of band 6 nurses from 23% in 2009 to 26.4% in 2010.
- There has been a 9.5% increase in the numbers of qualified nursing staff, bands 5-8, when comparing the total whole time equivalents in post in units in England and Wales in December 2009 and November 2010.
- The 2010 survey shows that 23.5% of the units meet Standard 164 Appendix 13 of the PICS guideline (June 2010), with at least 7.01 WTE of qualified nurses being required to staff one critical care bed.
- The snapshot survey shows that the majority of the medical staff are middle grades (ST 4-8) (45% in 2010 and 2009).
- Over half of the trusts had junior medical staff (FY1-2, ST 1-3) working on PICU (66% in 2010).
- 95 percent of the units with ≤ 10 beds and over 85 percent of the units with > 10 beds have access to the named support services with the exception of psychological support for families and staff – Standard 144.
- 100% of units have dedicated time from the physiotherapist, 100% of units with > 10 beds have dedicated time from the pharmacist and 92% from the dietician, 90% of units with ≤ 10 beds have dedicated time the pharmacist and dietician - Standard 170.

References

- 1 The Agenda for Change (AfC) website: <http://www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingPay/fs/en> (accessed 24 April 2006).
2. Paediatric Intensive Care Society Standards for the Care of Critically Ill Children 4th Edition version 2 June 2010.

10. Using PICANet data

Data and information requests

There were 47 requests for data and information since last year's annual report was prepared. The requests are all sent to the chair of the Paediatric Intensive Society Study Group to ensure that there is good collaboration in the clinical community and no overlap of effort. Often the chair, currently Dr Mark Peters from Great Ormond Street, is able to give valuable advice to applicants.

PICANet publishes all data and information requests on our website (www.picanet.org.uk) and the requests since last year are published in the online appendices to this report.

The requests vary substantially – from those that require information on a specific condition queries about patient flows to help plan services delivery. We have had one request from a pharmaceutical company for information about meningococcal septicaemia/meningitis in relation to the development of a new vaccine.

Some of these requests have resulted in publication in academic journals: recent topics have included palliative care, the efficacy of retrievals services, children admitted to PICU with severe brain injury and Severe Acute Disseminated Encephalomyelitis.

The PICANet dataset is a valuable resource that should be exploited to the full. With the addition of the referrals and transport

data items, we expect that there will be further opportunities to audit these services against the newly published Paediatric Intensive Care Standards for the Care of Critically Ill Children.

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



www.picanet.org.uk
picanet@leeds.ac.uk

University of Leeds

Roger Parslow
Phil McShane
Thomas Fleming
Lee Norman
Sara Skinner

PICANet
Paediatric Epidemiology Group
Centre for Epidemiology & Biostatistics
The Leeds Institute of Genetics
Health and Therapeutics
University of Leeds
Worsley Building
Leeds
LS2 9LN

r.c.parslow@leeds.ac.uk
0113 343 4856

University of Leicester

Elizabeth Draper
Caroline Lamming
Martin Perkins
Rachel Hobson

PICANet
Department of Health Sciences
University of Leicester
22-28 Princess Road West
Leicester
LE1 6TP

cr14@le.ac.uk
0116 252 5414



PICANet Annual Report 2008 – 2010 ISBN #####