

Annual Report of the Paediatric Intensive Care Audit Network

**January 2009— December 2011
Summary Report**



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Key

A	Cambridge University Hospitals NHS Foundation Trust
B	Brighton & Sussex University Hospitals NHS Trust
C	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
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/K3 Great North Children's Hospital
	K2 Newcastle Freeman Hospital
	<i>(In 2010 the General and Royal Victoria PICU's merged within the Great North Children's Hospital)</i>
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	Harley Street Clinic (non- NHS)

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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.

PICANet is funded by the National Clinical Audit & Patient Outcomes Programme, administered by the Healthcare Quality Improvement Partnership (HQIP), Welsh Health Specialised Services Committee Specialised Services, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, Our Lady's Children's Hospital Crumlin and 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.

Foreword

PICANet has been operating since 2001 and collecting data, initially from English and Welsh units since November 2002. This 9th report now provides baseline information on PICU activity and risk adjusted outcomes covering all PICU admissions in the UK and Ireland.

We have an established PIC families group to involve users of the PIC service in its appraisal and to develop appropriate patient reported outcomes measures. As part of this initiative, we have expanded our remit to conduct a survey of the information and facilities available to families and compare this to the PICS standards published in 2010.

The development of the transport and referral dataset has taken some time. Its integration into the new web-based data entry system was critical. This has been a major technical challenge but data are now beginning to flow into the database. Next year, we hope to publish some preliminary data and analysis alongside the current data.

As part of the government's transparency agenda, PICANet have provided raw, anonymised data that forms the annual report dataset. We will also endeavour to make our reporting tools on the web even easier to use to ensure all stakeholders are able to optimise their use of the data for the continued improvement of PIC care provision. Mortality in PICU is very low and looking to the future, we need to develop new performance

measures that incorporate patient reported outcome measures as well as a better assessment of morbidity post-discharge. The higher risk-adjusted mortality observed in South Asian children between 2004 and 2007 has increased slightly over the subsequent four years. A plan is being developed to address this issue and determine its cause.

PICANet data has been used widely by clinicians, commissioners and academics to facilitate local audit and commissioning, research, clinical trials and government funded review panels. Our challenge is to keep this impetus going and to create the opportunity for local and national changes in practice and policy that will help PIC services improve the quality of care they provide. The collaborative work with the Health Protection Agency and the Institute for Child Health linking PICANet data and information on bloodstream infections is an example of one such opportunity. The proposed participation with the Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection as well with the PICU Clinical Reference Group indicate the high level of influence PICANet has on healthcare policy.

Roger Parslow
Liz Draper

Principal Investigators, PICANet

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.
- 2) With additional support provided by Welsh Health Specialised Services Committee 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 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.
- 4) PICANet was established in 2001 and functions in close collaboration with members of the Paediatric Intensive Care clinical community.
- 5) 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.
- 6) Data quality is rigorously monitored through central validation procedures and regular site visits by the PICANet team.
- 7) 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 result in the published tool overestimating the expected risk of mortality.
- 8) Data are presented on 55,032 paediatric intensive care admissions aged under 16 years and; 1314 admissions 16 years and over, to 28 NHS organisations, one non NHS PICU in the UK and 2 hospitals in Ireland over the three year period January 2009 to December 2011. Data from the Irish hospitals is not given for 2009.
- 9) Detailed tables present information nationally, by Strategic Health Authority/Health Board (SHA/HB), Primary Care Organisation (PCO), named individual NHS Organisation and other healthcare providers. Data are available for downloading from the Web in spreadsheet format.
- 10) Children under 1 year make up 48% of all admissions with significantly more boys (57%) compared to girls (43%). A large proportion of admissions (58%) are unplanned. Over three quarters (77%) of children who are retrieved are done so by specialist paediatric intensive care transport teams.
- 11) Invasive ventilation procedures are recorded for 67% of admissions. This showed wide variation, from 4% to 89% of patients by NHS Organisation in 2010. Invasive ventilation rates also vary by geographical region reflecting the different patient case-mix for admissions to PICUs based on residential address at admission.
- 12) More than 300,000 bed days were delivered between 2009 and 2011, the increase over the last year reflecting 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 PICU for seven or more days.
- 13) It is extremely rare for a child to die in paediatric intensive care and 96% of children were discharged alive in 2009-2011. The death rate has reduced from 4.2% in 2009 to 3.9% in 2011.
- 14) Children of South Asian origin have a 40% higher risk-adjusted mortality than other children admitted to PICU in England and Wales in 2008-2011. This reflects similar

findings in research published by PICANet in 2007.

- 15) Risk-adjusted performance of all Providers fell within acceptable limits in each individual year and aggregated across the three year period using the recalibrated mortality risk adjustment tool.
- 16) The majority of PICUs are achieving or working towards the Paediatric Intensive Care Standards for the Care of Critically Ill

Children in relation to the provision of information and facilities for parents and carers although not all standards are met.

- 17) In 2011, only five units meet Standard 164 Appendix 13 of the PICS guideline (June 2010), that requires at least 7.01 WTE of qualified nurses to staff one critical care bed.

Recommendations

1. All UK NHS Organisations and other healthcare providers 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 enhancing current reporting tools that enable 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 not currently submitting referral and transport data to PICANet should do so as soon as possible (PICS Standard 127).
5. PICANet should continue working 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.
6. 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.
7. The excess risk-adjusted mortality in South Asian children admitted to paediatric intensive care should be investigated formally to determine its possible causes.
8. All PICUs should take the necessary steps to meet the PICS standards for facilities and information for parents and carers.
9. 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.
10. Staffing levels on PICUs should be reviewed regularly and all reasonable attempts made to meet professional standards.

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 them 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 give the best quality care 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 closely with the teams of doctors and nurses who care for children in Paediatric Intensive Care Units. We have also established a PIC Families Group and have reviewed 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 55,000 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 2009-2011.
- Nearly 60% of children admitted to the 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 (57%) 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 96% left this type of specialist care alive in 2011. The death rate has fallen in recent years.
- Children of South Asian ethnicity have a greater risk of dying in paediatric intensive care even after taking into account how sick they were when they were admitted. The reason for this is not clear from the information received by PICANet.
- PICANet is working with the Paediatric Intensive Care Society, the professional society of doctors and nurses who work in paediatric intensive care, to measure how well PICUs meet professional standards.
- Not all PICUs meet the professional standards laid down by the Paediatric Intensive Care Society in relation to facilities and information for patients and carers although all units are working hard to comply with these standards.
- In 2011, our survey of nursing and medical staffing shows that only five units meet standards laid down by the Paediatric Intensive Care Society for the number of qualified nurses required to staff one critical care bed.

PICANet makes a number of recommendations for improving the Paediatric Intensive Care service.

In 2012 these include:

- 1) All PICUs should take the necessary steps to meet the PICS standards for facilities and information for parents and carers.
- 2) PICANet should investigate further why children of South Asian origin are more likely to die in PICU even taking account of how sick they were on admission.
- 3) NHS Organisations and other healthcare Providers should make sure that there are enough qualified nurses to care for critically ill children.

1. Background

PICANet was established in 2001, 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, submitted anonymised data to PICANet from 2010. 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 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 Paediatric Intensive Care Society.

2. Introduction

This 9th annual report from PICANet follows the same format as last year with a short printed summary report and the bulk of the report containing the data tables, appendices and descriptions of methods 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 and reflects government policy on transparency.

As in previous years, we have encountered delays in receiving finally validated data from some PICUs. 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 Providers allocate sufficient resources to enable data collection and transmission to PICANet without placing an additional burden on already busy PICU staff. This is especially important with the implementation of the transport and referrals dataset which will create a small additional burden. This dataset has been approved by the Paediatric Intensive Care Society and data from it will be used to measure against published standards.

We are grateful to the authors of commissioned articles in this report: they reflect the extent to which PICANet data are seen as the gold standard source of information on paediatric intensive care activity in the UK and Ireland.

Progress with IT: the PICANet web development project

Since our last annual report, the PICANet IT team has been working hard to transition the PICANet database to the new Web system. This change has essentially meant a 'ground up' rebuild of the software used to collect and store the PICANet dataset. We have also implemented the web-based collection of referral and transport data to provide a more comprehensive picture of critical care delivered to children by the paediatric intensive care service.

By centralising PICANet data collection mechanisms we will be able to deliver a service that is more responsive to change, easier to diagnose issues and also quicker to deliver results. PICANet web works in conjunction with a reporting services element that allows us to develop complex reports for units and other interested parties. The new infrastructure has enabled us to build-in a full audit trail that can track all user interactions. User access is centrally controlled which allows us to assign permissions at different levels, dependent on need. Access to the PICANet web application is limited to a list of pre-approved locations specified by the clinical lead of each participating unit.

The transition to PICANet web has not been without issues, it would be impossible to move a system as complex as PICANet to a new set of technologies and paradigm without some issues. Many of the issues have been caused by the increase in complexity of the system. Data collection/input, data transmission, validation, analysis and reporting had previously been done in distinct stages – PICANet web now carries out all of these actions at the time of import/data input.

It was considered important to continue to allow units to export data in the same format from their clinical system as they had for earlier versions of PICANet. Maintaining this backwards compatibility has meant a more complex import schema than expected and it has caused some issues with imports from third party software applications. We have also expanded the number and complexity of validation checks that we perform on the data, this has exposed differences in data collection procedures at some units and it has also been difficult to spot processing problems due to the number of data transactions involved.

The transfer to the new system has been performed on a unit by unit basis, currently 24 of the 33 units submitting data have transferred to PICANet Web. One unit will not be transitioning as they are no longer collecting data and, of the remaining 8 units, 6 can be transferred

immediately after completion of the annual report. One unit requires an additional feature adding to PICANet Web before it can transition. The final unit is working on their in house clinical system to be able to supply a compatible data export.

In the near future we will be deploying the following additional features:

- Units will be able to download a full data export from PICANet Web in a number of formats. Units will be able to nominate a range of data to export in identifiable/anonymised form.
- Units will be able to choose a date range and export a Generic xml file containing PCCMDS data that can be used to support payment by results submissions.
- The PICANet team will be working on an expanded validation system, we hope to be able to implement a system that can monitor for unexpected changes in data.

The next major project will be to develop custom audits in PICANet, we would like to be able to define extended data collection that would allow users to input additional data when required for a particular audit/short term project.

Data and information requests

There were 44 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. 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 to queries about patient flows to help plan services delivery.

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 published Paediatric Intensive Care Standards for the Care of Critically Ill Children.

Anyone who receives data or information from PICANet must provide 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. Our document, *Data and information requests: policy on use of data, publication and authorship. Version 1.2.1 February 2011*, available from www.picanet.org.uk contains more details.

International collaboration

PICANet are working closely with PICE (Paediatric Intensive Care Evaluation) in the Netherlands, TIP.net (Network Italiano delle Terapie Intensive Pediatriche) in Italy and REUNIR-CIP (Nacional de Informacao Relevante em Cuidados Intensivos Pediatricos) in Portugal to standardise data collection for paediatric intensive care across Europe for structure, process and outcome measures. The team from Erasmus (PICE) are leading an EU funding application for this group. In addition to creating a standardised European dataset the project aims: to benchmark PICU practice across Europe; to identify areas of best practice; to empower parents of critically ill children and ensure high levels of satisfaction with PIC services; and to identify strategies for effective health care planning and skill mix. This work is being facilitated by ESPNIC ("the European Society for Paediatric and Neonatal Intensive Care").

3. Clinical Comment: moving beyond mortality and SMR plots to measure unit performance

Introduction

PICANet has been with us for 10 years and has undoubtedly been a huge success and a fine example of collaboration between clinician and academic partner. PICANet now captures information on paediatric intensive care activity from all UK and Eire units. It continues to strive to take things to the next level, with current initiatives being the launch of a retrievals dataset, the development of a web based portal which will support data submission and allow units to interrogate their own data and performance, and the forging of increasing international collaborations with European and Australasian partners.

PICU beds are a scarce and expensive resource which we must try to use efficiently whilst at the same time delivering safe and high quality care. Every year we collectively face a PIC capacity pressure as a result of winter respiratory infections, with the need for an additional 50-60 PIC beds across the UK relative to summer demands (Figure 34). Collectively we must learn to increase efficiency and to manage local and 'national' capacity cleverly if we are to avoid a winter of cancelled elective surgery, refused admissions and greater numbers of children and families being transferred to distant PICUs.

Measuring unit activity and efficiency

At its simplest level efficiency can be inferred from the number of PICU admissions and PICU bed days delivered against the number of staffed PICU beds. From a resource perspective a highly efficient unit is one that can put more patients through each PICU bed each week, month or year. This should be reflected in a shorter PICU length of stay compared to other units. The PICANet report includes nice plots of numbers of PICU beds, the number of patients admitted into those beds, the number of bed days delivered, as well as length of stay broken down across units, age bands and diagnostic groups. Unfortunately the significant variation in case-mix and, importantly, in patient acuity between

different PICUs prevents us from being able to use LOS ("Length of Stay") to assess unit efficiency or performance – we are left comparing apples and oranges. Review of the 2011 PICANet data shows huge variation in predicted mortality (Table 11), invasive ventilation rate (Table 29), and the proportion of children meeting HDU rather than PIC HRG levels (Figure PCCMDS1) across UK and Eire PICUs, reflecting a significant difference in the threshold for PIC admission between units. Overall LOS will be shorter if a unit admits lower acuity patients, regardless of whether or not they are more efficient in using PICU beds, severely limiting our ability to interpret the current LOS data. ANZPICS ("the Australia and New Zealand Paediatric Intensive Care Registry") have confirmed a significant effect of diagnostic category, type of admission (elective vs emergency) and level of intervention (for example invasive ventilation) on LOS and have begun to present 'risk adjusted LOS' data for each unit (1) which then allows a more meaningful comparison with other units. I would challenge colleagues at PICANet to look to present LOS data in a more meaningful way so that we can begin to use it in our assessment of unit performance.

Measuring quality and safety – beyond mortality

Historically we have relied on SMR plots to compare patient outcomes between PICUs. A unit is assumed to be performing at a satisfactory level if it's adjusted SMR falls within the 99.9% control limits on the funnel plot but this fails to differentiate between a unit consistently on the 75% centile from one on the 25% centile – their performance is almost certainly not the same. Should we not be looking beyond outliers and trying to learn from units who consistently have a low adjusted SMR?

In this year's report PICANet report, for the first time, the finding that observed mortality exceeds predicted mortality (based on PIM2) in children who require more complex interventions, as measured by increasing HRG category (Figure PCCMDS2). This is not surprising given that the

Paediatric Critical Care HRGs were largely derived through expert consensus and designed to reflect increasing complexity of management. This finding does question how much we can rely on SMR comparisons between units with very different admission thresholds, case-mix and intervention profiles. As with the discussions about LOS above should PICANet be presenting additional risk adjusted plots of mortality to take into account additional factors such as escalating PICU intervention complexity?

Given the above limitations, together with the fact that crude PICU mortality is less than 4% and death is a rather blunt outcome measure, we should be looking beyond mortality to develop measures centred on delivery of a high quality and safe service, and measures of morbidity. This has been highlighted in PICANet plans for the coming year. The new commissioning structure has mandated the setting up of a Clinical Reference Group to advise on commissioning matters relating to PIC (see Section 12). One of the key outputs of this work will be a Quality Dashboard which is not yet finalised but is likely to consist of around 15 items which aim to provide a measure of the safety and quality of the PICU (and retrieval service). Some of the candidate measures include the number of refused

admissions, cancelled elective operations, emergency readmissions to PICU in 48 hours, unplanned extubations, catheter-associated blood stream infection, proportion of discharges leaving PICU with a written discharge letter, proportion of deaths undergoing a formal review process, availability and timely mobilisation of a retrieval service, along with the completeness and timeliness of PICANet and PCCMDS data returns. A number of these measures will rely heavily on data already collected for PICANet; we should ensure that all of the items become incorporated into an expanded PICANet dataset so that, along with the measures described above, as a PICU community we can begin to look in increasing detail at the performance of our PICUs.

Reference

- 1) ANZPIC Registry Report, 2010.
<http://www.anzics.com.au/core/anzpicr?start=2>

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4. Commentary

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

Admissions

There were 55,032 admissions of children under 16 recorded in the PICANet dataset between 2009 and 2011, nearly half of whom (26,466) 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. Trust X has under-reported admissions by 13% during the period of this report, because of staffing issues. Efforts are being made to deal with this outstanding data.

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. In collaboration with clinical colleagues, the PICANet team reported on the effect of H1N1 between 2009 and 2011 at the 2011 meeting of the European Society for Paediatric and Neonatal Intensive Care in Hannover.

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 13% and 86% in 2011, reflecting the differences between PICUs in diagnostic case-mix and admission criteria. Mapping this data by National/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 320,000 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 increase in 2010 and 2011 over 2009 partly reflects the inclusion of the Irish units.

Outcomes

The overall mortality rate in the PICANet dataset has continued to fall, with a three year average of 4.0% and 3.9% in 2011. Mortality rates in PICUs varied between 0 and 10% in 2011.

Once again the coefficients of PIM2 were revised to reflect current mortality. This year the revision incorporates an adjustment in which children discharged and readmitted shortly afterwards are treated as a single admission. The methods are described in chapter 5 of this Summary Report.

The effect of this revision is clearly seen in the funnel plots of SMRs with the scatter of points representing the PICUs becoming more evenly distributed across the plots. In this report all units fall below the upper control limit.

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 are transferred out of a Provider hospital 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

More than 41,000 individual children were admitted to a PICU contributing data to PICANet during 2009-2011. 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

This year, Tables 62-67 include cases for 2009 & 2010 supplied by the South West Audit of Critically Ill Children (SWACIC) as well as the adult Intensive Care National Audit and Research Centre ("ICNARC"). There is very limited data available on these children admitted to adult ICU 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 Provider 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. There is also a proportion where care is not classed as 'high dependency' under the current criteria.

As expected, both predicted and observed mortality are increased in children needing more intense intervention on their first day (Fig PCCMDS2 in the Tables and Figures spreadsheet). However, the difference is more striking in actual mortality; showing that clinical decisions about interventions reflect disease severity in ways not captured by PIM2.

The relative proportions of the different levels of care vary markedly between Providers. We recommend that Providers 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 soon be accessible via the new web-based data entry and reporting system. Currently three Providers 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.

Information and facilities available to the PIC family

The majority of PICUs are achieving or working towards the Paediatric Intensive Care Standards for the Care of Critically Ill Children monitored by completion of this questionnaire. All PICUs provide written information about the unit including visiting arrangements, unit routine and a telephone number for contact. All units report that parents are '*welcome to visit the PICU at all times*'; however 62% of PICUs will ask parents to leave the bedside in specific circumstances such as the main ward round.

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 web system is validated dynamically. Validation reports are available from this system in different formats to allow users to work on correcting existing or adding new data.

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 following staff changes with new staff unfamiliar with the PICANet dataset and definitions. The evidence presented in the data tables spreadsheet suggests that validation visits are followed by an improvement in data quality.

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 the live dataset 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. PICANet is also able to provide information and data to support local, regional and national audit, research and commissioning.

5. Mortality and risk adjustment in PICANET:2012

Last year's report showed the decline in mortality, both absolute and risk adjusted, among children admitted to PICU. Because of this we introduced a policy of updating PIM2 every year, based on the 3 years in the report, so that it reflects current rather than historical performance. The 'recalibrated' score, PIM2r, was used for calculating the Standardised Mortality Ratios (SMR) presented in last year's report and in analyses carried out since.

We are happy to report that risk adjusted mortality continues to fall. A very slight increase in unadjusted death rate in 2011 compared to 2010 is more than compensated for by an increase in predicted mortality, whichever score is used. As a result we have carried out a fresh recalibration has, leading to a revised PIM2r.

In developing this, we also took into account another issue discussed in last year's report, the effect of discharging children from PICU and re-admitting them afterwards, as compared to treating them as one single admission. The effect of the former policy is to increase the number of admissions and reduce mortality compared to the latter. Last year's report showed that the effect of this policy on SMR was quite limited. However concerns continued to be raised and this year we have decided to take this into account, both in the development of the recalibrated score and in its application. Where a child is discharged and re-admitted to the same unit (treating the 2 GOSH units as separate) in under 12 hours this is counted as one admission and the initial values of PIM2 or its components are used, whilst outcome is taken as that for the final admission. 929 admissions (1.65%) were identified as rapid re-admissions on these criteria.

Multivariate logistic regression was used to determine the effect of PIM2 components on mortality.

Only data from units contributing throughout the period were used for estimation of coefficients in order to avoid possible bias due to changes in

mortality over the period and one other unit was excluded because of a known data issue. 50,288 admissions were included.

All factors were very highly significant except for the cardiac bypass variable. Coefficients for each are shown in Table 1, together with previous values. The coefficients have changed only very slightly from those produced in 2011, and the mean predicted mortality differs by only 0.06%. Although it has no significant effect cardiac bypass is still included in the model for consistency with PIM2.

Applied to the dataset on which it was derived the area under the ROC curve was 0.85, comparable to that reported for PIM2; however the fit was not perfect, with a significant Hosmer-Lemeshow statistic ($\chi^2=27.7$, 8 degrees of freedom, $P=0.0005$) and in particular overprediction in the lower deciles.

The values of PIM2r obtained in this way were used to generate the standardised mortality ratios shown in Tables 47-50 and Figures 47b-50b. No unit fell above the upper control limit in any period.

The effect on SMR of counting rapid repeat admissions as separate rather than as one was also investigated. Figure 1 shows the proportion of rapid readmissions by Provider, together with SMR calculated by both methods: overall there is little difference, as was also reported last year.

These coefficients for PIM2r should be used in future. In doing so repeat admissions should be treated as one: however the impact of failing to do so is likely to be very limited.

As PIM2r is to be updated every year, we will identify updates with the year in brackets thus PIM2r[2012].

Factor	PIM2r[2012]		PIM2r[2011]	PIM2	PIM
	Coefficient	Standard error	Coefficient	Coefficient	Coefficient
Pupils unreactive	3.7872	0.1555	3.7758	3.0791	3.549
Elective admission	-0.6830	0.0967	-0.6041	-0.9282	-1.45
Mechanical ventilation	0.9392	0.0791	0.9084	1.3352	0.661
Cardiac bypass	-0.0785	0.1394	-0.0493	0.7507	
Recovery from surgery	-0.9530	0.1099	-0.9100	-1.0244	
High risk diagnosis	1.4068	0.0568	1.3639	1.6829	1.33
Low risk diagnosis	-1.5751	0.1406	-1.4365	-1.577	
FiO2/PaO2 ratio*	0.2985	0.0314	0.2765	0.2888	0.301
Absolute base excess	0.0655	0.0043	0.0724	0.104	0.053
Absolute (Systolic blood pressure -120)	0.0145	0.0012	0.0149	0.01395	0.017
Constant	-4.6360	0.0821	-4.6422	-4.884	-4.135

FiO2/PaO2 ratio =100(FiO2 as fraction)/PaO2 in mmHg)

Table 1. Coefficients (log-odds ratios) for PIM2r[2012], PIM2r[2011], PIM2 and PIM

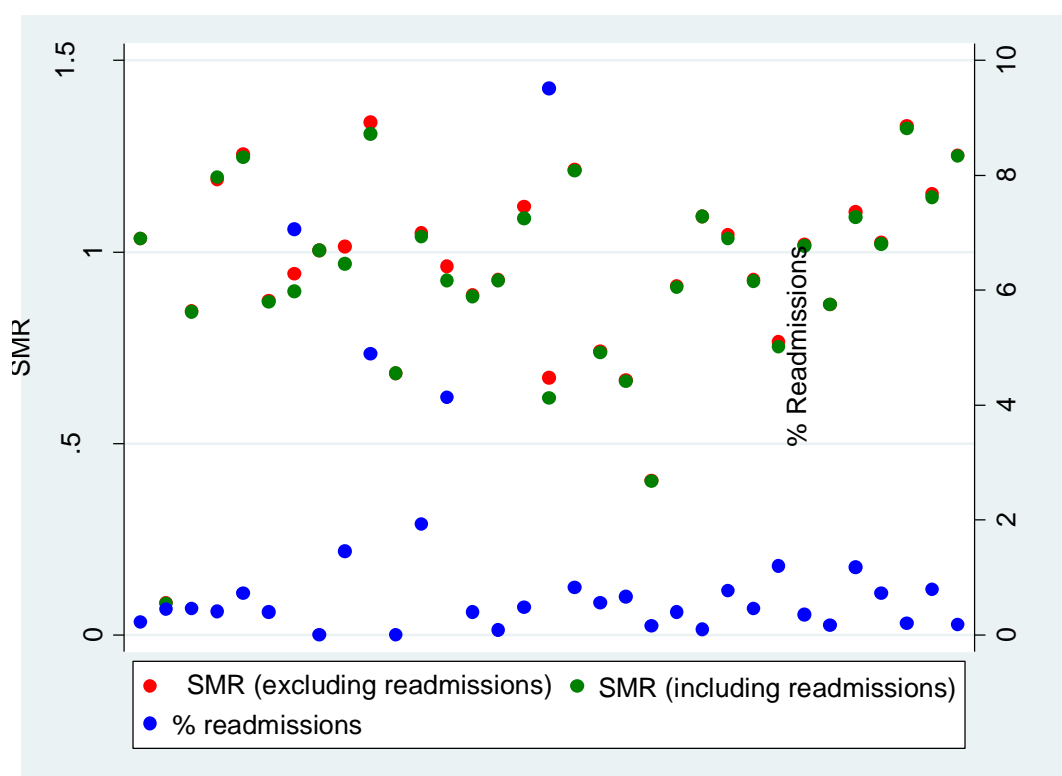


Figure 1. Rapid readmissions and effect on SMR

Notes:

Blue symbols show % of children readmitted to same unit within 12 hours of discharge

Green shows the SMR treating such admissions as separate.

Red shows the SMR treating them as one admission.

Red and green markers often overlap.

6. Data Quality

This section describes the results of validation visits to units. Results of central validation of data are presented in the 'Tables and Figures' spreadsheet. Figures and tables are numbered consistently in both sections.

Unit Validation Visits

A validation visit for 24 PICUs was carried out by a PICANet observer between April 2011 and February 2012; this completed visits to all 33 units submitting data to PICANet during the fourteen months prior to February 2012.

At each visit the units are asked to provide 10 sets of case notes for consecutive admissions before a specified date three months prior to the visit.

Ideally 100% of the records should be available and Table DQ1 shows that this was achieved in 21 of the 24 units visited with a range of 8-11 admissions reviewed. In 4 units the records for 11 admissions were reviewed; in these cases the same child had been discharged and readmitted to PICU within the specified time period creating two PICANet admission records.

At the time of the validation visits 8 units (PICU ID 6, 9, 12, 15, 18, 23, 27, 34) had been migrated to the PICANet Web, 16 units continued to submit data to PICANet DE. The number of discrepancies found during each visit is shown in Table DQ1

Date visited		PICU ID	No. of sets of notes examined	No. of discrepancies
Year	Month			
2011	April	04	10	58
		16	10	20
		14	10	38
	May	22	10	18
		21	9	0
		32	10	26
	June	10	11	18
	July	19	10	6
	Oct	05	10	23
		24	10	20
		27	8	13
	Nov	13	10	29
		34	11	24
		35	10	18
	Dec	36	10	21
		33	10	26
		03	10	6
		18	10	26
		23	10	16
		15	10	20
		01	11	29
2012	Jan	09	9	18
		12	11	23
		06	10	9
	Feb			

Table DQ1. Number of case-notes reviewed, visit date and number of discrepancies noted during validation visits performed April 2011-February 2012

During validation visits twenty-four fields are examined for discrepancies between the case notes and the PICANet data collection forms and/or PICANet database. The total number of discrepancies found was 507 in 240 admission records giving a mean per episode (per set of case notes reviewed) of 2.11 (range 0-11) and an overall discrepancy rate of 8.8 per field. This finding is very close to the discrepancy rate of 9.0 reported in 2011.

The validation visits provide an opportunity to assess data accuracy and to detect systematic errors. In total 240 sets of admission notes were

reviewed on the day of the visits. The number of discrepancies found per episode (set of admission notes reviewed on the day of the visit) is shown in Figure DQ1. No differences were found in around 25% of the case notes reviewed. The number of differences found ranged from 11 in one set of admission notes to ≤ 1 in around half of the notes reviewed. The discrepancy rate per field from recent validation visits was 8.8%. This compares with 8.4% in validation visits reported in 2011, 9.6% in 2010 and 8.2% in 2009.

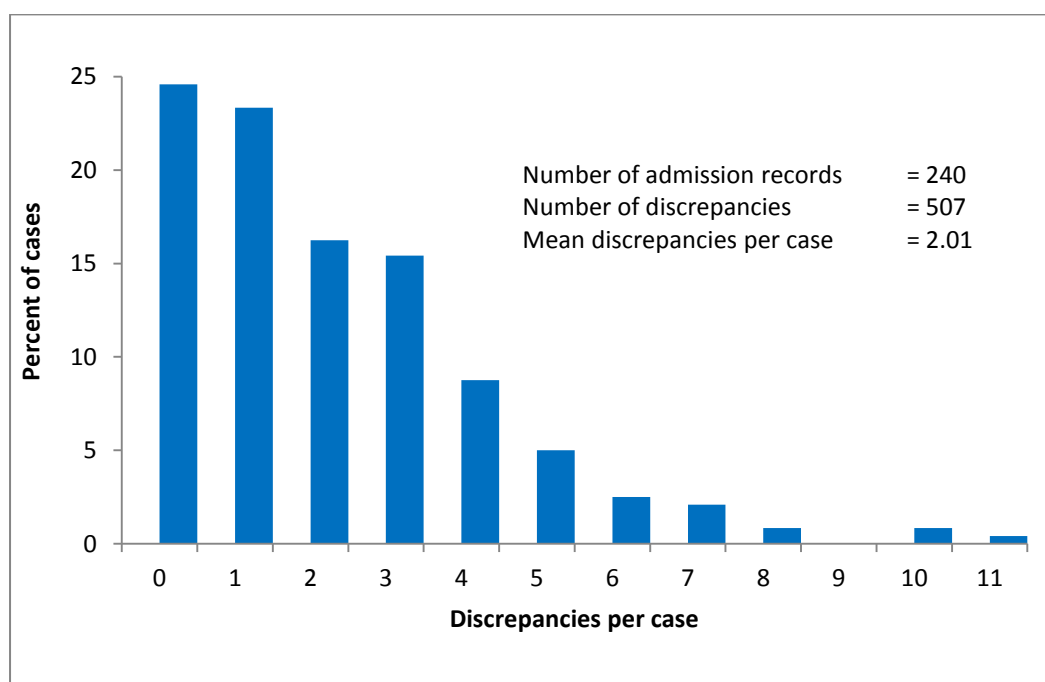


Figure DQ1. Number of discrepancies per set of admission notes reviewed.

Sources of discrepancies shown in Figure DQ2 reveal that the majority of errors were for the physiology variables associated with the Paediatric Index of Mortality 2 (PIM 2); admission

criteria and the recording of the provision and number of days of invasive and non-invasive ventilation recorded for daily interventions.

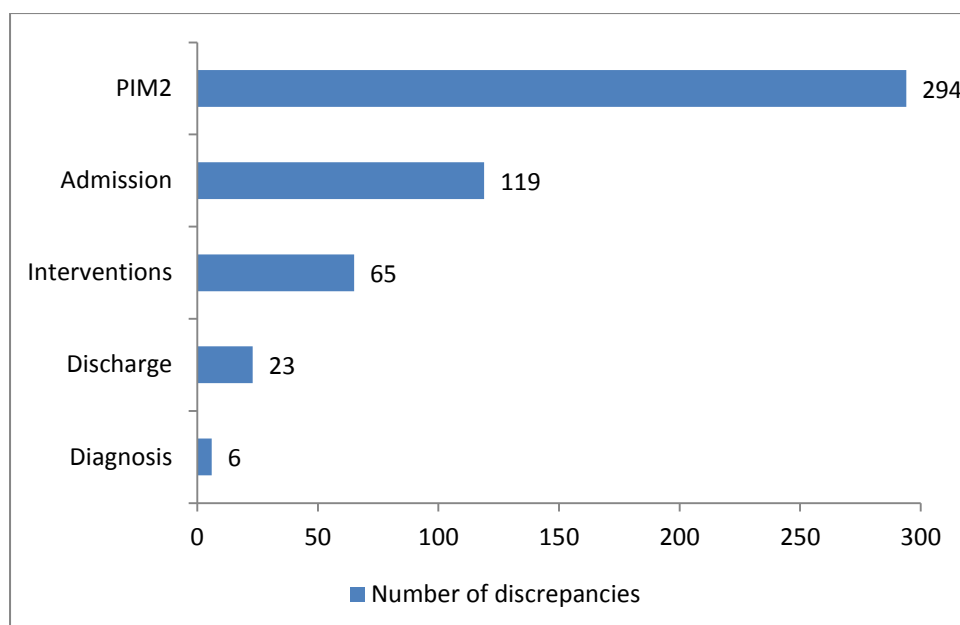


Figure DQ2. Number of discrepancies found by category.

Figure DQ3 shows that most discrepancies 58% (294), involved data items used to calculate PIM2, especially base excess, PaO₂, systolic blood pressure and FiO₂, which together account for 40% (204) of the total differences found and 69% of the PIM2 discrepancies. Many of these discrepancies are due to earlier values being found on review of transport documentation, results being recorded from an incorrect blood gas sample, or the unit failing to enter the results of a valid blood gas and recording the blood gas was not measured in the PICANet dataset. PIM2 records the first value measured and recorded within the period, from the time of first contact with a paediatric intensive care doctor to one hour after admission to PICU. Only arterial blood gas measurements are acceptable for the PaO₂ and for the base excess arterial or capillary blood gas measurements measured within the specified period are required.

During the series of visits reported an error was noted for units who export data from a named clinical information system (CIS); fields left blank at data entry onto the CIS on export to PICANet were populated with 'unknown' or one or more '9s'. In PICANet "unknown" or one or more "9s" are used in fields to explicitly indicate that the data is missing in that it has not/never been recorded and therefore will never be available. This finding has been addressed and corrected by the individual CIS provider. It is important to discriminate between a field that is left blank and a field where the unit state the data has not/never been recorded and will therefore never be available. Missing data fields in PICANet Web are included in the "live" PICANet validation report; enabling the unit to complete missing variables, resulting in improved data completeness and quality.

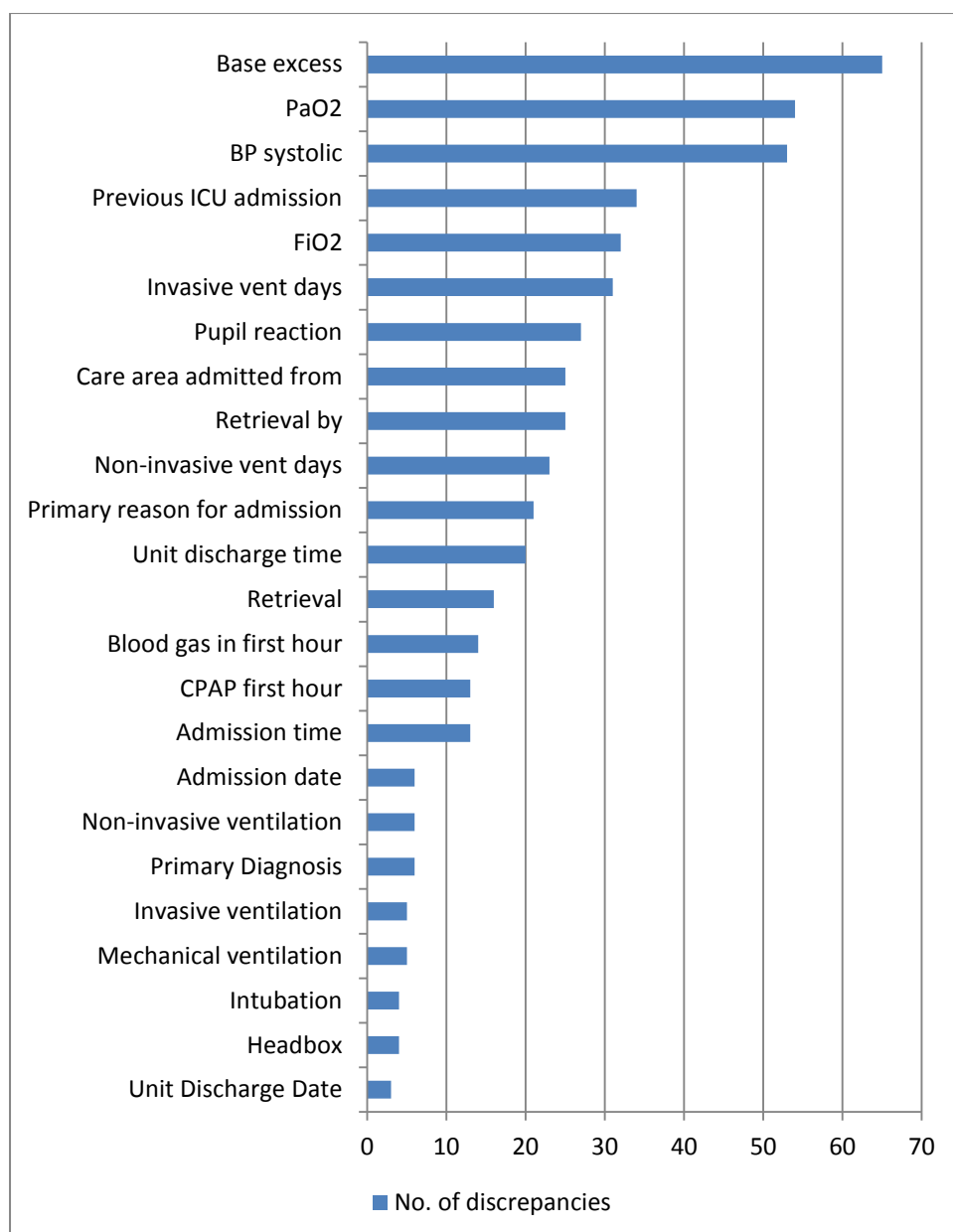


Figure DQ3. Number of discrepancies found by variable

Discrepancies 20% (100) found in admission criteria related to source information from the time period prior to and at admission to PICU. The main categories with this problem were previous ICU admission (34), which specifies that the child has had a previous admission to an intensive care environment, ICU, PICU or NICU during the current hospital stay; the care area admitted from immediately before admission to PICU (25); also for information about the retrieval; specifying whether the child was transferred to the unit by a retrieval team (16) and which type of retrieval team transported the child (25).

Days of ventilation (invasive and non-invasive), are recorded as part of the Paediatric Critical Care Minimum Data Set (PCCMDS). The recording of days of ventilation has improved over time. Incorrect recording of the days of ventilation accounted for 18% of the total discrepancies found during the series of validation visits in 2007/09 and 2010/11 and reduced to 11% of the total discrepancies found during visits in 2011/12. Any ventilatory support, invasive or non-invasive, at any time during the 24 hour period from 00.00 to 23.59hrs, should be recorded on the PCCMDS record as one day. An admission can be recorded as receiving both invasive and non-invasive

support during the same 24 hour period. An error in the reporting of days of ventilation identified for one unit was attributed to the export programme from the inhouse CIS.

During the validation visit the numbers of admissions per month, recorded in the PICU admission record, are counted independently to identify any differences between this record and the number of admissions recorded on the PICANet database. The unit are asked to scrutinise any differences identified to ensure that all admissions to the PICU are submitted to PICANet.

Table DQ3 shows the result of the count, for a twelve month period prior to the validation visit, in 19 of the 24 units visited. For 5 units the number of PICU admissions could not be specifically identified from the admission book or equivalent record and counted for a complete twelve month period. At the time of the validation visit 4 units had a difference of greater than 100 admissions (possible cases not submitted to PICANet). 15 units had a difference of less than 100, of which nine had between nil and 10 differences. Review of the PICANet admission record in May 2012 showed 16 units had less than

10 differences and 3 units greater than 10 differences (range 41-68). Many of the differences identified had been resolved, with additional cases submitted to PICANet ensuring completeness of data collection for all admissions to PICU. Three units had no differences on review, two of these units export direct from clinical information systems to PICANet.

	Number of differences		
	< 10	10-100	>100
Validation visit	9	6	4
June 2011	16	3	0

Table DQ3. Differences in admission count between unit's admission book and number submitted to PICANet.

7. 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 2011 and is presented here compared with previous data from 2009 and 2010. This data has been used to monitor the PIC Standards for the Care of Critically Ill Children (4th Edition); Version 2, June 2010. Annual staffing surveys were previously carried out in 2003, 2004, 2005, 2009 and 2010.

Staffing survey returns

The staffing questionnaires, designed in order to assess levels and grades of PICU staff, have been refined and updated for each round of surveys. The most recent questionnaires were distributed in November 2011. Data is compared to that obtained in December 2009 and November 2010 where appropriate, reporting on three consecutive years.

The questionnaires were sent to the lead doctor and senior nurse in each PICU. Information was collected on numbers of nursing staff and medical staff employed on units during a specified week in November 2011. Details were recorded at four specific 'snapshot' time periods (a weekday and a

weekend at noon and midnight). Information was also collected about other professionals working on PICU. Complete data was returned by 91% of all units participating in PICANet (31 out of 34 units in 30 Providers and one non-NHS Provider). Partial data was received from one additional Provider.

For copies of the most recent questionnaires, please see Appendix E.

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 in 2011, for the purpose of this report grades A-C were mapped to bands 2-4, grades D-E to band 5, grade F to band 6, grade G to band 7 and grades H-I to band 8. Table S1 shows the total number of qualified nurses in post and the proportion of specially trained children's nurses and nurses with additional training in paediatric intensive care identified as working in PICU in November 2011. Nursing and medical staffing by Provider is shown in Tables S2 –S7 of the Tables and Figures spreadsheet.

BAND	W.T.E. in post	Number of qualified nurses (persons) in post	% of children's trained nurses	% with additional intensive care qualification	% with valid paediatric resuscitation ^a training	% with valid advanced paediatric resuscitation training
Band 5	1513.7	1653	75	32	76	12
Band 6	527.9	608	94	92	75	54
Band 7	249.5	274	95	93	76	66
Band 8	25.1	27	96	96	81	59

Table S1. Total number of qualified nurses in post and the proportion by level of paediatric qualification, intensive care qualification and additional life support training.

^avalid paediatric resuscitation training includes Hospital Life Support Training
 Organisation B data not available for 2011
 Provider G and ZC did not provide data for additional qualifications and training

Figure S1 shows the proportion of nurse whole time equivalents by band in the same Providers in 2009, 2010 and 2011. There has been little change over time for bands 7 and 8. The proportion of band 5 nurses shows an increase from 58% in

2010 to 63% in 2011 with a decrease in the proportion of band 6 nurses from 26% to 22%. This compares 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 at this time. The change during the last twelve months may be contributed to by units appointing new staff at band 5 prior to attaining an additional intensive care qualification. The

proportion of band 2 to 4 staff employed on the unit shows a small reduction over the reporting period.

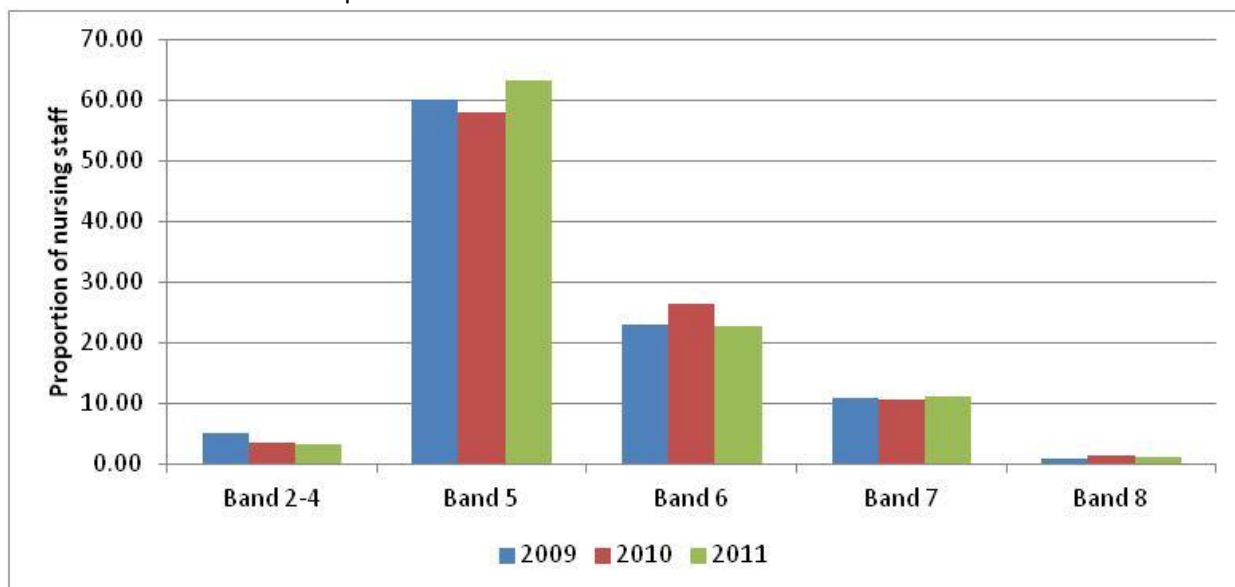


Figure S1. Proportion of nursing staff (WTE) by band (December 2009, November 2010 and 2011)

Providers B, T, ZD and ZE not available for 2009-2011 incl

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 one critical care bed is, at least 7.01 whole time equivalents (WTE).**

Previous standards endorsed the benchmark of 6.4 WTE per bed. The RCN recommends a 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 and the previous guideline of 6.04 WTE per bed are shown on the graph S2.

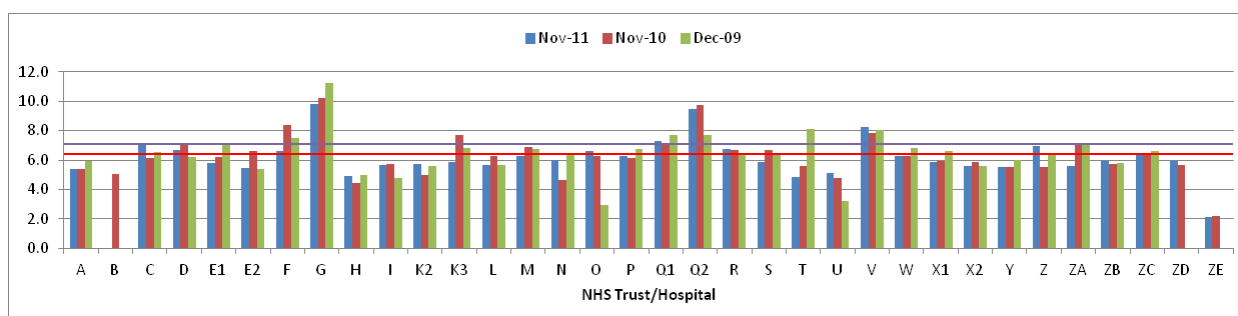


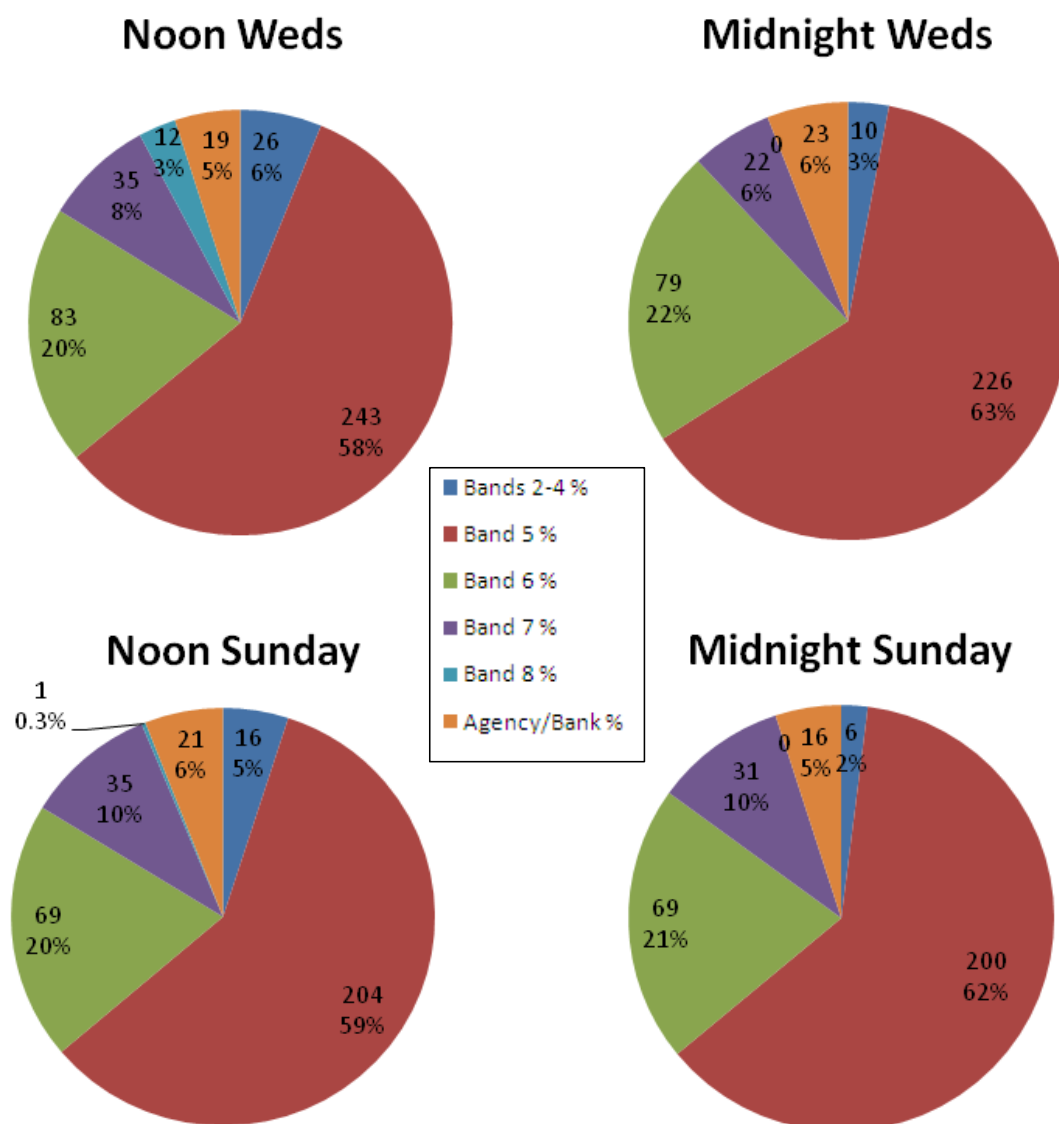
Figure S2. Number of clinically qualified nursing staff (WTE) in post per bed, by NHS Organisation (October 2005, November 2010 and 2011) with the current (7.01 WTE per bed -purple line) and the previous (6.04 WTE per bed-red line) recommended benchmark levels

Organisation B did not submit data in 2009 and 2011
 Organisation E1 submitted data for PIC beds only in 2011
 Organisations ZD and ZE were not included in PICANet in 2009
 Unit ZE has 40% nursing establishment complemented by agency/bank staff.

Figure S2 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 December 2009 and November 2010 and 2011. 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). The figures reported 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 S2 shows that in November 2011 five 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; compared with eight units in 2010. An additional six units meet the previous standard of 6.4 WTE per bed indicated by the red line, compared with five units in 2010.

Figure S3. Number (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 14th November 2011).



Note:

Provider T, H and ZC did not submit data for the snapshot survey

Figure S3 shows the actual number and 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 2011. The highest proportion of band 8 nurses are on duty at noon on Wednesday (3%) with none on duty at midnight on Wednesday and Sunday. A similar proportion of agency/bank nurses (range 5-6%) are on duty at each of the snapshot times.

The proportion of band 5 (range 58-63%) and band 6 (range 20-22%) nurses on duty is similar at all the snapshot times. There are a slightly higher proportion of band 2-4 nurses (range 2-6%) on duty at noon on Wednesday and Sunday than at midnight on these days.

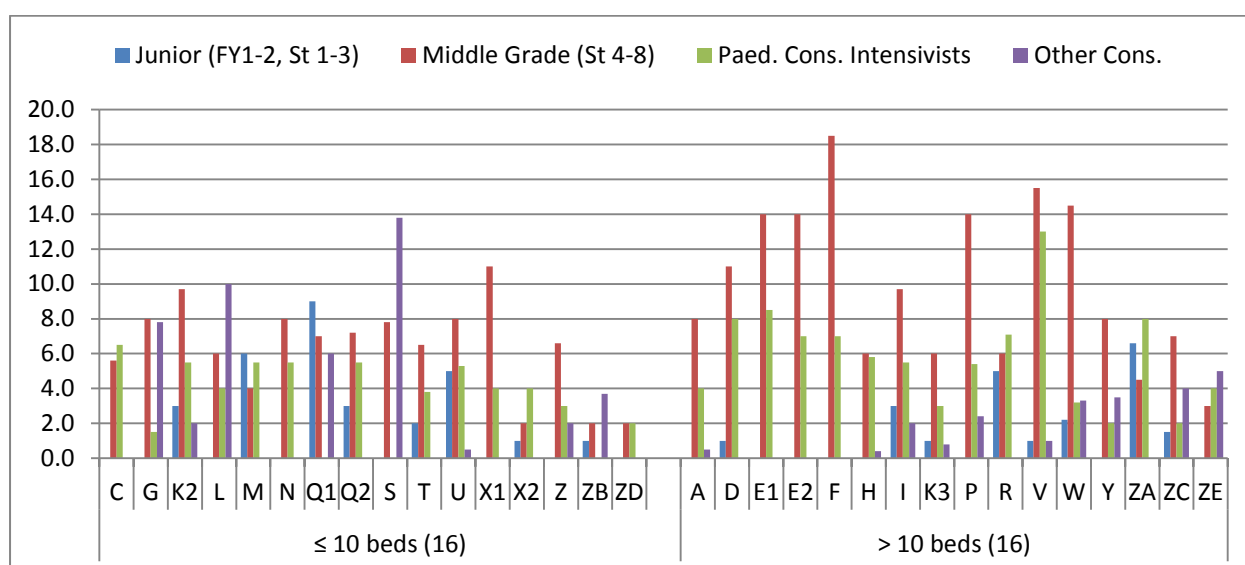


Figure S4 Numbers of medical staff (WTE) by position, NHS Organisation and size of unit, less than or equal to 10 beds and more than 10 beds

Notes:

Research posts have been recorded as 50% clinical hours

Organisation B and O did not submit data in 2011

Organisation G is a 10 bedded ICU with 2 designated beds

Organisation T has 3 physician assistants

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

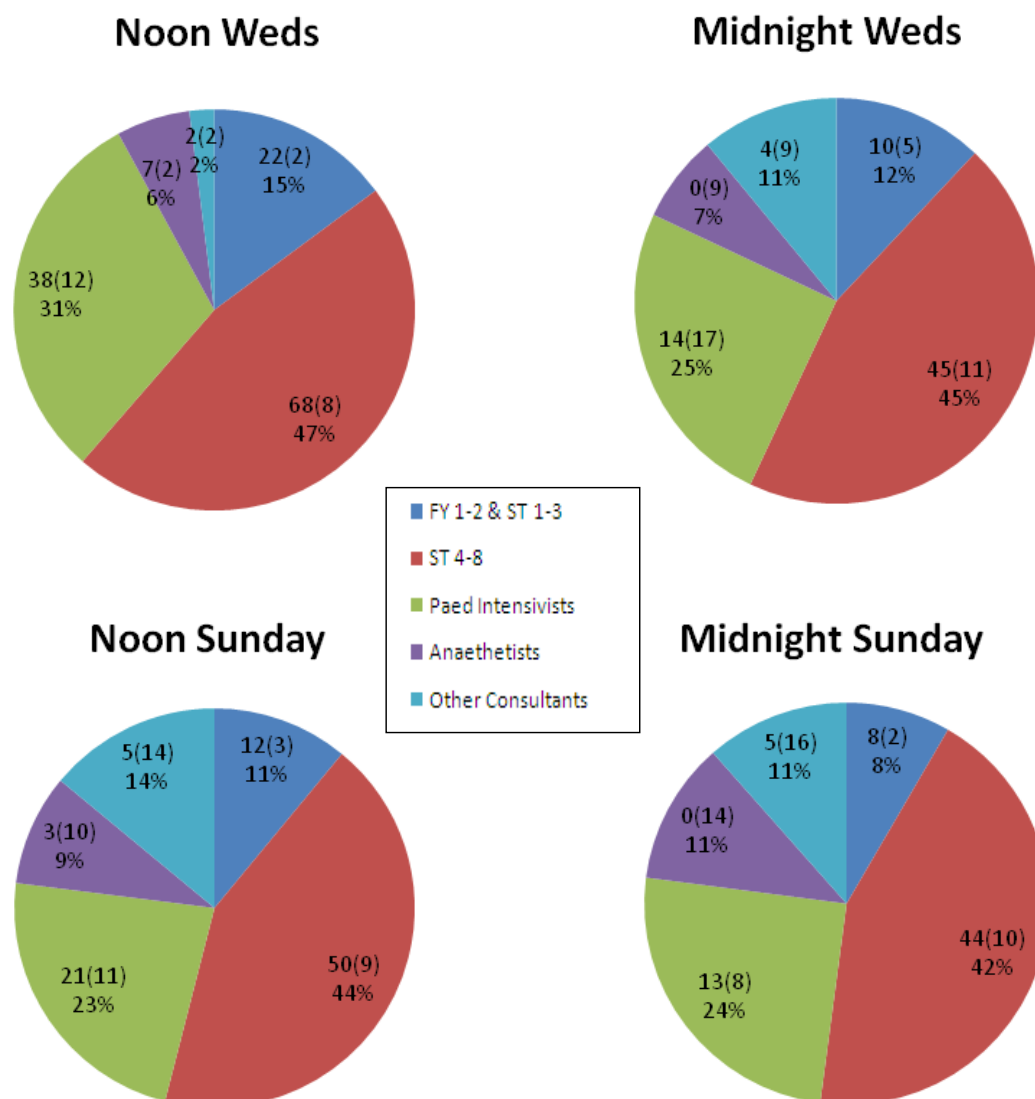
Unit ZE has 3 ST 4-8 doctors contracted for employment and up to 8 additional middle grade locums employed on PICU

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.

The snapshot surveys look at the numbers of medical staff working on a weekday (Wednesday) at midday and midnight and a weekend (Sunday) at midday and midnight. Figure S5 shows the proportion of Junior, Middle Grade and Consultants (paediatric consultant intensivists, anaesthetists and others) at four different time periods in 2011.

The largest proportion of Junior doctors (FY1-2, ST 1-3) (15%, n=24) are on duty and call at noon on Wednesday and the smallest proportion (8%, n=10) at midnight on Sunday. The number of Consultant Paediatric Intensivists on duty and call is highest at noon on Wednesday (31%, n=50); but at all snapshot times provide around a quarter of the workforce on PICU (range 23-31%). Just under half of the medical staff working at all times are grade ST4-8 (range 42-47%, n=54-76).

Figure S5. Number and proportion 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 14th November 2011. Numbers on call in brackets.



Note:

Provider B, O and ZC did not submit data in 2011

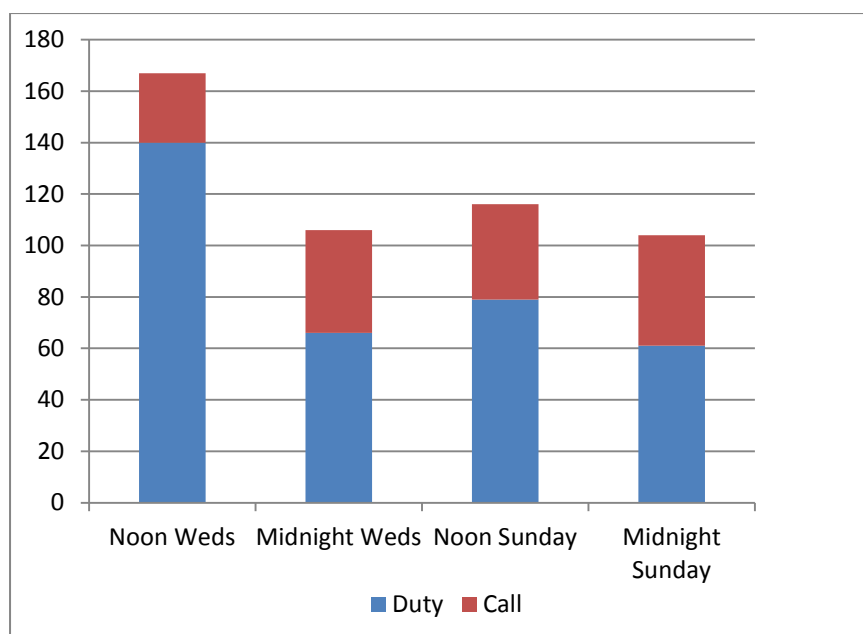


Figure S6. Number of medical staff on duty and on call at the four snap shot time periods.

Figure S6 shows that the greatest numbers of medical staff are on duty at noon on Wednesday, followed by noon on 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.

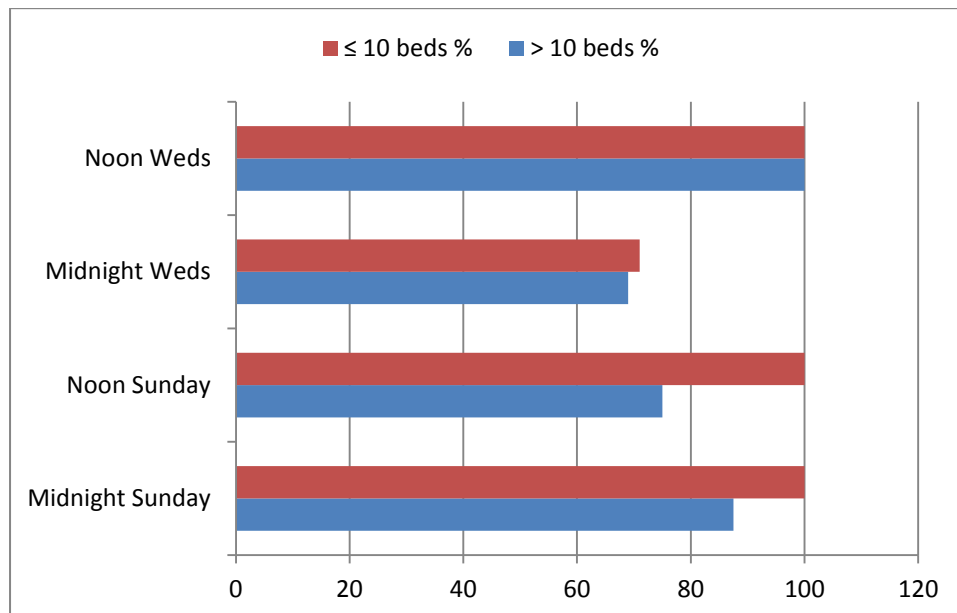


Figure S7. Proportion of units with less than or equal to and more than 10 beds who have at least one consultant available to the unit for every 8 to 10 PICU beds at each of the specified times.

All units have at least one consultant available for every 8 to 10 beds at noon on Wednesday. All units with less than or equal to 10 beds meet standard 147 at all specified times except midnight on Wednesday. All units with more than

10 beds have at least one consultant available to the unit at all times but only 69% meet standard 147 at all specified times, providing at least one consultant for every 8-10 PICU beds (Figure S7).

Occupancy

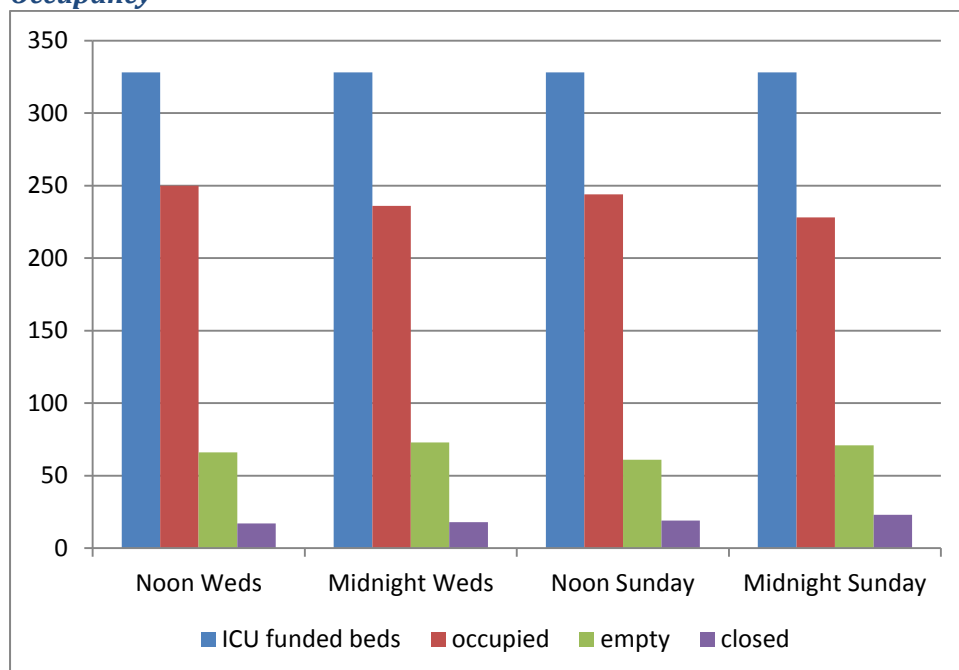


Figure S8. Total number of critical care beds and the number occupied at the four snapshot time periods.

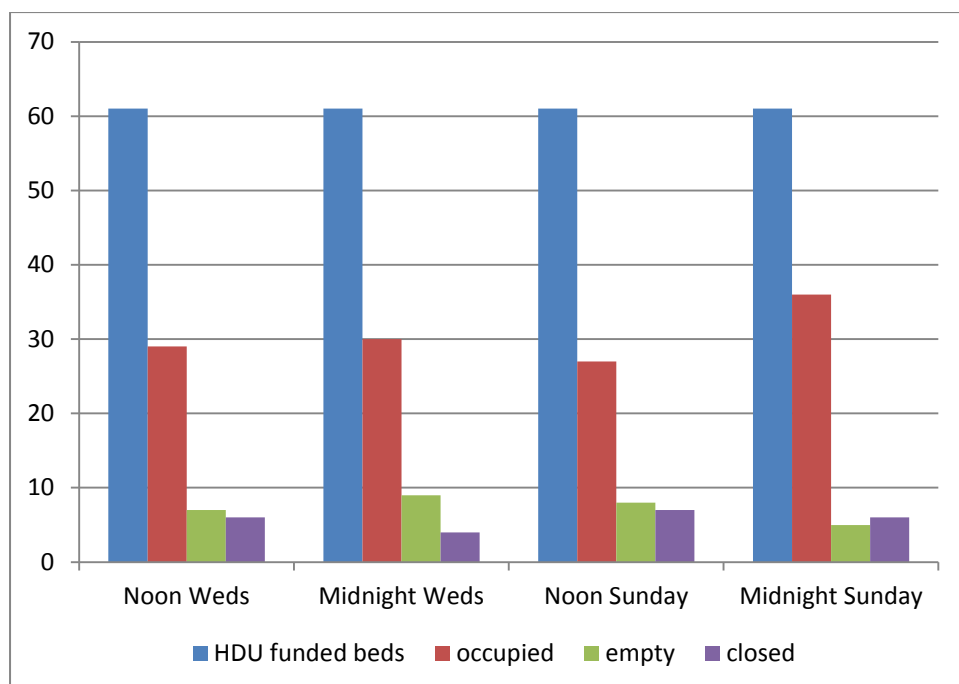


Figure S9. Total number of high dependency beds and the number occupied at the four snapshot time periods

Figures S8 and S9 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, 328 intensive care and 61 high dependency beds were funded in

November 2011. High dependency beds are included in those critical care units where PICA Net data is submitted for both intensive care and high dependency patients and staffing is provided by the paediatric intensive care nursing and medical establishment.

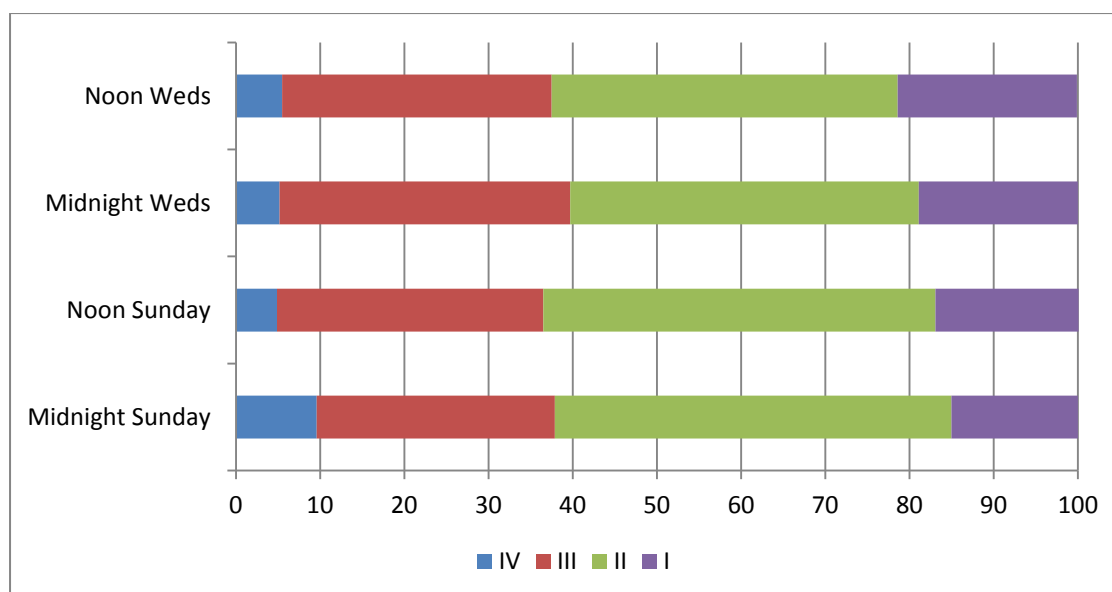


Figure S10. Proportion of patients receiving Levels I, II, III and IV of care at the four snap shot time periods.

Figure S10 shows the greatest proportion of patients, mean 44% (range 41-47%, n=103-115) were receiving level two care during each of the four snap shot times, noon and midnight Wednesday and Sunday. At any specified time PICUs are treating around 18% (range 15-21%) of patients who only require high dependency care.

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.

Other professionals

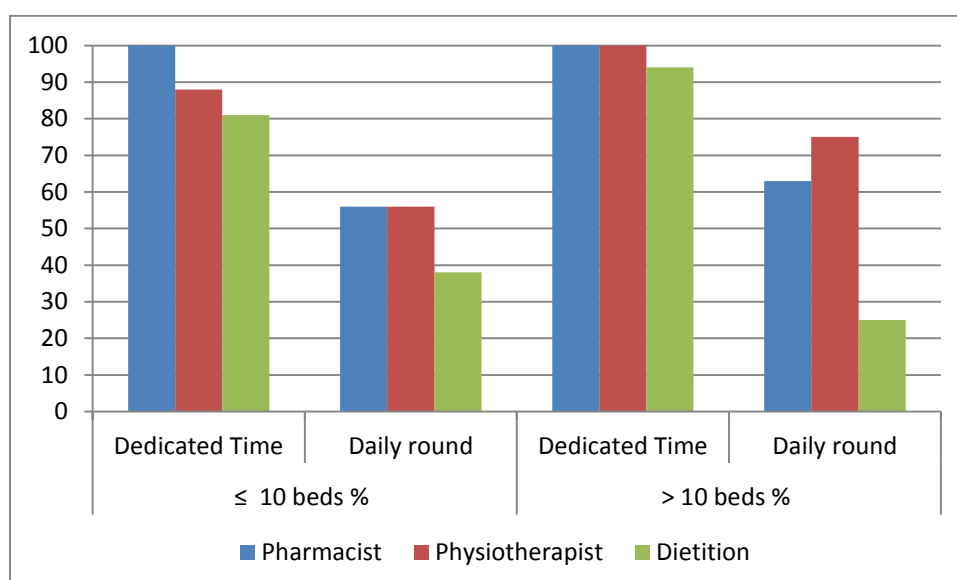


Figure S11. Proportion of units with less than or equal to and more than 10 beds and the availability of other named professionals.

Figure S11 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 a pharmacist, physiotherapist and

dietician and the proportion of these units where the named professional attends the daily ward round. All the units have dedicated time from a pharmacist and all units with > 10 beds have dedicated time from a physiotherapist and 92% from a dietician. 94% (n=32) of all units have dedicated time from a physiotherapist and 82% (n=28) have dedicated time from a dietician, 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.

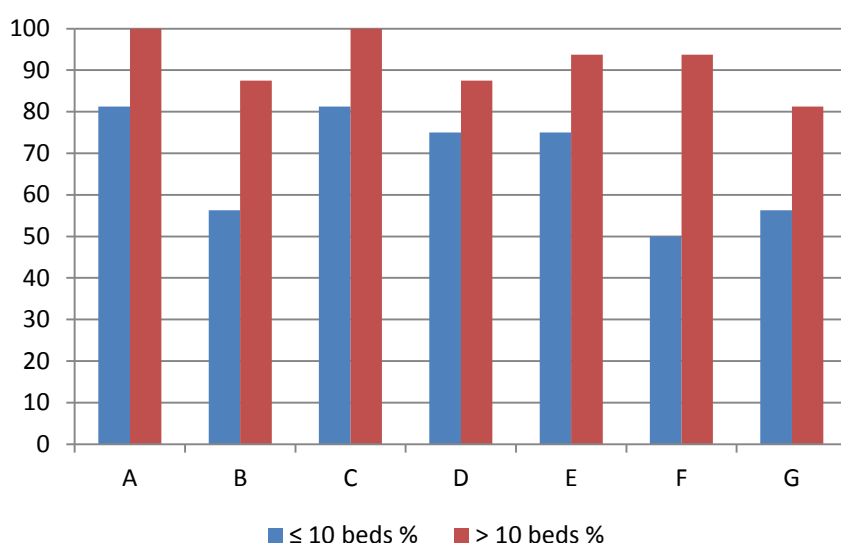


Figure S12. Proportion of PICUs with less than or equal to and more than 10 beds and the availability of specified support services.

Figure S12 shows the proportion of units with more than 10 beds and the proportion of units with equal to or less than 10 beds; in which the support services specified in Standard 144 are available. 81% of units with ≤ 10 beds provide interfaith and spiritual support and interpreting services, 75% provide access to bereavement support and patient advice and advocacy, and 56% provide access to social workers and a service providing psychological support for staff; only 50% report availability of psychological support for families.

All units with > 10 beds provide access to interpreting services and interfaith and spiritual support, 94% provide patient advice and advocacy, and psychological support for families; 88% provide social workers and bereavement support and 81% psychological support for staff.

One large unit admits patients electively from overseas and additional support is provided to the family by the embassy.

Summary

- In 2011 the response rates to the PICANet survey were 91%. This compares with 2010 when PICANet achieved a 100% return.
- The majority of nurses employed are band 5 (63% in 2011 compared with 58% in 2010). The small increase in the proportion of band 5 nurses compares with a decrease in the proportion of band 6 nurses from 26% in 2010 to 22% in 2011.

- There has been no significant change in the numbers of qualified nursing staff, bands 5-8, when comparing the total whole time equivalents in post in units November 2010 and 2011.
- The 2011 survey shows that only five 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 2009 and 2010, 47% in 2011).
- Most units have access to the named support services with the exception of psychological support for families and staff – Standard 144.
- All units have dedicated time from a pharmacist, all units with > 10 beds have dedicated time from the physiotherapist and 94% from the dietician; over 80% of units with ≤ 10 beds have dedicated time from a physiotherapist and a dietician - Standard 170.
- The greatest proportion of patients were receiving level two care at each of the daily snapshot times

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

8. PIC Families Group

PICANet are working with the clinical community to consider and develop processes enabling the family to be involved in determining quality standards of care within the PICU.

The group has multidisciplinary members who are interested in the perspective of patient and public involvement in paediatric intensive care and participate in meetings as representatives of their PICU. During 2011 the group were pleased to welcome two new lay representatives who have experience of PICU.

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

During 2011/2012 the group have:

- Developed a unit staff survey of the availability of services, facilities and support for families during their PICU stay which has been completed and is reported below.
- Developed a questionnaire asking families about the availability of services, facilities and support during their PICU stay. The questionnaires were distributed to parents and families, prior to discharge, for a three week period in May and June 2012 and findings will be compared with those from the staff survey. This will also enable individual units to review themselves against comparable PICUs in the United Kingdom and Eire.
- Supported the development of a questionnaire by the PICS National Retrieval Group to collect parental feedback.
- Agreed to establish a web resource of information and leaflets for families of children admitted to PICU.

PICANet would welcome additional lay representatives to join the PICU Families Group and suggestions for future projects.

9. Survey of Information and Facilities available to the PIC Family

This study was developed to assist with the monitoring of the Paediatric Intensive Care Society (PICS) Standards for the Care of Critically Ill Children (version 2 June 2010), relating to information and facilities available to the family during admission to PICU. Questionnaires were completed during routine validation visits to all units. The data was collected by one of two observers over a fourteen month period, between January 2011 and February 2012. The recommendations in the PICS standards document and Appendix 9 -*Facilities & Support for Families of Critically Ill Children* - represent the gold standard which should be met in Tertiary Centres containing PICUs.

For the analysis the 34 units were divided into three groups depending on the number of admissions during 2011: 'large' (over 750 admissions p.a.), 'medium' (500-750 p.a.) and 'small' (less than 500 admissions p.a.) as previously used to report 'Facilities and Information for Families' (PICANet National Report 2006/08) (Table 2).

	SIZE OF UNIT		
	Large	Medium	Small
No of units in group	11	6	17
Proportion of all admissions to PIC	54%	19%	27%

Table 2 Size groups of PICUs.

SECTION 1 INFORMATION

A. Transport

Standard 99: Parents of children needing emergency transfer should be given all possible help regarding transport, hospital location, car parking and location of the unit to which their child is being transferred

28 (88%) of the unit or centralised retrieval services provide written information about the PICU to which the child is being transferred. Table 3 shows 20 (59%) of the PICUs reported that at least one parent is offered transport to the PICU and 21 (62%) usually offer at least one parent a

seat in the emergency ambulance, this facility is more likely to be available when a specialist paediatric transport service moves the child. 18 (53%) of PICUs reported the availability of other transport provision when required although this is often funded and arranged by the original referring hospital.

B. Admission

Standard 142: Parents should be given written information about the unit, including visiting arrangements, unit routine and location of facilities within the hospital that the parents may want to use (*Appendix 9*).

All units provide parents with written information about the PICU - Figure 2. 28(82%) units provide individual booklets/leaflets for parents, six units provide information on a noticeboard or within a laminated folder available either within the unit or at the individual bed space. Four units were revising or developing parent information leaflets at the time of data collection.

Written details of visiting arrangements, unit routine and the location of other hospital facilities such as the canteen and shop were available to all parents. 26 (76%) of units included advice about the availability of interpreting services, in those units where written information about interpreting services is not included the unit report that inclusion was inappropriate for non-English speaking parents but the service is available and provided when required. All units can access interpreting support.

		SIZE OF UNIT			All Units
		Large	Medium	Small	
1	Written information about PICU is provided by transport service (unit or stand-alone)	10 (75%)	6 (100%)	12 (70%)	28 (82%)
	containing				
	a map	7 (64%)	3 (50%)	9 (53%)	19 (56%)
	directions to the unit	7 (64%)	5 (83%)	11 (65%)	23 (68%)
	car parking advice	5 (54%)	4 (67%)	8 (47%)	17 (50%)
	telephone number for the PICU	6 (55%)	6 (100%)	12 (71%)	24 (71%)
2	At least one parent is offered transport to the PICU	9 (82%)	6 (100%)	5 (29%)	20 (59%)
	a seat in the emergency ambulance	9 (82%)	5 (83%)	4 (24%)	21 (62%)
	other transport i.e. hospital funded taxi	6 (55%)	5 (83%)	7 (41%)	18 (53%)

Table 3 Availability of written information and transport for parents of children requiring emergency transport to PICU.

Notes:

Two units in Dublin did not have a specialist paediatric transport service at the time of data recording. Transfers were undertaken by the referring hospital.

Two small units do not accept critically ill children transferred from an original admitting hospital

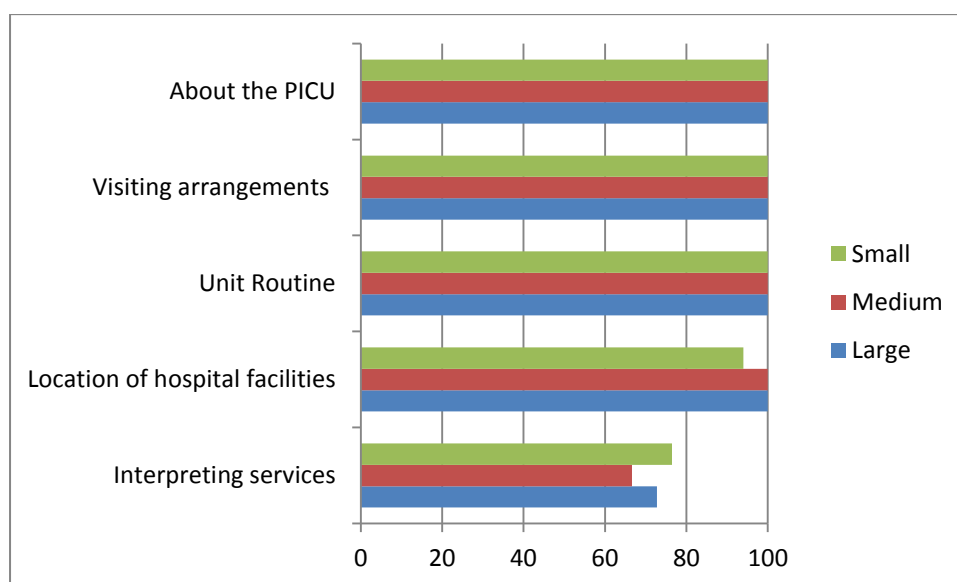


Figure 2 Proportion of admissions to PICU that receive written information about the PICU including the above details.

C. Communication

Standard 141: Parents should be informed of the child's condition, care plan and retrieval (if necessary) and this information should be updated regularly.

	SIZE OF UNIT			All units
	Large	Medium	Small	
No. of units with written documentation	7 (64%)	2 (33%)	9 (52%)	18 (53%)

Table 4 PICU philosophy including reference to communication with parents or guardians

18 (53%) of the 34 units confirmed that they have a written philosophy or other documentation which includes reference to communication with parents about their child's condition, care plan and retrieval.

For example:

"The role of the Multidisciplinary Team will promote effective communication, support, empathy, sensitivity and a sense of value towards the child and family and between team members in order to provide good teamwork."

Thomas Cook Critical Care Unit, November 2011

"Our philosophy is based on family centred care and we recognise and respect the essential role of the family in the lives of the children. We care for critically ill children in partnership with their families and encourage open communication."

Our Ladys Children's Hospital, November 2011.

Standard 143: Parents should have information, encouragement and support to enable them fully to participate in decisions about, and in the care of, their child.

All units provide parents with a telephone number for contact, 8 (24%) units provide business cards with unit contact details, four large, two medium and two small units. 7 (21%) units reported dedicated telephone lines for parental calls and some units can transfer the call to the bed space enabling the nurse to speak directly to the parents.

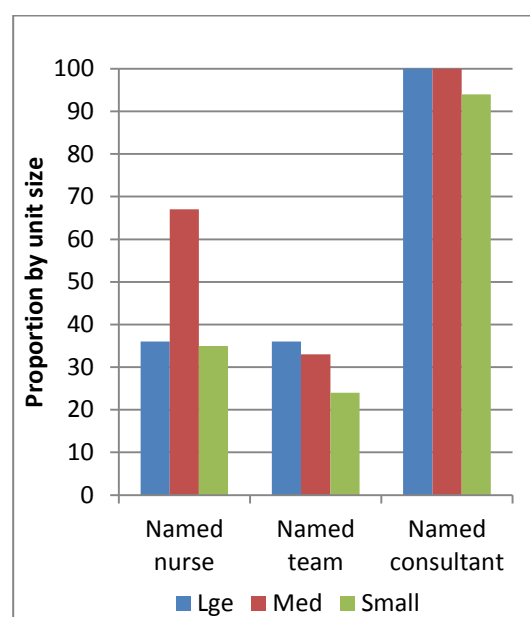


Figure 3 Proportion of units allocating each child to a named nurse, team and consultant.

Units were asked if each child is allocated to a named nurse, team or a named consultant and the results are shown in Figure 3. All patients will have a named nurse for the shift and units frequently endeavour to maintain continuity of care through shift allocation, 7 (21%) units, equally distributed by size, report allocating a named nurse to long stay patients either as an individual patient or part of a team. 33 (96%) of units report the allocation of patients to a named consultant, for 25 (74%) of units the consultant is allocated on admission. 11 (32%) of units will allocate or review the allocation of a named consultant after a prescribed length of stay but the duration at which this occurs for an individual patient varies between ten and

fourteen days. It can be seen that the allocation of patients to nursing teams is not routine practise; only 29% of all units allocate admissions to named teams and half of this number only allocate long stay patients.

Standard 140: There should be parental access to the child at all times except when this is not in the interest of the child or the privacy and confidentiality of other children and their families.

All units (100%) report that parents/guardians are welcome "to visit the PICU at all times" in line with Standard 140. 26 (76%) of units will ask parents to leave the bedside in specific circumstances.

In 13 (38%) of the units parents are welcome to be present at the bedside during the clinicians' main ward round and in 8 (61%) of these units the main ward round is conducted in a separate room, away from the bedside; eliminating the need to exclude parents from the PICU at this time. Where parents are routinely excluded from the unit during the main ward round, this requirement may be relaxed if the child is nursed in isolation. Reasons cited for excluding the parents/guardians from the bedside include patient confidentiality and privacy, the proximity of bed spaces and space restrictions when needing to accommodate a large number of clinical personnel; also to facilitate teaching on the round.

Standard 148: Children should be offered appropriate information to enable them to share in decisions about their care.

Only 4 (12%) units reported the availability of leaflets specifically designed to tell children and teenagers about PICU; an additional ten units have leaflets relating to specific conditions usually provided by specialist support groups, charities or specialist nurses. One hospital has a specialist adolescent nurse available to provide support to teenagers and many units welcome children and families to visit PICU prior to a planned admission.

SECTION 2 FACILITIES

Standard 139: There should be a child friendly environment. There should be visual and sound separation from adult patients.

Appendix 11:

11.4-patient care area

11.12- the unit design should create a pleasant, safe environment that reduces stress for patients, families and staff.

26 (77%) of the 34 units routinely accept admissions up to 16 years of age, 5 (15%) accept admissions to 18 years of age and of the remaining three units, one specialist cardiac PICU accepts congenital cardiac cases up to 45 years of age, the upper age limit for referral to one specialist neonatal unit is two months and one PICU only routinely accepts admissions up to 14 years of age with the exception of those under long-term specialist care who may be accepted up to 18 years of age. For those units who routinely accept admissions to 16 years, 17 (65%) will extend this to 18 years for patients in full time education or receiving long-term care from a specialist within the hospital.

In all units efforts are made to provide some visual and sound separation for older patients particularly those of a different sex. Two units reported a trust requirement to make all reasonable attempts to comply with the Department of Health commitment to the 'Elimination of mixed sex hospital accommodation' publ.2005. Most PICUs are of open plan design with cubicles for isolation. The use of beds is managed to facilitate the care of the patients and the provision of privacy for older children up to the age of 19 years. Where possible units will often nurse adolescents in cubicles, or additional privacy may be provided by use of screens.

All paediatric intensive care units provide specialist care in an environment which is as safe as possible. Natural light, curtains and pictures or colour on the walls are often used to make the unit a more child friendly environment. A philosophy which seeks to provide family centred care and the use of play therapists and access to schooling assists in the promotion of a child friendly environment.

Standard 145: Facilities should be available for the parent of each child, including: somewhere to sit away from the ward

- A quiet room for use by relatives whose child is critically ill.

- A kitchen, toilet and washing area together with changing facilities for other young children in the family.
- Provision for breast feeding mothers

See Figure 4.

(Appendix 9 and 11.9)

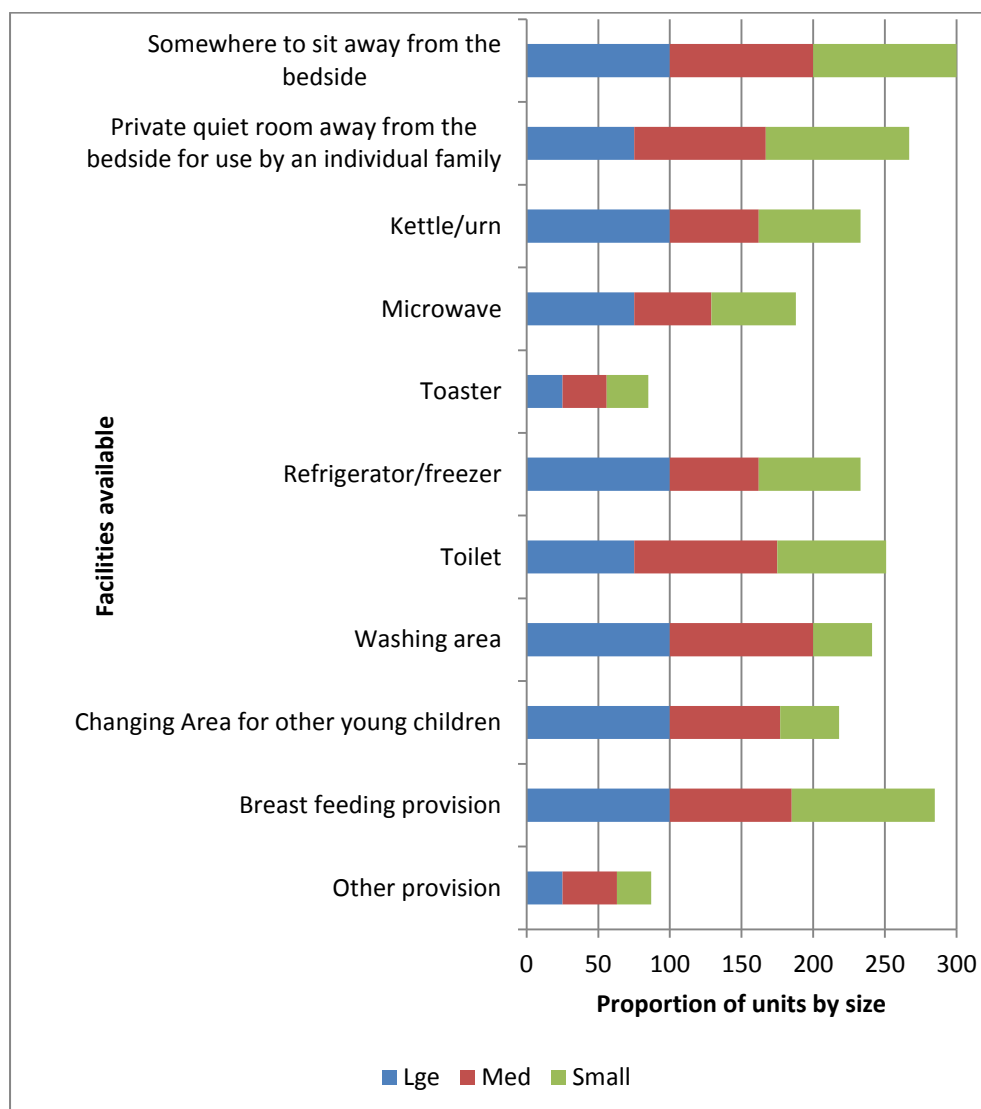


Figure 4. Facilities available in PICUs

Standard 146: Overnight facilities should be available for the parent or carer of each child including:

- A foldaway bed or pullout chair-bed next to the child.
- A bed at “dressing gown” distance (adjacent to the unit so that the parent can be called quickly but has some privacy)

- Accommodation on site but away from the unit.
- Hostels in specialist centres for parents to stay with their children as a preparation for discharge home, when complex home care is required.

(Appendix 9)

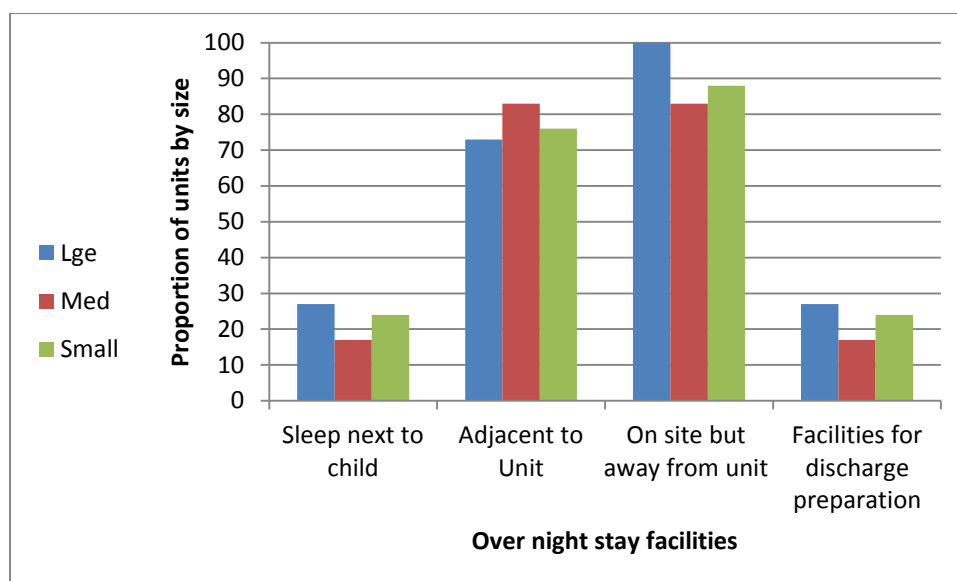


Figure 5. Overnight stay facilities.

All units provide overnight stay facilities. 31 (91%) provide accommodation on site but away from the unit, which is particularly useful for specialist referral units where children are further from home and have longer stays. Often set up and provided by charity, this facility may enable whole families to stay and kitchen facilities allow parents to prepare simple meals to reduce the cost of purchasing hospital meals. On site accommodation but away from the unit is not available in one medium and in two small units but accommodation is funded and arranged in local hotels. 26 (77%) provide accommodation adjacent to the unit; this is often limited to use by parents of critically ill children or immediately following transfer to the unit. 2 units can access day care wards for parental overnight emergency accommodation if required. Only 8 (24%) units provide a chair bed next to the child for the parent to sleep and half of this number are small units. Six (18%) units reported facilities for training parents to provide complex home care, this may be provided within a long stay ward or the child may be transferred to a unit closer to home to prepare for discharge (Figure 5).

None of the units reported the availability of a written policy on financial support for families of critically ill children but all had agreed guidance for providing support to parents, which included referral to family liaison nurse, hospital or area social worker, patients advice and liaison service (PALS), and often out of hours referral to the bleep holder to access hospital provision. Two units have access to an emergency monetary fund. Many units reported that they will make drinks and toast for families transferred to the unit as an emergency and local arrangements may facilitate access to taxi services or emergency accommodation out of normal working hours.

For 28 (82%) of the units parents/guardians will be charged car parking fees. In 24 (86%) of these units there are special arrangements for reduced or free car parking for parents of children hospitalised on PICU.

Only two hospitals charge parents a nightly fee for overnight accommodation. One hospital reported a refundable charge for a key deposit.

D. Financial Support

Standard 147: A policy on financial support for families of critically ill children should be developed and communicated to parents.

10. Mortality in south Asian children admitted to PICU

In 2009, PICANet published data that indicated that South Asian children admitted to PICU had a 36% higher risk of mortality than the rest of the PICU population in England and Wales. The study was based on admissions from 2004-2007 inclusive and used the original Paediatric Index of Mortality, PIM, to adjust for expected probability of mortality.

In an updated analysis, we have examined whether this effect persists in our later data. We have used exactly the same methods for comparability, repeating the analysis for the years 2004-2007 and then 2008-2011.

The data show that there has been an increase in admissions of South Asian children from 10.8% of the PICU population in 2004-2007 to 12% in 2008-2012.

The risk adjusted odds ratio (OR) for mortality in South Asian children has increased from 1.36 (95% CI 1.32-1.40) in 2004-2007 to 1.41 (1.21-1.64) in 2008-2011 using PIM. Repeating the

analysis for 2008-2011 using PIM2 gave the same result after rounding.

These results suggest that the excess risk-adjusted mortality seen in South Asian children admitted to PICUs in England and Wales has increased by 4 percentage points. The data held by PICANet do not indicate what factors may be influencing this excess risk.

We hope to obtain funding to investigate these findings further, in collaboration with the PIC community.

Reference

Parslow RC, Tasker RC, Draper ES, Parry GJ, Jones S, Chater T, Thiru K, McKinney PA, on behalf of the Paediatric Intensive Care Audit Network. Epidemiology of critically ill children in England and Wales: incidence, mortality, deprivation and ethnicity. *Arch Dis Child*, 2009; 94:210-215

11. Confidential Enquiry into Major Burns in Children (CEMBIC)

PICANet have been contracted to work with the four burns care networks that serve England and Wales to establish a national review of the quality of care and avoidable or remediable factors associated with severe burns in children in England & Wales.

Burn injury is the third most common cause of traumatic death in children with the greatest length of inpatient stay from all paediatric trauma admissions (Yarrow et al, 2009). Approximately 1,000 patients are admitted with severe burns requiring fluid resuscitation each year, about half of whom are children under 16 years (NBCRC, 2001; Young, 2004). Burn injuries therefore place distinctive demands on health provision and although severe burn injuries remain relatively uncommon, they require very specialised and long term care with considerable expense to the healthcare community (NHS, 2005).

There is currently limited national data on burn injury epidemiology, factors affecting outcomes (survival, functional outcome, length of hospital stay) and information about the facilities and staffing available to care for those injuries (NBCRC, 2001).

The aims and objectives of the review are to:

- Determine the national incidence of severe burns in children over the defined period by collecting basic demographic and clinical information on all children aged between 0 and 16 years (15 years and 364 days) who are admitted to hospital with burns \geq 40% Body Surface Area ("BSA"). This includes children who have suffered a scald injury or flame burn, who may or may not have had smoke inhalation and whether the injury is accidental or intentional.
- Describe and compare the aspects of care provided to children up to 16 years old (15 + 365 days) with burns \geq 40% BSA or who die having experienced cutaneous burns \geq 1% BSA and to review the care provided and

service delivery against current guidance/standards.

- Identify avoidable factors/lessons to be learned from the individual cases using multidisciplinary panels of experts. Panels determine whether outcome was associated with care given or other avoidable/remediable factors.
- Examine the effectiveness of the management of severe burns in children by reviewing practice against the standards set out in the National Burn Care Review (2001) and available evidence from the literature. Newly revised standards are now in draft form and will be assessed as appropriate. The project will build on areas where evidence is weak in support of the recommendations made in these guidelines.
- Generate and disseminate recommendations to healthcare professionals, commissioners and network services on how to improve the care received by children with severe burns as regards facilities and standards of clinical care impacting on outcomes.

Methods

All cases fulfilling the inclusion criteria (detailed below) for the project will be identified and notified to the CEMBIC office. Multidisciplinary confidential enquiry panels will be convened to investigate standards of care related to burns, to examine whether the relevant guidance/standards are applied in practice, whether adherence to guidance/standards make a difference to outcome and whether there is evidence that adverse outcomes could be avoided with better care and if so, how. A flow chart describing the methodology for the review can be found in Figure 6.

Study inclusion criteria

Children up to 16 years (15 years and 364 days) who have burns of $\geq 40\%$ BSA.

Children up to 16 years (15 years and 364 days) who have died having experienced cutaneous burns of $\geq 1\%$ BSA.

These groups include children who have experienced a scald or flame injury, and who may or may not have had smoke inhalation and children where there is suspicion of non accidental injury.

Sample size and period of study

The first 40 cases occurring during the period 01/01/2011 to 31/12/2015 will be selected and reviewed. Data from the national burns database for England & Wales 2003-2009 indicated that up to 10 cases fulfilling the study criteria occur annually.

References

National Burn Care Review (NBCRC) (2001) Standards and Strategy for Burn Care. Available from:

<http://www.NNBC.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=25770>

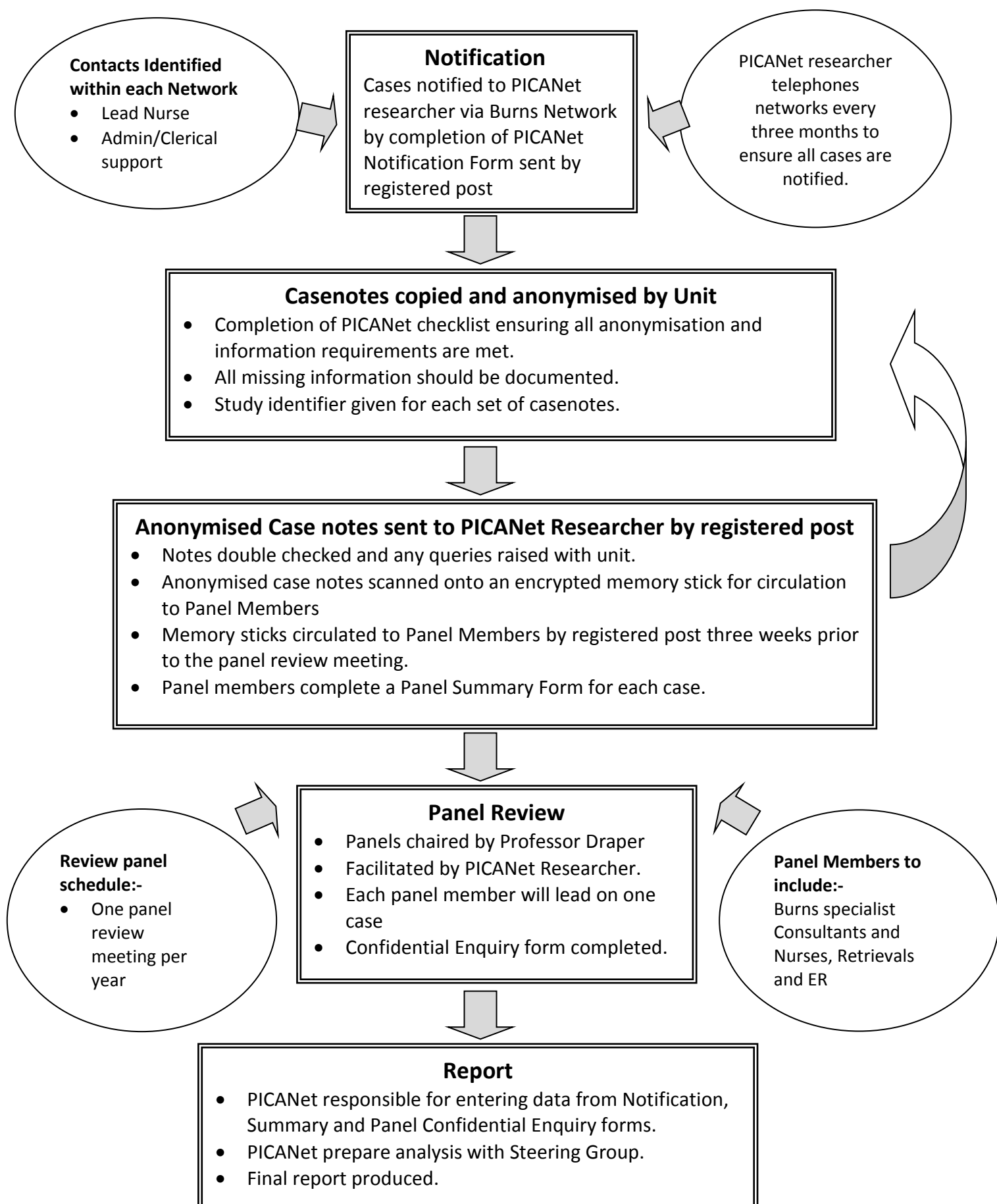
NHS (2005) Optimising burn care provision in England and Wales: National Burn Care Group briefing paper. Available from:

<http://www.NNBC.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=25772>

Yarrow, J., Moiemmen, N., & Gulhane, S. (2009). Early management of burns in children. *Paediatrics and Child Health*, 19(11), 509-516.

Young, A. E. (2004). The management of severe burns in children. *Current Paediatrics*, 14(3), 202-207.

Figure 6. Confidential Enquiry into Major Burns in Children: Enquiry Process.



12. Future Commissioning Arrangements for Paediatric Intensive Care

Paediatric Intensive Care is one of a number of Specialised Services. These are services which generally have a planning population of a million or more, are low volume, have a high cost of treatment and undergo rapid changes in technology. They are also characterised by the restricted number of Providers able to provide the services. In England, specialised services are currently either commissioned regionally, by one of 10 Specialised Commissioning Groups (SCGs) who are funded by, and accountable to, local Primary Care Trusts (PCTs) or nationally, for highly specialised services.

The national definition set for specialised services consists of 34 service definitions. Paediatric Intensive Care is included in *Definition 23, Specialised Services for Children* and is commissioned by the regional SCGs in slightly different ways taking into account local history and other factors.

After the implementation of the Health and Social Care Bill 2012, it is anticipated that most specialised services will be commissioned nationally by the National Health Service Commissioning Board (NHSCB) from 2013/14. The year 2012/13 is being used to ensure that each specialised service is commissioned consistently across the country and that those commissioning arrangements make clinical sense. This work is being led by a Transition Oversight Group. This group has three streams; patient and public engagement, finance assurance and clinical assurance.

The clinical reference groups (CRG) have been established to ensure that the commissioning framework has the widest possible clinical engagement and that it makes clinical sense. There are 59 clinical reference groups which have been divided into five programmes of care. Paediatric Intensive Care sits within the Women's and Children's Health, Congenital and Inherited Diseases programme of care alongside groups for paediatric medicine, surgery, cancer services, cardiac services, neurosciences and neonatology amongst others.

Each CRG has a similar membership. They are chaired by clinician who has been appointed following a national advertisement who will work alongside public health and commissioning leads. Each of the four, newly established, commissioning group clusters has nominated two clinical representatives. In addition, the chair has been given the discretion to nominate a further four clinicians to cover all disciplines and subspecialties. Up to 4 national organisations can be affiliated to each of the groups each nominating a representative member. In addition to PPE members should have been nominated to each group. At the time of writing our group only has one PPE representative. The group is supported by a national Clinical Engagement Coordinator. Membership of the group for PIC is described in Table 5 overleaf.

Position	Name	Title	Organisation
Chair	Mark Darowski	Intensivist	Leeds Children's Hospital
Public Health Lead	Marilena Korkodilos	Public Health Consultant	London SCG
Commissioning Lead	Jessica Whitton	Senior Commissioning Manager	South West SCG
London Cluster Rep	Duncan Macrae	Intensivist	Royal Brompton
London Cluster Rep	Ian Murdoch	Intensivist	Evelina Children's Hospital
South and West Cluster Rep	Michael Marsh	Intensivist	Southampton General Hospital
South and West Cluster Rep	Peter Davis	Intensivist	Bristol Children's Hospital
Midlands And East Cluster Rep	Reinout Mildner	Intensivist	Birmingham Children's Hospital
Midlands And East Cluster Rep	Sanjiv Nichani	Intensivist	Leicester Hospitals
Northern Cluster Rep	Steve Kerr	Intensivist	Alder Hey Children's Hospital
Northern Cluster Rep	Iain Johnstone	Intensivist	Newcastle Hospitals
British Congenital Cardiac Association Rep	Alan Magee	Cardiologist	Royal Brompton
British Association of Perinatal Medicine Rep	Alan Fenton	Neonatologist	Newcastle Hospitals
Association of Paediatric Anaesthetists	Karen Bartholemew	Anaesthetist	Carderdale Hospital
Royal College of Paediatrics and Child Health	Mike Linney	Paediatrician	Chichester Hospital
Paediatric Intensive Care Society - Nursing	Michelle Milner	Nurse Manager	Alder Hey Children's Hospital
Paediatric Intensive Care Society - Medical	Kevin Morris	Intensivist	Birmingham Children's Hospital
Paediatric Intensive Care Audit Network	Roger Parslow	Senior Lecturer	University of Leeds
Children's Acute Transport Service	Andy Petros	Intensivist	Great Ormond Street Hospital
Patient and Parent Involvement	Madeline Wang	PPI rep	London
Patient and Parent Involvement	Vacant		

Table 5. Membership of the Clinical Reference Group for Paediatric Intensive Care.

The purpose of the CRGs is to produce six "products" For the NHSCB. These products are:

1. The scope of the service and its specification, ultimately with a three-year strategic plan.
2. Commissioning policies that are linked to clinical outcome measures.
3. An information algorithm; that is a description of the information that needs to

be gathered in order to pay for the service and to assure its quality.

4. A portfolio of nationally reported and published clinical outcome measures - the Quality Dashboard.
5. CQUINs which are nationally agreed for the service and linked to the three-year strategic plan.
6. Quality Improvement and Productivity Program (QIPP). This is linked to both outcome measures and CQUINs but also includes a plan to enable the specialty to deliver its part of the overall NHS cost savings.

In addition the group has been asked to develop an innovation portfolio, in which it is required to identify potential innovations, set research questions, benchmark against international standards and generate ideas. The national programme has set aside a pot of money to support research into innovations generated from this process.

Some of the work in paediatric intensive care has already been started and in those areas where a reasonable amount of work has been done the role of the clinical reference group will be to

ensure that the work has widest possible clinical support. It is anticipated that the work will be completed by the end of the financial year 12/13, at which point it will be handed over to the NHSCB.

We are very encouraged by the fact that senior clinicians have been given the opportunity to influence the future commissioning agenda. We hope that we can make use of the opportunity to iron out some of the existing inconsistencies in the service and to develop a coherent strategy for the future. We think that there will be challenges in defining the scope of the service. Ideally it should encompass the entire patient pathway but there will be tensions between the role of the NHSCB and of local commissioning. As you will all be aware, we are entering a period of shrinking budgets and it is naive to pretend that paediatric intensive care will be shielded from these pressures. Hopefully, with adequate clinical engagement, we can ensure that our patients can continue to benefit from the highest standard of care that we can deliver.

Dr Mark Darowski, Chair Clinical Reference Group.

Dr Marilena Korkodilos, Public Health Lead.

Jessica Whitton, Commissioning Lead.

13. Using linked infection PICANet data to generalise results from a large randomised controlled trial to the wider NHS: the CATCH trial of impregnated CVCs in PICU

Background

Routine clinical data, such as those collected on a national basis by PICANet, can potentially be useful for all stages of randomised controlled trials (RCTs):

1. to identify patient populations for recruitment into trials;
2. to derive event rates for study design and sample size estimation;
3. to capture patient characteristics and outcomes particularly for long-term follow up;
4. to determine the generalisability of trial findings;
5. to monitor the implementation or scaling-up of interventions that have been shown to be effective.

In this article, we describe how linked PICANet data can be used to assess the generalisability of RCTs (4 above).

CATCH (CATHeters in Children) is an RCT to determine the effectiveness of impregnated central venous catheters (CVCs) compared with standard CVCs for preventing hospital-acquired blood stream infection (BSI) in paediatric intensive care units (PICUs). As part of the funding for CATCH, the NIHR HTA programme sponsored a generalisability study to run in parallel to the main trial.

The generalisability study aims to determine how trial findings relating to the effect of different types of CVC on BSI rates apply to PICUs across the NHS. The rationale for this is twofold. Firstly, the context of changing infection rates needs to be considered – on-going improvements in infection control, primarily due to CVC care bundles, are leading to falling rates of BSI. Secondly, it may not be appropriate to generalise BSI rates in the CATCH trial to similar patients outside the trial, since participation in CATCH

itself may increase the reported infection rate due to increased sensitivity of blood culture testing.

Linkage between PICANet and national bacteraemia surveillance data collected by the Health Protection Agency (HPA) will allow us to generalise trial results by estimating the baseline risk of infection with standard CVCs and identifying children like those enrolled in CATCH. We will also take into account information from two national surveys of PICUs in the NHS reporting use of CVCs and infection control practices before and during the trial [1].

If CATCH finds that impregnated CVCs are effective, we will determine the number of infections that could be avoided, by applying relative risks from the trial results to our estimates of current baseline risks of BSI in similar patients in both trial and non-trial PICUs across the UK. These findings will have implications for the cost-effectiveness of purchasing impregnated CVCs across the NHS.

Methods

As CATCH results will not be available until 2013, we conducted preliminary analysis using data from two PICUs and an estimated relative risk of infection based on a recent meta-analysis (studies involving mainly adults) [2]. Infection data from these two PICUs included well completed, accurate unique identifiers (NHS number, Hospital number, name) and so deterministic linkage (i.e. exact matches) with PICANet data was possible. PICU-acquired BSI was defined as episodes of BSI occurring between two days after admission to PICU and two days following discharge to PICU. The estimated absolute difference in infection rates, given the use of impregnated CVCs, was derived using the predicted baseline rate for the end of CATCH and estimated relative-risk from the recent meta-analysis. In this preliminary analysis, a Poisson model was used for a simple prediction of the baseline risk at the end of CATCH. Results for all PICUs will be updated when trial results become available (up-to date data will be used and there will be no need for predictions).

Preliminary Results

Predicting the baseline risk of BSI after the study:

Linkage of PICANet and microbiology data in two PICUs showed the rate of PICU-acquired BSI in children staying for more than 48 hours in PICU decreased by 8% (95% CI 6%-10%) each year (Figure 7). This corresponds to a 29% reduction (a reduction of 5.8 per 1000 bed-days) in the risk-adjusted rate of PICU-acquired BSI between 2003 and 2011.

If this trend continues, rates would reach 9.6 per 1000 bed-days by the end of 2012 (figure 7). In these preliminary analyses, we assume that the PICU-acquired BSI rate for PICU patients staying >48 hours who have a CVC inserted (the majority of patients) is similar to the PICU-acquired BSI rate for all PICU patients staying >48 hours. CVC insertion and removal are not yet routinely recorded within PICANet, but children enrolled in CATCH with CVCs will be identified within PICANet.

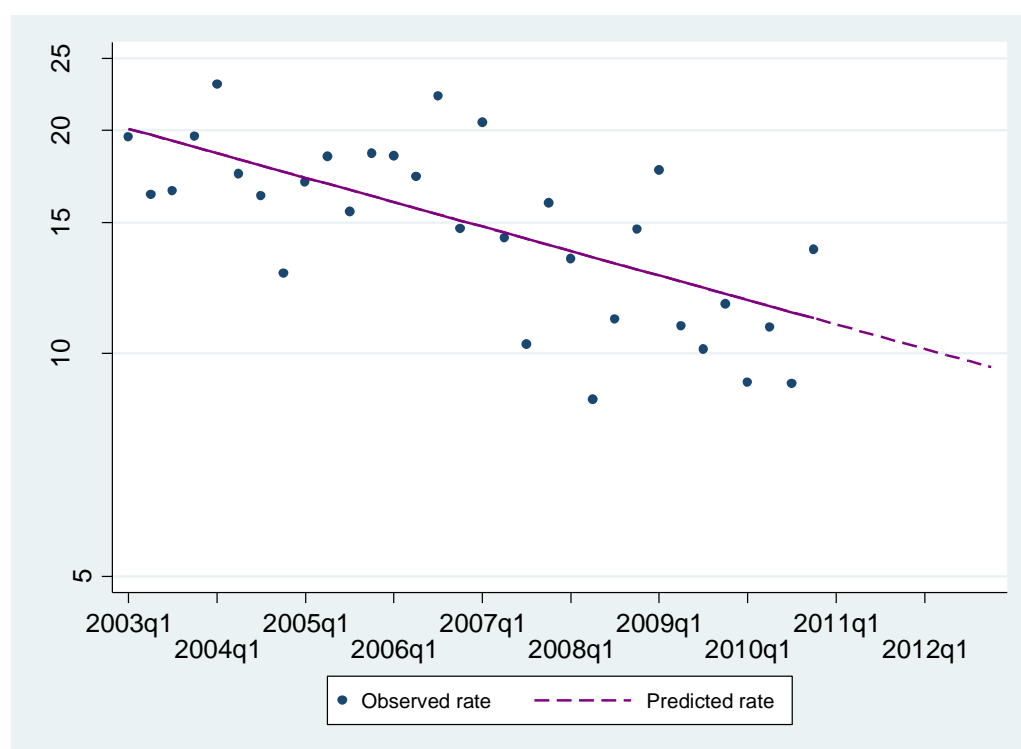


Figure 7. Observed and predicted rate of PICU-acquired blood-stream infection in two PICUs.

Predicting the absolute risk difference (benefit) in the NHS

The range of the relative-risk for PICU-acquired BSI with impregnated versus standard CVCs from the meta-analysis was 0.06-0.54. Based on the predicted baseline rate (9.6 per 1000 bed days), we estimate a potential decrease of 4.4-9.0 infections per 1000 bed-days or 46-95 fewer admissions per year with PICU-acquired BSI at these two PICUs if impregnated CVCs were used instead of standard CVCs.

Discussion

Our preliminary analysis of two PICUs shows that linkage of routinely collected data such as PICANet can help to determine the generalisability of trial results when the quantities of interest cannot be estimated using a single data source. When scaled-up nationally, this approach will allow us to identify units that would benefit most from adopting impregnated CVCs by estimating the absolute risk reduction for each PICU if they use impregnated instead of standard CVCs, using their predicted baseline risk of BSI (taking into account case-mix) and the relative risk from the trial results. These techniques allow the

rapid translation of important research findings to practice through targeted quality improvement and more rapid adoption of innovation in units most likely to benefit.

Implications for scaling up implementation of effective interventions

Record linkage methods

Our preliminary analysis using data from two PICUs has also given us insight into the steps needed to develop national monitoring of BSI in PICU. Although linkage was straightforward for these two PICUs, national surveillance data does not contain well-completed unique identifiers. Linkage between PICANet and these national data will require an approach that takes into account the potential impact of linkage error.

When unique identifiers such as NHS number are missing or inaccurate, probabilistic linkage is often used. Weights are assigned to potentially linked records, based on contributions from each partial identifier, so that agreement on name for example contributes more weight than agreement on sex. Only the record with the highest weight is retained. However, it has long been recognised that even small errors in linkage can lead to biased results [3]. Excluding records for which a link cannot be identified can lead to underestimated rates and important biases also arise if linkage success differs between groups, for example biased mortality ratios due to differential linkage by ethnic-group [4, 5]. Similarly, variations in data-quality between hospitals can affect linkage, resulting in erroneous rankings of relative performance [6].

For linkage projects such as ours, efforts to assess linkage error and determine its potential impacts on results are vital. To overcome these issues, we will use a number of approaches. Firstly, subsets of gold-standard data where true links are known will be used to estimate linkage sensitivity and specificity and adjust results accordingly. Secondly, measures of linkage certainty, such as match weights for probabilistic linkage, will allow the comparison of characteristics of linked and unlinked records to identify potential sources of bias, and enable sensitivity analyses using a range of linkage criteria. Finally, alternative statistical methods – such as those incorporating the concepts of multiple imputation - will be used to

help quantify uncertainty by providing a range of plausible results [7].

Data access and governance

The evaluation described in this project is only possible thanks to the high quality data collection PICANet has been conducting over the past decade. National level analyses of infection rate trends rely on organisations, such as the HPA, that have special dispensation to access identifiable data. Collaboration with academics (KH, AW, HG, RG), data providers (BMP, RP) and clinicians (QM) was essential to combine the necessary methodological and clinical expertise with such data access.

An exemption under Section 251 of the NHS Act 2006 (previously Section 60 of the Health and Social Care Act 2001) allows the HPA to receive patient-identifiable data from other organisations without patient consent in order to monitor infectious disease. Specific permission for the linkage carried out in this project was granted by the National Information Governance Board (NIGB). Oversight of the linked data is detailed in a data sharing agreement between, HPA, UCL-ICH, PICANet and the MCRN CTU. PICANet has implemented stringent confidentiality and data protection arrangements to comply with the provisions of the Data Protection Act 1998, and has exemption from requirements for parental consent under Section 60 of the Health and Social Care Act 2001. PICANet has research ethics approval to link with clinical trial data provided consent for linkage is obtained (i.e. CATCH) and permissions explicitly allow linkage to BSI surveillance data.

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14. The future of intensive care unit hospital-acquired infection surveillance

Background

Many Adult and Paediatric ICUs have been taking part over the last few years in the NPSA Matching Michigan project. This programme has been very successful overall in reducing Blood Stream Infection (BSI) in PICUs and it was clearly important to try and maintain this success and even, if possible, improve on it. It is also recognised that BSI was only a part of HAIs in PICUs and that nosocomial viral infections, VAP, urinary catheter infections and other HAIs remain poorly quantified and clinically important. It is also accepted that many HAI definitions have not been well validated in children and this could lead to under reporting. It is also clear that equally there are some areas where there could be shared learning opportunities between adult, paediatric and neonatal intensive care. This has led to the possibility of developing a national ICU infection surveillance programme that was professionally led and focussed on quality improvement rather than single target orientated.

The Intensive Care Unit Hospital-Acquired Infection Surveillance (ICU HAI) sub-group of the Department of Health's Expert Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI) was therefore recently formed to determine, with stakeholders, the best way to develop a quality improvement programme for hospital-acquired infection in critical care units following on from the Matching Michigan Project.

The multi-disciplinary group have been working on determining the most appropriate means of effecting reporting of an indicator of hospital-acquired infection in critical care, by voluntary reporting. The key aim is to identify a single comparative performance indicator with the aim of reducing infection rates in adult, paediatric and neonatal ICUs.

The advantages, limitations and practicalities of existing and future surveillance systems for data capture have been considered. These included:

- the computer data entry Reporting Infections in Critical Care (RICC) system used by National Patient Safety Agency system,
- the Health Protection Agency (HPA) Surgical Site Surveillance System,
- the HPA Data Capture System currently being developed for mandatory bacteraemia and *C. difficile* surveillance,
- the Critical Care Flu Surveillance System.

In discussion the group determined that, for maximum utility, any surveillance system used should be based at the HPA to facilitate future data linkage between the different ICU audit programmes and LabBase2.

It was agreed that, for the present, the catheter-associated bacteraemia definition is most suitable to use for benchmarking rather than catheter-related bacteraemia. The latter requires microbiological data (semi quantitative analysis of blood samples or roll tip cultures of catheter tips), which are not widely available (30% of hospitals). Further discussion is needed to agree the denominator and data fields.

Interim conclusions

The interim conclusions and recommendations of the ICU HAI surveillance sub-group were presented and agreed by ARHAI on 31st May 2012:

- A voluntary Continuous Quality Improvement Programme across critical care (general adult, paediatric and neonatal) should be established. The programme should be professionally led by a collaboration between the Faculty of Intensive Care Medicine, Intensive Care Society, Paediatric Intensive Care Society, ICNARC, NDAU, NNAP, PICANet and the HPA (Public Health England).
- A Supervisory Board should be established to oversee the surveillance. A possible name may be National Intensive Care Infection Surveillance System (NICISS). This would include representation from the Intensive

Care Society, Paediatric Intensive Care Society, Faculty of Intensive Care Medicine, NDAU and NNAP, British Association of Critical Care Nursing, HPA (PHE), British Association of Perinatal Medicine, Healthcare Infection Society and Infection Prevention Society.

- For the present, the quality indicator selected should be central venous catheter-associated infection expressed as a proportion of CVC patient-days using the European Centre for Disease Prevention and Control definition. In the longer term, it would be desirable for microbiology departments to develop capacity for routine semi-quantitative cultures so that the more rigorous catheter-related BSI definition could be used for benchmarking and quality improvement.

It is the intention to establish the Supervisory Board in the autumn of 2012. PICS and PICANet

have been at the core of these discussions. As well as demonstrating clear leadership in taking this initiative forward, the group has recognised that there is a lot to learn still about HAI in PICU. The recent ARHAI national Antimicrobial Stewardship programme, Start Smart – the Focus, has also highlighted the need for further research in how best to conserve antibiotics in high risk areas. Antimicrobial resistance, antibiotic stewardship and HAI all need to be considered together within any quality improvement programme. One of the key challenges for the new national ICU infection programme will be how to use rapid diagnostic techniques, biomarkers, and complex interventions to maintain and improve clinical outcomes in an era with increasing antimicrobial resistance and an extremely limited antibiotic pipeline.

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