

## The Paediatric Intensive Care Audit Network (PICANet):

A national database of paediatric intensive care activity

### PROTOCOL

Version 2  
September 2006

Professor Patricia McKinney <sup>§</sup>, Roger Parslow <sup>†</sup>,  
Dr Elizabeth Draper <sup>‡</sup> & Dr Krishnan Thiru\*<sup>\*</sup>

<sup>§</sup> Chief Investigator, Paediatric Epidemiology Group, Centre for Epidemiology & Biostatistics,  
The Leeds Institute of Genetics, Health & Therapeutics, 30 Hyde Terrace, University of Leeds,  
Leeds. LS2 9LN

Tele: (0113) 343 4843

Email: [p.a.mckinney@leeds.ac.uk](mailto:p.a.mckinney@leeds.ac.uk)

<sup>†</sup> Senior Research Fellow, Paediatric Epidemiology Group, Centre for Epidemiology &  
Biostatistics, The Leeds Institute of Genetics, Health & Therapeutics, 30 Hyde Terrace,  
University of Leeds, Leeds. LS2 9LN

Tele: (0113) 343 4856

Email: [r.c.parslow@leeds.ac.uk](mailto:r.c.parslow@leeds.ac.uk)

<sup>‡</sup> Reader, Department of Health Sciences, University of Leicester, 22-28 Princess Road West,  
Leicester. LE1 6TP

Tele: (0116) 252 3200

Email: [msn@leicester.ac.uk](mailto:msn@leicester.ac.uk)

\* Pan Thames Co-ordinator, Cardiorespiratory & Critical Care Division, Room 8086, Level 8,  
Nurses Home, Great Ormond Street Hospital for Children, Great Ormond Street, London.  
WC1 3JH

Tele: (0207) 762 6713

Email: [thiruk1@gosh.nhs.uk](mailto:thiruk1@gosh.nhs.uk)

## **Background**

The Paediatric Intensive care Audit Network (PICANet) is a national audit of paediatric intensive care activity in England and Wales and parts of Scotland and Ireland.

This document forms a revision of the protocol submitted to the Research Ethics Committee (version 1.1, 9<sup>th</sup> August 2005). This substantial revision was necessitated by: (1) personnel changes within PICANet, including the departure of the previous Chief Investigator, Dr Gareth Parry; (2) the physical relocation of the core tasks of the organisation from Sheffield to Leeds and (3) the fact that this is an on-going activity and some minor updates in processes and procedures needed to be documented. Therefore, the current protocol reflects present practice.

## **Aims & Objectives**

PICANet was established in 2001 with the aim of providing a secure and confidential, high quality clinical database of paediatric intensive care activity in England and Wales, including case mix, structure and utilization, to facilitate the following:

- identification of best practice;
- monitoring of supply and demand;
- monitoring and review of outcomes of treatment episodes;
- strategic planning and resource requirements;
- study of the epidemiology of critical illness (see Appendix A).

The aims of PICANet have been met in the past and will continue to be addressed through the collaboration of the two academic groups (the Universities of Leeds & Leicester) and clinical colleagues throughout the UK. The Leeds and Leicester researchers are members of the United Kingdom Paediatric Intensive Care Society (PICS), the professional body representing those involved in, or with an interest in, the provision of paediatric intensive care. A subgroup of PICS, the United Kingdom Paediatric Intensive Care Society Study Group (UK PICS SG), was established with the aim of promoting multidisciplinary and multi-centre clinical studies relating to children admitted for intensive care. The UK PICS SG has very strong links with PICANet. Clinicians involved in the UK PICS SG are represented on both the PICANet Steering Group (see Appendix B) and the Clinical Advisory Group (see Appendix C).

## **Location of study and investigators**

### **University of Leicester**

The investigator from the University of Leicester (Draper) has been working with large scale obstetric, perinatal and paediatric epidemiological studies for over 20 years. At present, Dr Draper runs a collaborative pan-regional group of studies for the Trent Region: the Trent Infant Mortality and Morbidity Studies (TIMMS), which are conducted under the auspices of the Trent Institute for Health Services Research. There are four main TIMMS studies:

- the Trent Paediatric Intensive Care Study;
- the Trent Neonatal Survey;
- the Trent Confidential Enquiry into Stillbirths & Deaths in Infancy (part of the national CESDI program);
- the Trent Congenital Anomalies Register.

The main aim of these studies is to investigate the causes and consequences of morbidity and mortality of the foetus, infant and child related to pregnancy, delivery, infancy and childhood in the Trent region.

### **University of Leeds**

The investigators from the University of Leeds (McKinney & Parslow) have wide experience in paediatric epidemiology, particularly in the design, implementation, management and analysis of high quality population data sets. Prof. McKinney's work with the Information and Statistics Division of the NHS in Scotland provides extensive experience of managing large datasets and routine reporting to clinicians and government.

The success of the Paediatric Epidemiology Group is underpinned by effective collaboration with clinicians, including paediatricians from various specialties. In Leeds, outputs are focused on the use of demographic, particularly census data and clinical information (including routine and specific data collections) for health services and academic research. Particular expertise has been developed in analyzing the geographical distribution of disease in relation to characteristics of the population, such as deprivation and ethnicity. Descriptive and analytical epidemiological research is undertaken not only across the Northern and Yorkshire region but in large scale collaborative UK and European studies.

## **Funding**

PICANet is currently funded by the Department of Health (DOH), Health Commission Wales Specialised Services, the Royal Hospital for Sick Children, Edinburgh and the Pan Thames PICU Commissioning Consortium.

## **Organisation**

2006 has seen the closure of the PICANet centre based at the University of Sheffield and the departure of the previous Chief Investigator, Dr Gareth Parry. The PICANet server has been relocated at the University of Leeds with the new Chief Investigator, Professor Patricia McKinney. The server is being hosted by the Leeds Teaching Hospitals Trust. This move provides an enhanced environment for the server and security is assured by the Trust (a copy of the Leeds Teaching Hospitals Trust data security policy is available on request).

The full PICANet Management Team now consists of the investigators and staff from the Universities of Leeds (McKinney, Parslow) and Leicester (Draper) and the pan Thames commissioning region (Thiru). This team meets monthly to review progress against the timelines and contract deliverables, to consider any actual or potential difficulties identified and to agree the detailed work programme for the next quarter.

The entire project is overseen and guided by the PICANet Steering Group, which consists of external members and representatives of PICANet and the clinical community; the membership list is provided in Appendix B. The Steering Group is charged with ensuring that implementation of the database matches the agreed specification and that it should be evidence-based. The Steering Group has representatives from a broad range of organisations with an interest in paediatric intensive care, e.g. Action for Sick Children, the Department of Health, the Healthcare Commission, Health Commission Wales, health services and public health medicine research, the Intensive Care National Audit Research Centre, the Paediatric Intensive Care Society, and the Royal Colleges of Paediatrics and Child Health, Anaesthetists and Nursing.

In addition to these formal management structures, we established a Clinical Advisory Group, consisting of representatives of units that submit data to PICANet (see Appendix C for a list of the membership). This Advisory Group is a forum in which units can raise practical issues with regard to the operation of PICANet, and contribute to discussions around the long term development of its content and the results obtained from analysis

of the database. It also acts as the natural forum for the co-ordination of multi-centre clinical research studies. This Group has two central functions (1) to identify important research questions that the PICANet database could address; and (2) to review the results and interpretation of analyses of the database from a clinical perspective. The Clinical Advisory Group has a representative on the Steering Group.

### **Unit Identification and Recruitment**

All PICUs in England and Wales contribute data to PICANet, and, from Scotland, The Royal Hospital for Sick Children in Edinburgh. Interest in joining PICANet has been shown by PICUs based in Dublin, Belfast and Glasgow.

### **PICANet Dataset Specification**

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

The current data set is collected onto a form (see Appendix D) and consists of 94 variables (including five address elements and the option for a second family name).

Further details can be found in the latest national PICANet report [1]. The data definitions manual is available at [www.picanet.org.uk](http://www.picanet.org.uk).

### **Data Entry and Transmission Software**

Custom data entry software has been developed by PICANet and distributed to all units to enable a consistent national data set to be assembled. Those units who use their own or commercial data collection software have been provided with an export file specification, to enable data to be imported by the PICANet software.

The PICANet software performs internal logical consistency and range checks as data are entered and provides an on-screen summary of outstanding validation checks on the completion of a record. Following feedback from users, validation errors / queries are highlighted in the software and moving to the relevant field has been made easier. Units importing data from their own databases are provided with an import log detailing which records have been imported and any outstanding validation issues. Units are

regularly provided with monthly admission reports, data validation reports and error status reports following central validation checks at the server level.

Contributing units make regular data submissions to the central PICANet server, originally based at the University of Sheffield, but recently relocated to the Leeds Teaching Hospitals Trust who have agreed to provide accommodation, maintenance, security and back-up services for the PICANet in a contractual arrangement with the University of Leeds.

The PICANet data entry software includes the facility to transmit data electronically via NHSnet if the local IT infrastructure can be configured appropriately. The data is first encrypted using public key encryption and then placed on the server in a folder specific to each unit. Periodically, uploaded data is moved to a secure holding area, decrypted and uploaded onto the central server database.

Where local IT departments have been unable or unwilling to configure their systems and firewalls to allow electronic transfer via NHSnet, the data is encrypted and placed in a local folder and then sent as an email attachment. Data security measures were agreed to be adequate by the Regional Security Manager of the NHSIA before an NHSnet connection was permitted.

### **Data Collection Training**

All units have received training in data extraction, coding and input for the programme. This training covered the principles of good practice, the specific definitions of all data being collected, the use of the data entry software and the validation procedures. All people involved in the data extraction, punching or the management of either of these processes are required to attend training before data collection can commence at the unit. Training sessions were organized over two days to familiarize clinical and data entry staff with data definitions, data collection issues and software. Since the original training sessions, ad hoc training has been provided by the PICANet team for new staff concerned with data collection and entry. At least 3 members of staff from each unit should be fully trained. In addition, these staff have been furnished with materials to undertake in-house training at their own units.

In addition to the above requisite training, the consent, confidentiality and data protection arrangements for each unit had to be demonstrated to meet with the

standards agreed between the programme and the Data Protection Registrar, NHSIA, Caldicott Guardian and Multi-Centre Research Ethics Committee.

Data collection has been ongoing in all PICUs in England and Wales since November 2002, with the exception of nine units comprising the Pan Thames consortium, who started in March 2003. Edinburgh's Royal Hospital for Sick Children began in December 2004. The Contributing Units are listed in Appendix E.

### **Consent and confidentiality**

PICANet collects patient identifiable information including names, addresses, date of birth and NHS number. With this information, PICANet can identify multiple admissions for the same individual, making the dataset person *and* episode-based. In the future, personally identifiable information can be linked with death registration details held by the Office for National Statistics, to assess long-term mortality in children admitted to PIC. In addition, national census and other geographical data can be linked with individual children using validated postcodes, enabling PICANet to assess the association between social class, population density and other geo-demographic and environmental information and PIC admissions.

To comply with the provisions of the Data Protection Act 1998 [2], PICANet has implemented stringent confidentiality and data protection arrangements. The Patient Information Advisory Group (PIAG) has granted PICANet exemption from gaining signed parental consent under Section 60 of the Health and Social Care Act 2001 [3]. This class support enables PICANet to collect and process patient identifiable information for the purpose of auditing, monitoring and analyzing patient treatments, to ensure that adequate and appropriate paediatric intensive care services are available for all children admitted for PIC in England and Wales. Exemption was given under specified conditions in December 2002 and has been renewed annually since this date. The feasibility of obtaining informed parental consent is addressed in a study carried out by PICANet in 2004 [4]. The PIAG approval for Section 60 exemption can be found at <http://www.advisorybodies.doh.gov.uk/piag/register.htm> in an Excel spreadsheet (Application Number 16).

## **Reporting processes**

### ***Contractual Reports***

Reports are submitted to the Department of Health on a monthly and an annual basis.

These documents report on:

- The management of PICANet and the status of data submission
- The risk-adjusted performance of the contributing units (annual report)
- The epidemiology of critical illness observed in contributing units
- 

### ***Ad-hoc reports***

Ad-hoc reports are produced on request using a formal application form (see Appendix F). Many requests for information or data have been received since PICANet was established. Guidelines exist regarding the release of such information (see Appendix G).

### ***Publications***

To date, PICANet have produced three consecutive national annual reports [1, 5, 6]. The most recent provided information at the level of individual units who were identifiable [1]. This was a new procedure agreed by all the contributing units.

### ***Uses of the data***

As well as providing routine and ad hoc information to the PIC clinical community, the data are used for a range of health service and epidemiological research. For example, in order to assess long-term mortality, children admitted to PICUs will be followed up via the Office for National Statistics from whom death records will be sought.

### **Procedures and Policies**

In recent years, it has become evident that there ought to exist strict PICANet policies and procedures, that might act as guidelines or safeguards in the event of certain circumstances. As a result, we now have in place the following:

- procedure for submission of data to PICANet (Appendix H);
- Freedom of Information Act Guidance Information (Appendix I);
- PICANet publication procedures (Appendix J);
- PICANet policy on PICUs lying outside the control limits of the mortality ration funnel plots (Appendix K).

## References

1. Paediatric Intensive Care Audit Network National Report 2004 – 2005 [published May 2006]: Universities of Leeds, Leicester and Sheffield. ISBN 0 85316 249 2
2. The Data Protection Act (1998). The Stationery Office Limited, ISBN 0 10 542998 8. (<http://www.opsi.gov.uk/ACTS/acts1998/19980029.htm>)
3. The Health and Social Care Act (2001). The Stationery Office Limited, ISBN 0 10 541501 4 (<http://www.opsi.gov.uk/ACTS/acts2001/20010015.htm>)
4. McKinney PA, Jones S, Parslow RC, Davey N, Darowski M, Chaudhry B, Stack C, Parry G, Draper ES for the PICANet Consent Study Group (2005). A feasibility study of signed consent for the collection of patient identifiable information for a national paediatric clinical audit database. *British Medical Journal* **330** 877 – 879
5. Paediatric Intensive Care Audit Network National Report March 2003 – February 2004 [published May 2004]: Universities of Leeds, Leicester and Sheffield.
6. Paediatric Intensive Care Audit Network National Report 2003 – 2004 [published May 2005]: Universities of Leeds, Leicester and Sheffield. ISBN 0 85316 254 9

## **APPENDICES**

### **Appendix A Statement on objectives and benefits of PICANet**



#### **Paediatric Intensive Care Audit Network (PICANet)**

##### **1. Objectives**

PICANet aims to establish a secure and confidential high quality clinical database of paediatric intensive care activity in the United Kingdom. The objectives are to:

- Identify best practice.
- Monitor supply and demand.
- Monitor and review outcomes of treatment episodes.
- Facilitate strategic health care planning and quantify resource requirements.
- Study the epidemiology of critical illness in children.

##### **2. Management structure**

PICANet has formalised links to the clinical community via a Clinical Advisory Group. A Steering Group monitors the progress of the project, and provides professional advice. This group comprises of members of the paediatric intensive care clinical community, a representative from the voluntary sector, and representatives from other appropriate bodies offering a broad range of expertise in public health, epidemiology and other health related disciplines.

##### **3. Benefits of PICANet for the clinical community**

Benefits of a national audit database will be wide-ranging.

**Comparability** – For the first time a high quality core dataset of demographic and clinical data on all paediatric admissions to PICUs will be available. The data will be collected systematically, validated and held in a secure, common database. Comparisons for each unit with the national picture can be reported.

**An evidence base** – An evidence base on outcomes, processes and structures will be available at a national level and permit planning for future practice, research and interventions. Clinical data on diagnosis and severity will enable outcome assessments to be based on large samples.

**Support and training** – The PICANet team provide technical expertise, ongoing support, and staff training for data collection. Data validation is also an integral part of the project. Further details of the support structure are described in the attached document.

**Software / manuals / data collection forms** – These documents are provided to ensure consistent data collection. Input from the clinical community has resulted in an agreed standardised dataset that will simplify data capture and return. The software has been specifically designed for the paediatric intensive care environment, and data can be securely sent to a central server via NHSNet.

**Feedback** - Each unit will receive a quarterly report on their own data and an annual report on aggregated data. Information can be aggregated at different levels. On a wider scale, information will be made available to the Clinical Advisory Group, Steering Group, Paediatric Intensive Care Society (PICS), the Department of Health and the Specialist Health Service

Commission for Wales. Dissemination of findings to the clinical community will ensure that appropriate actions are taken.

**Patient benefits** – The existence of a national database with data regularly provided to those delivering care allows performance indicators to be robustly compared. Patients, parents and families are then assured that the optimum level of care is available. Views of these user groups are represented on the PICANet Steering Group via the charity 'Action for Sick Children'.

#### **4. Contacts**

PICANet is co-ordinated by the Universities of Leeds and Leicester.

##### **University of Leeds:**

Roger Parslow  
PICANet  
Paediatric Epidemiology Group  
Centre for Epidemiology & Biostatistics  
The Leeds Institute of Genetics, Health & Therapeutics (LIGHT)  
University of Leeds  
30-32 Hyde Terrace  
Leeds LS2 9LN

[r.c.parslow@leeds.ac.uk](mailto:r.c.parslow@leeds.ac.uk)

Tel: 0113 343 4856

Prof. Tricia McKinney  
PICANet  
Paediatric Epidemiology Group  
Centre for Epidemiology & Biostatistics  
The Leeds Institute of Genetics, Health & Therapeutics (LIGHT)  
University of Leeds  
30-32 Hyde Terrace  
Leeds LS2 9LN

[p.a.mckinney@leeds.ac.uk](mailto:p.a.mckinney@leeds.ac.uk)

Tel: 0113 343 4843

##### **University of Leicester:**

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

[msn@leicester.ac.uk](mailto:msn@leicester.ac.uk)

Tel: 0116 252 3200

*Appendix B PICANet Steering Group membership*

<b>Name</b>	<b>Position</b>	<b>Organisation</b>	<b>Representation</b>
Mrs Pamela Barnes	Chair	Action for Sick Children	Lay member
Prof. Nick Black (Chair)	Head of Health Services Research Unit	London School of Hygiene and Tropical Medicine	Health Services Research / Public Health
Mr William Booth	Clinical Nurse Manager	Bristol Royal Hospital for Children	Royal College of Nursing
Dr Jean Chapple	Consultant in Public Health Medicine	Westminster Primary Care Trust	PICNET founder
Dr Mark Darowski	Consultant Paediatric Anaesthetist	Leeds Teaching Hospitals NHS Trust	Royal College of Anaesthetists
Mr Noel Durkin	Policy Officer, Child Health Team	Child Health Services Directorate	Department of Health
Dr Steve Kerr	Consultant in Paediatric Intensive Care	Royal Liverpool Children's NHS Trust	Chair of PICS
Ms Helen Laing	Head of Clinical Audit	Healthcare Commission	Healthcare Commission
Dr Michael Marsh	Consultant in Paediatric Intensive Care	Southampton University Hospitals NHS Trust	Royal College of Paediatrics & Child Health
Dr Jillian McFadzean/ Ms Laura Reekie	Consultant in Anaesthesia and Intensive Care / PA	NHS Lothian - University Hospitals Division	Edinburgh Royal Hospital for Sick Children
Prof. Jon Nicholl	Director of Medical Research Unit	School of Health and Related Research University of Sheffield	Health Services Research / Statistics
Dr Gale Pearson	Consultant in Paediatric Intensive Care	Birmingham Children's NHS Trust	Chair of PICANet Clinical Advisory Group
Ms Tanya Ralph	Nursing Research Lead	Sheffield Children's NHS Trust	Paediatric Intensive Care Society
Lucy Scott (representing Dr Kathy Rowan, Director)	Casemix Programme Manager	ICNARC	ICNARC
Mr Stuart Rowe	PCT Commissioner	Commissioning Department, Hammersmith & Fulham PCT	PCT Commissioner (Pan Thames)
Dr Ian Jenkins	Consultant in Paediatric Intensive Care	Bristol Royal Hospital for Children	Paediatric Intensive Care Society
Dr Edward Wozniak	Medical Advisor in Paediatrics and Child Health	Child Health Services	Department of Health
Dr Robert Tasker	Lecturer in Paediatrics	University of Cambridge Clinical School	PICS SG
Ms Dominique Sammut	Audit Coordinator	Health Commission Wales	Health Commission Wales

*Appendix C PICANet Clinical Advisory Group membership*

Dr Paul Baines	Consultant in Paediatric Intensive Care	Royal Liverpool Children's NHS Trust
Dr Andrew Durward	Consultant in Paediatric Intensive Care	Guy's & St. Thomas' NHS Foundation Trust
Ms Georgina Gymer	Research & Audit Co-ordinator	Nottingham University Hospitals NHS Trust
Dr Peter Davis	Consultant in Paediatric Intensive Care	United Bristol Healthcare NHS Trust
Dr Hilary Klonin	Consultant in Paediatric Intensive Care	Hull & East Yorkshire Hospitals NHS Trust
Ms Chris Mackerness	Sister	Newcastle upon Tyne Hospitals Foundation Trust
Dr Jillian McFadzean	Consultant in Anaesthesia and Intensive Care	NHS Lothian - University Hospitals Division
Dr Roddy O'Donnell	Consultant in Paediatric Intensive Care	Cambridge University Hospitals NHS Foundation Trust
Ms Victoria McLaughlin	Audit Nurse	Central Manchester & Manchester Children's University Hospitals NHS Trust
Dr Gale Pearson (Chair)	Consultant in Paediatric Intensive Care	Birmingham Children's Hospital NHS Trust
Ms Geralyn Oldham	Information Support Manager	Great Ormond Street Hospital for Children NHS Trust
Dr Allan Wardhaugh	Consultant in Paediatric Intensive Care	Cardiff & Vale NHS Trust
Ms Debbie White	Research Nurse	Cambridge University Hospitals NHS Foundation Trust



## Data Collection Form

Affix patient sticker here if required

### Admission Information

Admission number	<input type="text"/>	Family name	<input type="text"/>
NHS Number	<input type="text"/>	2nd Family name	<input type="text"/>
Case note number	<input type="text"/>	First name	<input type="text"/>
Address	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date of birth	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Postcode	<input type="text"/> <input type="text"/>	If DOB estimated, (or missing, or partly anonymised)	<input type="checkbox"/> 1 = Estimated <input type="checkbox"/> 2 = Partly anonymised <input type="checkbox"/> 9 = N/K
Ethnic category	<input type="text"/> Use standard NHS ethnic category and code (see back of form)	Gestational age at delivery (If age < 2 years)	<input type="text"/> <input type="text"/> weeks Answer range 20 to 44 wks Enter 99 if not known
Ethnic code	<input type="checkbox"/>	Sex (Tick one box)	Male <input type="checkbox"/> Female <input type="checkbox"/> Ambiguous <input type="checkbox"/> N/K <input type="checkbox"/>
		Multiple birth	<input type="checkbox"/> 1 = Singleton 2 = Twin 3 = Triplet 4 = quad 9 = N/K
		If not 1 or 9	Delivery order <input type="checkbox"/>

Date of admission to your unit	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Time of admission to your unit	<input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/>
-----------------------------------	---	-----------------------------------	---

Type of admission to your unit (Tick one box)	<input type="checkbox"/> Planned - following surgery	Previous ICU admission (during current hospital stay) (Tick one box)	<input type="checkbox"/> ICU	<input type="checkbox"/> PICU	<input type="checkbox"/> NICU	<input type="checkbox"/> None	<input type="checkbox"/> N/K
	<input type="checkbox"/> Unplanned - following surgery		<input type="checkbox"/> Planned - other	<input type="checkbox"/> Unplanned			
Source of admission	Same hospital <input type="checkbox"/> Other hospital <input type="checkbox"/> Clinic <input type="checkbox"/> Home <input type="checkbox"/>	Care area admitted from (includes care area where admitted from another hospital. Tick one box)					
Retrieval / transfer	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/> X-ray, endoscopy, CT scanner or similar <input type="checkbox"/> Recovery only <input type="checkbox"/> HDU (step up / step down unit) <input type="checkbox"/> Other intermediate care area (Not ICU / PICU / NICU) <input type="checkbox"/> ICU / PICU / NICU <input type="checkbox"/> Ward <input type="checkbox"/> Theatre and recovery <input type="checkbox"/> A & E					
If Yes, retrieved / transferred by	<input type="checkbox"/> Own team <input type="checkbox"/> Other specialist team (PICU) <input type="checkbox"/> Other specialist team (Non PICU) <input type="checkbox"/> Non specialist team <input type="checkbox"/> N/K						

<b>Primary diagnosis for this admission</b>

<b>Other reasons for this admission</b>

<b>Operations or procedures performed during this admission</b>

<b>Co-morbidity</b>

**PIM/PIM2 - Medical History**

Evidence available to assess past medical history?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes tick appropriate box (es)		
Cardiac arrest before ICU admission	<input type="checkbox"/>	→ <b>If yes: cardiac arrest OUT of Hospital?</b> <input type="checkbox"/>
Cardiomyopathy or myocarditis	<input type="checkbox"/>	Admitted following cardiac bypass <input type="checkbox"/>
Severe combined immune deficiency	<input type="checkbox"/>	Spontaneous cerebral haemorrhage <input type="checkbox"/>
Hypoplastic left heart syndrome	<input type="checkbox"/>	Neurodegenerative disorder <input type="checkbox"/>
Leukaemia / lymphoma after 1st induction	<input type="checkbox"/>	Severe developmental delay <input type="checkbox"/>
Liver failure (main reason for PICU admission)	<input type="checkbox"/>	Human Immunodeficiency Virus (HIV) <input type="checkbox"/>

**PIM/PIM2 - Reason for admission**

Please tick this box if the admission was elective:	<input type="checkbox"/>	
Please tick one of the boxes below if main reason for this PICU admission:		
Asthma <input type="checkbox"/>	Croup <input type="checkbox"/>	Recovery from surgery <input type="checkbox"/>
Bronchiolitis <input type="checkbox"/>	Obstructive sleep apnoea <input type="checkbox"/>	Diabetic ketoacidosis <input type="checkbox"/>

**PIM/PIM2 - Physiology** (valid time period: from 1st face to face contact with a doctor until **1 hour** after admission to your unit)

Systolic blood pressure	<input type="text"/> <input type="text"/> <input type="text"/> (mmHg)	Blood gas in 1st hour	Yes <input type="checkbox"/>	No <input type="checkbox"/>			
PaO <sub>2</sub> (arterial)	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> (kPa) <b>or</b> <input type="text"/> <input type="text"/> <input type="text"/> (mmHg)	Base excess (arterial / capillary)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>			
FiO <sub>2</sub> (at time of above sample)	<input type="text"/> . <input type="text"/> <input type="text"/>	Pupil reaction	Both fixed & dilated <input type="checkbox"/>	Other reaction <input type="checkbox"/>	N/K <input type="checkbox"/>		
Mechanical ventilation	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/K <input type="checkbox"/>	Intubation (at time of PaO <sub>2</sub> )	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/K <input type="checkbox"/>
CPAP (include mask / nasal / negative pressure)	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/K <input type="checkbox"/>	Headbox (at time of PaO <sub>2</sub> )	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/K <input type="checkbox"/>

**Interventions during this admission to your unit**

Invasive ventilation    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> If Yes total number of days given <input type="text"/> <input type="text"/> <input type="text"/>	Non-invasive ventilation    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> If Yes total number of days given <input type="text"/> <input type="text"/> <input type="text"/>
START invasive ventilation <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>	START non- invasive ventilation <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>
END invasive ventilation <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>	END non-invasive ventilation <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>
Please note that start and end dates are for your reference only and are not submitted to PICANet	
Tracheostomy    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> IV vasoactive drugs    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> Renal support    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> (If Yes to Renal Support please tick treatments given)	ECMO    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> LVAD    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> ICP device    Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/> (If Yes to ICP device please tick as appropriate)
Haemofiltration <input type="checkbox"/> Haemodialysis <input type="checkbox"/> Plasmafiltration <input type="checkbox"/> Plasma exchange <input type="checkbox"/> Peritoneal dialysis <input type="checkbox"/>	Ventricular drain <input type="checkbox"/> ICP bolt <input type="checkbox"/> Please note that ventilation for any part of a day (midnight to midnight) is counted as one day. EXAMPLE: If a child started ventilation at 23:00 and stopped at 07:00 the next day this would be counted as two days.

**Discharge Information**

Status at discharge from your unit	
Alive <input type="checkbox"/> Dead <input type="checkbox"/> Discharged for Palliative care? <input type="checkbox"/>	
Date of discharge <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>	Date of death <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>
Time of discharge <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/>	Time of death <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/>
Destination following discharge from your unit	Follow up 30 days post discharge from your unit
Normal residence <input type="checkbox"/> Hospice <input type="checkbox"/> Same hospital <input type="checkbox"/> Other hospital <input type="checkbox"/>	Status    Alive <input type="checkbox"/> Dead <input type="checkbox"/> N/K <input type="checkbox"/> Date of death <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input checked="" type="text"/> <input checked="" type="text"/> <input type="text"/> <input type="text"/>
ICU    PICU    NICU    HDU    SCBU    Ward    Other <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Normal residence <input type="checkbox"/> N/K <input type="checkbox"/> Hospice <input type="checkbox"/> Same hospital <input type="checkbox"/> Other hospital <input type="checkbox"/>
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	ICU    PICU    NICU    HDU    SCBU    Ward    Other <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

<b>Form completed by:</b>
---------------------------

<b>Comments</b>
-----------------

**User defined fields**

Variable name	Description				

**Ethnic categories**

These are the standard ethnic categories to be used for the collection of ethnicity information

Ethnic category			Codes
a	White	British	A
		Irish	B
		Any other White background	C
b	Mixed	White and Black Caribbean	D
		White and Black African	E
		White and Asian	F
		Any other mixed background	G
c	Asian and Asian British	Indian	H
		Pakistani	J
		Bangladeshi	K
		Any other Asian background	L
d	Black or black British	Caribbean	M
		African	N
		Any other Black background	P
e	Other ethnic groups	Chinese	R
		Any other ethnic group	S
f	Not stated	Not stated	Z

A query to [picanet@leeds.ac.uk](mailto:picanet@leeds.ac.uk) will reach every team member

Individual contact details

Roger Parslow  
0113 343 4856  
[r.c.parslow@leeds.ac.uk](mailto:r.c.parslow@leeds.ac.uk)

Krishnan Thiru  
020 7762 6713  
[ThiruK1@gosh.nhs.uk](mailto:ThiruK1@gosh.nhs.uk)

## Appendix E Units Contributing data to PICANet

<b>NHS Trust</b>	<b>Participating Hospital</b>	<b>Unit / Ward</b>
Cambridge University Hospitals NHS Foundation Trust	Addenbrookes Hospital	PICU
Birmingham Children's Hospital NHS Trust	Birmingham Children's Hospital	PICU
Brighton & Sussex University Hospitals NHS Trust	Royal Alexandra hospital for Sick Children	Lydia Ward
Cardiff & Vale NHS Trust	University Hospital of Wales	PICU
Central Manchester & Manchester Children's University Hospitals NHS Trust	Royal Manchester Children's Hospital	PICU
Great Ormond Street Hospital NHS Trust	Great Ormond Street Hospital for Children	CCCU, PICU & NICU
Guy's & St. Thomas' NHS Foundation Trust	Evelina Children's Hospital	PICU
Hull & East Yorkshire Hospitals NHS Trust	Hull Royal Infirmary	PICU beds on AITU
King's College Hospital NHS Trust	King's College Hospital	PICU
Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary	Wards 2 & 4
	St. James' University Hospital	PICU
Newcastle Upon Tyne Hospitals NHS Trust	Newcastle General Hospital	PICU
	Royal Victoria Infirmary	Ward 3
	Freeman Hospital	Ward 28
NHS Lothian – University Hospitals Division	Royal Hospital for Sick Children, Edinburgh	PICU
Oxford Radcliffe Hospitals NHS Trust	John Radcliffe Hospital	PICU
Queen's Medical Centre Nottingham University NHS Trust	Queen's Medical Centre	PICU
Royal Brompton & Harefield NHS Trust	Royal Brompton Hospital	PICU
Royal Liverpool Children's NHS Trust	Royal Liverpool Children's Hospital	PICU
Sheffield Children's Hospital NHS Trust	Sheffield Children's Hospital	PICU
	Sheffield Children's Hospital	Neonatal Surgical Unit
Southampton University Hospitals NHS Trust	Southampton General Hospital	PICU
South Tees Hospitals NHS Trust	James Cook University Hospital	PICU
St. George's Healthcare NHS Trust	St. George's Hospital	PICU
St. Mary's NHS Trust	St. Mary's Hospital	PICU
The Lewisham Hospitals NHS Trust	University Hospital, Lewisham	PICU
United Bristol Healthcare NHS Trust	Bristol Royal Hospital for Children	PICU
University Hospital of Leicester NHS Trust	Leicester Royal Infirmary	CICU
	The Glenfield Hospital	PICU
University Hospital of North Staffordshire NHS Trust	City General Hospital	PICU



**Request to use data from PICANet for research purposes**

**YOUR DETAILS**

<b>Name</b>	
<b>Position</b>	
<b>Place of Work</b>	
<b>Address</b>	
<b>Telephone No.</b>	
<b>Email</b>	
<b>Date request submitted</b>	___/___/___

**YOUR REQUEST**

<b>What is the aim of your research study?</b>	
<b>What data do you require?</b>	
<b>Why do you need this data from PICANet?</b>	
<b>What do you intend to use this data for?</b>	
<b>Who else will be involved</b>	

<b>in the project?</b>	
<b>What will you do with your results?</b>	
<b>Proposed timescale of project?</b>	
<b>Is your research funded?</b>	
<b>If so, by whom?</b>	
<b>Does your research require ethical approval?</b>	
<b>If so, has it been granted?</b>	
<b>Is your research compliant with Research Governance issues?</b>	
<b>Any other relevant information?</b>	

Please complete this form and return it to PICANet by email or post.

To be completed by PICANet Research Fellow

<b>Approval date</b>	
<b>Who dealt with request</b>	
<b>Total time spent on request</b>	
<b>Date data/ info provided</b>	
<b>Amount invoiced (if applicable)</b>	

**Request for information from PICANet**

**YOUR DETAILS**

<b>Name</b>	
<b>Position</b>	
<b>Place of Work</b>	
<b>Address</b>	
<b>Telephone No.</b>	
<b>Email</b>	
<b>Date request submitted</b>	___/___/___

**YOUR REQUEST**

<b>What information do you require?</b>	
<b>Why do you need this information?</b>	
<b>What will you do with this information?</b>	
<b>When do you require this information by?</b>	___/___/___ (Please give an actual date – required by database)
<b>Any other relevant information?</b>	

**Please complete this form and return it to PICANet by email or post.**

**To be completed by PICANet Research Fellow**

<b>Approval date</b>	
<b>Who dealt with request</b>	
<b>Total time spent on request</b>	
<b>Date data/ info provided</b>	
<b>Amount invoiced (if applicable)</b>	

**Policy / procedure for the release of PICANet data**

The PICANet team consists of the following people:

- The Principal Investigator, Research Fellow and clerical officer at the University of Leeds
- The Principal Investigator at the University of Leicester
- The Pan Thames co-ordinator

**Outside the PICANet team:**

Patient identifiable data (family name, first name, date of birth, case note number, NHS number, address) will not be released by PICANet (unless ethical approval is granted, see below). Postcodes may be released under particular circumstances (described below).

PICANet will produce a national report (annually) based upon aggregated data received from all participating paediatric intensive care units (PICUs). Until recently, data within the report presented by NHS Trust used a key, so that individual NHS Trusts could not be identified (although each Trust had their own key to enable them to identify themselves). The most recent report, however, published in May 2006, has identified all units. All PICUs will receive copies of the report. Release of data at any other time will require the following:

- Completion of either the 'Request for information' form or the 'Request to use data for research purposes' form.
- Requests will need to be approved either by the PICANet team or by the Chairs of the Clinical Advisory Group and Steering Group.

Following completion of the form, one of the Principal Investigators of the PICANet team can approve the release of data in the following circumstances:

- For the release to Strategic Health Authorities of data relating to their resident population. The signatory of the declaration on confidentiality and privacy should normally be the Director of Public Health.
- For the release to NHS Trusts of data relating to their own treated patients. *[Note: Release to an NHS Trust of data (anonymised) from other NHS Trusts would require written approval from a lead clinician at these Trusts].*
- For the release of anonymised aggregated national data (e.g. for press releases)
- For the release of anonymised data to the Department of Health.
- For the release of anonymised data to groups such as 'Action for Sick Children'.

It is the responsibility of the Clinical Advisory Group and the Steering Group to ensure that appropriate protocols are in place for access to, and release of, data. They also have a responsibility to consider requests for release of data in terms of ethics, validity of the proposed study and ability of researchers to comply with confidentiality and security requirements. Both groups have links with the Paediatric Intensive Care Society (PICS), in particular the PICS Study Group, to ensure the PICU clinical community are informed of requests for access to, and use of, the dataset.

In some cases, release of patient identifiable data may be possible, e.g. if there is approval for Section 60 Class Support under the Health and Social Care Act 2001 or signed parent / guardian consent has been obtained. This will require completion of an application form and proof of approval from appropriate Research Ethics Committees, in addition to completion of a 'Request to use data for research purposes' form. This includes any research projects that will involve:

- Record linkage of previously unlinked records
- Access to patients' medical records

- Direct approaches to patients or their relatives
- Collection or processing of any data relating to an individual

Release of data by NHS Trust would still require written agreement from each Trust.

### **Public and Media Enquiries**

Confidential data must not be released to answer enquiries from the public or the media. If a phone call is received from a member of the public or the media the following details must be recorded:

- Name of enquirer
- Name of the organisation they represent
- Date and time of call
- Name of person who took the call
- Contact telephone number or address of the enquirer
- Reason for enquiry, nature of the call
- Action taken (usually they would be requested to complete the 'Request for information' form)

Staff must be aware that fraudulent attempts may be made to obtain personal data and under no circumstances must any data or any individual be discussed or disclosed in this manner.

### **Timescale**

- It is anticipated that requests received during normal office hours, Monday – Friday, 9am – 5pm, will receive an email reply the same day, acknowledging receipt of the request.
- Requests for information / data will be prioritised by the research fellows after consultation with the PI's, if necessary.
- Timescales for data requests should be realistic and achievable for all concerned. Short turnaround times for data / information requests are unacceptable and may not be achievable.

### **Costings**

- Any work over and above routine analysis, such as linkage will incur a fee.
- Fees will be based upon the hourly rates of the research fellows.

### Procedure for requests to use data from PICANet for research purposes

To request data for research purposes from PICANet:

- E-mail request to PICANet team via [picanet@leeds.ac.uk](mailto:picanet@leeds.ac.uk).
- If e-mail is not available, then a faxed request should be made to both study centres, numbers below:

Leicester fax number: 0116 252 3272  
Leeds fax number: 0113 343 4877

- All fax transmissions should be clearly marked:  
"FOR THE ATTENTION OF THE PICANet TEAM".
- Requests will only be accepted if the appropriate request form is correctly completed.
- No telephone requests will be accepted.
- The request will be logged on a database held by PICANet in Leeds by the PICANet clerical officer.
- The applicant will receive e-mail / letter confirmation that PICANet has logged their request. The e-mail / letter reply will be sent out by PICANet personnel based in Leeds.
- The timescale by which the information is required should be realistic, to enable the research fellow(s) to respond to the request within their normal working hours.
- An e-mail will be sent to the research fellow(s), asking them to take the lead with the request. On the days when there is clerical support, they will send the e-mail. On the days when there is no clerical support, the research fellow in Leeds will attend to the matter directly.
- The PICANet clerical officer will be informed as to which research fellow (if applicable) is taking the lead with the request.
- The lead research fellow may liaise with their PI for advice and support.
- All requests for data for research purposes will be judged on their scientific merits by the PICANet management team.
- The PICANet Steering Group and Clinical Advisory Group may be involved in decisions regarding the release of data for research purposes.
- The applicant will be informed by the lead research fellow of their success / failure. When successful, they will be given an indication of the timeframe in which they can expect to receive the requested data. If unsuccessful, they will receive a written explanation of the reasons for refusal, and if appropriate, guidance on what relevant data could be released to meet their needs.
- The lead research fellow will inform the PICANet clerical officer of the success or refusal of the request.

- If agreement from other Trusts is required, it will be the responsibility of the applicant to obtain written permission (PICANet will provide an appropriate form for completion).
- Data will then released as appropriate.
- All applications to PICANet for data to be used for research purposes will be published in the PICANet annual report that is distributed to PICUs in the UK.
- The lead research fellow will inform the PICANet clerical officer of the following so that it can be logged in the request database in Leeds:
  1. Whether request was approved or rejected, and reason for approval / rejection.
  2. Date request was approved
  3. Date data was provided
  4. What data was provided
  5. Length of time data extraction took
  6. Length of time data analysis took
  7. Length of time spent presenting the data

### Procedure for requests for information from PICA Net

To request any information from PICA Net:

- E-mail request to PICA Net team via [picanet@leeds.ac.uk](mailto:picanet@leeds.ac.uk).
- If e-mail is not available, then a faxed request should be made to both study centres, numbers below:

Leicester fax number: 0116 252 3272  
Leeds fax number: 0113 343 4877

- All fax transmissions should be clearly marked:  
"URGENT, FOR THE ATTENTION OF THE PICA Net TEAM".
- Requests will only be accepted if the appropriate request form is correctly completed.
- No telephone requests will be accepted.
- The request will be logged on a database held by PICA Net in Leeds by the PICA Net clerical officer.
- The applicant will receive e-mail / letter confirmation that PICA Net has logged their request. On the days that there is clerical support, they will send the e-mail / letter. On the days when there is no clerical support, the research fellow based in Leeds will send the e-mail / letter reply.
- The timescale by which the information is required should be realistic to enable the research fellow(s) to respond to the request within their normal working hours.
- An e-mail will be sent to the research fellow(s) asking for them to take the lead with the request. On the days that there is clerical support, they will send the e-mail. On the days when there is no clerical support, the research fellow based in Leeds will attend to the matter directly.
- The PICA Net clerical officer will be informed as to which research fellow is taking the lead with the request.
- The lead research fellow may liaise with their PI for advice and support.
- All requests for information will be discussed in full by the PICA Net management team.
- The Chairs of the PICA Net Steering Group and Clinical Advisory Group may be involved in decisions regarding the release of information.
- The applicant will be informed by the lead research fellow of their success / failure. When successful, they will be given an indication of the timeframe in which they can expect to receive the requested information. If unsuccessful, they will receive a written explanation of the reasons for refusal, and if appropriate, guidance on what relevant data could be released to meet their needs.
- The lead research fellow will inform the PICA Net clerical officer of the success or refusal of the request.

- If agreement from other Trusts is required, it will be the responsibility of the applicant to obtain written permission (PICANet will provide an appropriate form for completion).
- Information will then released as appropriate.
- All applications to PICANet for information will be published in the PICANet annual report that is distributed to all PICUs in the UK.
- The lead research fellow will inform the PICANet clerical officer of the following, so that it can be logged on the request database in Leeds:
  1. Whether request was approved or rejected, and reason for approval / rejection.
  2. Date request was approved
  3. Date data was provided
  4. What data was provided
  5. Length of time data extraction took
  6. Length of time data analysis took
  7. Length of time spent presenting the data

**1 Current situation**

- 1.1) Data is requested via NHSNet. Interim alternatives are encryption and emailing, or via disk.
- 1.2) Validation reports are sent monthly
- 1.3) PICA Net team members are available to answer questions on clinical coding and other data definitions via email or phone. Ad hoc visits to resolve specific problems can be arranged.

**2 Non-submission of data**

- 2.1) From 1<sup>st</sup> October 2004, all units will be requested to submit data at least once a month (or more frequently if feasible).
- 2.2) They will receive details of how non-compliance is to be addressed (copies of letters) (Letter 1).
- 2.3) Data will only be accepted in the correct format.
- 2.4) Data must be current – it would be expected that the most recent admission would be no more than a month prior to the submission date.

**3 Procedures for dealing with non-submission of data**

- 3.1) Data returns will be monitored on a weekly basis.
- 3.2) Any unit who has not supplied data in the last 42 days (6 weeks) will receive an email and hard copy letter (Letter 2) addressed to the primary contact and lead clinician, requesting data submission or contact with PICA Net, to indicate why data submission has been delayed.
- 3.3) If no data has been received in the following 14 days (2 weeks) a further letter/email (Letter 3) will be sent to the lead clinician/primary contact, indicating that the next step is to contact the hospital's Chief Executive if issues regarding lack of data submission cannot be resolved, to see what they may be able to do to help.
- 3.4) If no data has been received after a further 14 days (2 weeks), then an email/letter (Letter 4) will be sent to the hospital's Chief Executive (copied to the unit and additionally to the Pan Thames Consortium for London units and Health Commission Wales Specialist Services for the Welsh unit).

It is expected that there will be continuous communications between PICA Net and the unit primary contact, and there will be some flexibility with the above procedures if there are genuine reasons for lack of data submission.

**4 Use of NHSNet**

All units are being encouraged to supply their data via NHSNet, and we are hoping that everyone will be able to transfer data via this method by the end of 2004. PICA Net will do whatever they can to facilitate the process, but units should try and identify who, within the IT department, has the authority and technical expertise to enable the necessary modification to the Trust firewalls etc.

## **Paediatric Intensive Care Audit Network**

### ***Freedom of Information Act***

### ***Guidance Information July 2006***

#### **Summary of PICANet's responsibility under the Freedom of Information Act 2000**

##### **1. Policy Statement**

PICANet will use all appropriate and necessary means to ensure that it complies with the provisions of the UK Freedom of Information Act 2000.

##### **2. General Rights of Access**

Section 1 of the Act gives a general right of access from 1<sup>st</sup> January 2005 to recorded information held by PICANet, subject to certain conditions and exemptions contained in the Act (see Appendix a). These provisions are fully retrospective and are not limited purely to British citizens.

##### **3. Received Requests**

All requests to PICANet should be made in writing (received by e-mail, fax or postal service). The applicant should clearly define the following:

- who they are
- what agency they are employed by, if any.
- contact details including telephone numbers and mail addresses
- what it is they want to know
- how they wish to receive the information if the request is accepted

Please note that PICANet cannot ask the applicant why they require the information and what they intend to do with the information. It must be assumed that once provided to the applicant the information is effectively available within the public domain. The Information Commissioner and Lord Chancellor have issued a statement to the effect that the purpose for which information is used is irrelevant.

##### **4. Conditions and Exemptions**

The duty to confirm or deny that information is held is subject to certain conditions and exemptions listed in Appendix (a) of the Act. If information requested is available in any reports that have already been produced by PICANet, the applicant will be advised that the information they require may be available and they will be directed to the relevant report.

##### **5. Charges and Fees**

PICANet will not charge for information that it has chosen to publish in its Annual Reports. Applicants requesting such information will be directed to the reports. There will be a charge for information that is requested that cannot be provided within two and a half working days or for less than the threshold of £450 set out in the Act. It should be noted that the £450 limit equates to 18 person hours of work at £25 per hour, this hourly rate is fixed regardless of the grade of staff. Applicants will be advised in writing (sent by

e-mail or postal service) that a charge will be incurred for the information they have requested and it will be made clear how much this will be.

**EXPLANATION: Any information provided within 2.5 days has to be supplied for free.**

The Act states that a threshold charge of £450 (equating to a delivery time of 2.5 days), below which information must be provided free of charge, is acceptable for all public authorities with the exception of central government and parliament. . As such, PICANet may calculate a cost for providing information above this threshold which takes into account only the costs that PICANet can reasonably expect to incur in relation to the request in: –

- a) determining whether or not it holds the information
- b) locating the information, or a document which may contain the information
- c) retrieving the information, or a document which may contain the information,
- d) extracting the information from a document containing it.

If a request would cost more than the appropriate limit, PICANet are not obliged under Section 1 of the Act to answer it. However, in deciding how to handle a request PICANet must remember its duty under Section 16(1) which requires PICANet to “provide advice and assistance” to persons making requests for information. If a request is particular wide ranging, and therefore likely to be expensive to answer, PICANet should consider discussing this with the applicant to see if the question could be refined to a more manageable level.

If the request is still over the threshold limit PICANet has a number of options:

- 1) It can decide not to provide the information
- 2) It can answer and charge any permitted fee
- 3) It can answer without charging
- 4) It can supply such information as is readily available under the £450/2.5 day/18 person hour threshold.

Section 13 of the Act allows public authorities to charge fees when they choose to reply to a request that they do not have to, because it exceeds the appropriate limit. However, Section 13 does not displace any existing statutory legal power (including court orders), to charge for the disclosure of such information. If a public authority already has a legal power to charge, it can continue to rely on this existing power.

## **6. Time Limits for Compliance**

PICANet will ensure that it complies with the duty to confirm or deny and to provide the information requested within twenty working days of a request in accordance with Section 10 of the Act.

The time limit starts the day **after** the request is received, or the day PICANet receives from the requestor the additional clarification or information it reasonably requires, in order to identify and locate the information requested.

The Information Commissioner recommends the following good practice points:

- To cover periods of absence, it would be advisable for staff to use the automated “out of office” facility for e-mails and to provide alternative contacts.
- Where an alternative contact is provided by an “out of office” message, the contact should advise the original recipient of action taken in respect of the request.
- It would be good practice to acknowledge receipt of requests and to refer to the 20 working day time limit, so applicants know their request is being dealt with.
- It would also be good practice to let applicants know when they might expect a full response.

These points are written into PICANet's 'Policy / procedure for the release of PICANet data' July 2006.

There are circumstances where the time limit of 20 working days may stop. If PICANet is charging a fee (which must be calculated according to the fees regulations), the applicant has a maximum period of 3 months to pay. According to Section 9 of the Act, the 3 months would begin on the day the fees notice is "given" to the applicant.

According to Section 10 of the Act, the period starting with the day the notice is given and ending on the day the payment is received is disregarded from the 20 working day calculation. This means the 20 working day clock would in effect stop the day before the notice is sent and would only re-start the day after the fee was received and the cheque had cleared.

## **7. Means of Providing Information**

When an applicant, on making a request for information, expresses a preference for communication by any particular means PICANet shall so far as reasonably practicable give effect to that preference in accordance to Section 11 of the Act. If the requested medium incurs a cost the applicant will be informed.

## **8. Refusal of Requests**

If PICANet chooses to refuse a request for information under any of the exemptions under Part II of the Act, the applicant shall be informed in writing (by e-mail, fax or postal service) of the reasons for this decision within twenty working days. The applicant shall also be informed of the procedures for making a complaint about the discharge of PICANet under the Act and of the right conferred by Section 50 of the Act.

PICANet will keep a record of instances where estimates of the date for compliance are exceeded, and where this happens more than occasionally, take steps to identify the problem and rectify it.

PICANet will keep a record of all notices issued to refuse requests for information.

Section 41 of the Act is one of many that sets out an exemption from the right to know if the information in question was provided to the public authority (PICANet) in confidence and its disclosure (other than under the Act) could lead to legal action for breach of confidence. More information on the exemptions can be found on the Office of Public Sector Information website: [www.opsi.gov.uk/acts/acts2000/20000036.htm](http://www.opsi.gov.uk/acts/acts2000/20000036.htm)

## **9. Duty to Provide Advice and Assistance**

PICANet will ensure that it will provide all reasonable advice and assistance, to persons who propose to make, or have made, requests for information. This is a duty under Section 16 of the Act.

In many cases, the nature of the advice and assistance to be offered will be clear at the outset. In other cases, communication with the applicant may be required to establish what advice and assistance might be appropriate, and therefore reasonable.

Examples of what is reasonable may include:

- Keeping an applicant advised of progress with regard to their request
- Advising a potential applicant of their rights under the Act
- Assisting an applicant to focus their request, perhaps by advising on the types of information
- Advising an applicant if information is available elsewhere, and explaining how to access this.

## APPENDIX (a) of the Freedom of Information Act 2000

### EXEMPT INFORMATION UNDER PART II OF THE FREEDOM OF INFORMATION ACT 2000

#### There are two types of class exemption:

- (a) **Absolute**, which do not require a test of prejudice or the balance of public interest to be in favour of non-disclosure.
- (b) **Qualified by the public interest test**, which requires the public body to decide whether or not it is in the balance of the public interest to disclose information. The interest in withholding must **outweigh** the interest in disclosure.

With the exception of Section 21 (information available by other means) exemptions apply not only to the communication of information but also to the duty to confirm or deny, if that itself would disclose information that it is reasonable to withhold.

#### The absolute exemptions under the Act are:

- Section 21, Information accessible to applicant by other means
- Section 23, Information supplied by, or relating to, bodies dealing with security matters
- Section 32, Court Records
- Section 34, Parliamentary Privilege
- Section 36, Prejudice to effective conduct of public affairs (so far as relating to information held by the House of Commons or the House of Lords)
- Section 40, Personal Information (where disclosure may contravene the Data Protection Act 1998)
- Section 41, Information provided in confidence
- Section 44, Prohibitions on disclosure

#### The exemptions that are qualified by the public interest test are:

- Section 22, Information intended for future publication
- Section 24, National Security
- Section 26, Defence
- Section 27, International Relations
- Section 28, Relations within the United Kingdom
- Section 29, The Economy
- Section 30, Investigations and proceedings conducted by public authorities
- Section 31, Law Enforcement
- Section 33, Audit Functions
- Section 35, Formulation of Government Policy
- Section 36, Prejudice to effective conduct of public affairs (for all public authorities except the House of Commons and the House of Lords)
- Section 37, Communications with Her Majesty, etc. and honours
- Section 38, Health and Safety
- Section 39, Environmental Information
- Section 42, Legal Professional Privilege
- Section 43, Commercial Interests

## **PICANet Publication Procedures**

Version 1.2 July 2006

### **Preamble**

One of the functions of PICANet is to disseminate information to the clinical and scientific community through publication in peer-reviewed journals. It is the aim of this document to provide clear guidelines on how authorship is determined and how the contribution of all those involved in the collection, validation and analysis of data are acknowledged.

The PICANet dataset has been used to produce summary reports on PIC activity at national and Trust level. In addition, data and information can be supplied on request to individuals and organisations following strict policy guidelines for its release. A number of requests have been made and approval for data given in most (but not all) cases; a list of these is available from PICANet ([www.picanet.org.uk](http://www.picanet.org.uk), email: [picanet@leeds.ac.uk](mailto:picanet@leeds.ac.uk)). Some of these requests may also result in publication in journals and reports.

Note that these procedures only relate to criteria for authorship and not to the approval process for using PICANet data.

### **Author Groups**

Establishing how publications are authored at the outset ensures there are no disputes concerning the ordering of authors and how PICANet is represented. In future, order of authors may be of less relevance if journals ask for a percentage contribution attributable to each author. All authors will be expected to describe their contribution (see 'Criteria for Inclusion' below)

There are 3 distinct potential author groups:

1. Members of the PICANet team, leading analysis that will result in publication in peer-reviewed journals.
2. Collaborations between specific groups or individuals and the PICANet team led by either party.
3. Specific groups or individuals reporting independent analyses of data provided without additional input from PICANet.

The proposed authorship for each group is given below.

There are four separate forms of acknowledgement given below, to deal with the use of national and local data and whether the project was led by or carried out in collaboration with PICANet. The exact form these take will change according to journal style. An example is given at the end of this document.

1 *Members of the PICANet team leading project*

Authorship as follows:

**First author:** Leader of project from PICANet  
**Second author:** EITHER clinical representative nominated by PICS SG or as 'Subsequent authors' below  
**Subsequent authors:** Others who have contributed appropriately (see note below).

This should then be followed by:

'On behalf of the Paediatric Intensive Care Audit Network' with the Acknowledgements **1** (see below). Note that research led by PICANet at a local level would always include a local collaborator.

2 *Collaborations between specific groups or individuals and the PICANet team led by either party.*

If the analysis only concerns data aggregated at National level:

**First author:** Leader of project  
**Second author:** Nominated member of the PICANet team if not leader of project  
**Subsequent authors:** Others who have contributed appropriately (see note below).

If the analysis looks at data at unit/trust level or by geographical area, and local investigators fulfil the criteria for authorship, then they should be recognised as second author if they are happy to participate.

**First author:** Leader of project  
**Second author:** Local investigator  
**Subsequent authors:** Nominated member of the PICANet team and others who have contributed appropriately (see note below).

Acknowledgements **1** or **2** (see below), as appropriate

Nominated members of the PICANet team should fulfil the criteria for authorship and would be expected to have made a significant contribution to the collaborative project.

3 *Specific groups or individuals reporting independent analyses of data provided without additional input from PICANet.*

If the analysis only concerns data aggregated at National level:

**First author:** Leader of project  
**Subsequent authors:** Others who have contributed appropriately (see note below). A request should be made to include a member of the PICANet team to be included as an author if they fulfil the criteria below and it is deemed an appropriate use of their time.

Acknowledgements **3** (see below).

If the analysis looks at data at unit/trust level or geographical area, and local investigators fulfil the criteria for authorship, then they should be recognised as second author.

**First author:** Leader of project  
**Second author:** Local investigator  
**Subsequent authors:** Others who have contributed appropriately (see note below). A request should be made to include a member of the PICANet team to be included as an author, if they fulfil the criteria below and it is deemed an appropriate use of their time.

Acknowledgements 4 (see below).

### **Citation of PICANet**

Any citation of PICANet should refer to the latest report:

Paediatric Intensive Care Audit Network National Report 2004 - 2005 (published May 2006): Universities of Leeds, Leicester and Sheffield. ISBN 0 85316 249 2.

### **Criteria for Inclusion**

**NOTE:** All authors must fulfil the criteria for inclusion as an author, detailed in the International Committee of Medical Journal Editors 'Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication' (Updated February 2006) (<http://www.icmje.org/index.html>, accessed July 11, 2006)

### **Named Authorship**

The notes below summarise the criteria for named authorship.

Any named author on a publication should have contributed to the study in a manner in keeping with the following Vancouver guidelines:

'All persons designated as authors should qualify for authorship, and all those who qualify should be listed. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. One or more authors should take responsibility for the integrity of the work as a whole, from inception to published article.'

### **Authorship Credit**

This should be based only on:

1. Substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;
2. Drafting the article or revising it critically for important intellectual content; and
3. Final approval of the version to be published.

Conditions 1, 2, and 3 must ALL be met. Acquisition of funding, the collection of data, or general supervision of the research group, by themselves, does not justify authorship.

Authors should provide a description of what each contributed, and editors should publish that information. All others who contributed to the work, who are not authors, should be named in the Acknowledgments, and what they did should also be described.

If authorship is attributed to a team or group, all members of that team or group who are named as authors should fully meet the above criteria for authorship. Team or group members who do not meet these criteria should be listed, with their permission, in the Acknowledgments or in an appendix. The order of authorship on the by-line should be a joint decision of the co-authors. Authors should be prepared to explain the order in which authors are listed.

### **Decisions Regarding Authorship**

Before the outset of a project, it is recommended that the named authorship is agreed and is recorded with study documentation. This can act as a point of reference at the publication stage, but can be changed if deemed appropriate, based on work actually carried out during the study.

## **Acknowledgements**

### **Acknowledgements 1 (National data)**

Data provided by PICANet has been released with the approval of the PICANet Clinical Advisory Group and Steering Group with the endorsement of the Paediatric Intensive Care Society (PICS). PICANet is funded by the Department of Health and by Health Commission Wales Specialised Services.

<Other significant contributions that do not warrant authorship>

<List of collaborators>

<Steering Group members>

### **Acknowledgements 2 (Local data)**

Data provided by PICANet has been released with the approval of the PICANet Clinical Advisory Group and Steering Group with the endorsement of the Paediatric Intensive Care Society (PICS) and the local Trust(s)/Unit(s) consultant lead(s). PICANet is funded by the Department of Health and by Health Commission Wales Specialised Services.

<Other significant contributions that do not warrant authorship>

<List of collaborators>

<Steering Group members>

### **Acknowledgements 3 (National data)**

Data provided by PICANet has been released with the approval of the PICANet Clinical Advisory Group and Steering Group with the endorsement of the Paediatric Intensive Care Society (PICS). PICANet is funded by the Department of Health and by Health Commission Wales Specialised Services.

<Other significant contributions that do not warrant authorship>

### **Acknowledgements 4 (Local data)**

Data provided by PICANet has been released with the approval of the PICANet Clinical Advisory Group and Steering Group with the endorsement of the Paediatric Intensive Care Society (PICS) and the local Trust(s)/Unit(s) consultant lead(s). PICANet is funded by the Department of Health and by Health Commission Wales Specialised Services.

<Other significant contributions that do not warrant authorship>

<List of local collaborators if appropriate>

## Sample acknowledgements

### Acknowledgements

We would like to thank all the staff in participating hospitals that have collected data for PICANet. We are grateful to the Paediatric Intensive Care Society for continued support and to the members of the PICANet Steering Group and Clinical Advisory Group listed below. Thanks also to Gill Ryder for assisting with data collection and administration.

List of participating NHS Trusts and hospitals:

List of participating NHS Trusts and hospitals:

Birmingham Children's Hospital NHS Trust: Birmingham Children's Hospital.  
Brighton & Sussex University Hospitals NHS Trust: Royal Alexandra Hospital for Sick Children.  
Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's Hospital  
Cardiff & Vale NHS Trust: University Hospital of Wales.  
Central Manchester & Manchester Children's University Hospitals NHS Trust: Royal Manchester Children's Hospital.  
Great Ormond Street Hospital for Children NHS Trust: Great Ormond Street Hospital for Children.  
Guy's & St. Thomas' NHS Foundation Trust: Evelina Children's Hospital  
Hull & East Yorkshire Hospitals NHS Trust: Hull Royal Infirmary.  
King's College Hospital NHS Trust: King's College Hospital.  
Leeds Teaching Hospitals NHS Trust: Leeds General Infirmary, St. James's University Hospital.  
Newcastle upon Tyne Hospitals NHS Foundation Trust: Newcastle General Hospital, Freeman Hospital, Royal Victoria Infirmary.  
NHS Lothian - University Hospitals Division: Royal Hospital for Sick Children (Edinburgh)  
Nottingham University Hospitals NHS Trust: Queen's Medical Centre  
Oxford Radcliffe Hospitals NHS Trust: The John Radcliffe Hospital.  
Royal Brompton & Harefield NHS Trust: Royal Brompton Hospital.  
Royal Liverpool Children's NHS Trust: Alder Hey Hospital.  
Sheffield Children's NHS Trust: Sheffield Children's Hospital.  
Southampton University Hospitals NHS Trust: Southampton General Hospital.  
South Tees Hospitals NHS Trust: James Cook University Hospital.  
St. George's Healthcare NHS Trust: St. George's Hospital.  
St. Mary's NHS Trust: St. Mary's Hospital.  
The Lewisham Hospital NHS Trust: University Hospital Lewisham.  
United Bristol Healthcare NHS Trust: Bristol Royal Hospital for Children  
University Hospitals of Leicester NHS Trust: Leicester Royal Infirmary, Glenfield Hospital  
University Hospital of North Staffordshire NHS Trust: University Hospital of North Staffordshire

Steering Group members:

Mrs Pamela Barnes, Professor Nick Black (Chair), Mr William Booth, Ms Bev Botting (2002 - Sept 2003), Dr Jean Chapple (2002-2006), Dr Bill Chaudhry (2002 - Sept 2003), Dr Mark Darowski, Mr Noel Durkin, Dr Ian Jenkins (2006 - ), Dr Steve Kerr, Ms Helen Laing (2002-2006), Mr Ian Langfield (2002 - Sept 2003), Dr Michael Marsh, Dr Jillian McFadzean, Dr Roddy McFaul (2002 - Sept 2003), Professor Jon Nicholl (2002-2006), Dr Gale Pearson, Ms Tanya Ralph (2002-2006), Ms Laura Reekie, Dr Kathy Rowan, Mr Stuart Rowe, Ms Dominique Sammut, Dr Jennifer Smith, Dr Charles Stack (2002 - 2006), Professor Stuart Tanner (2002 - 2006), Dr Robert Tasker, Dr Edward Wozniak (2006 - ), Dr Kevin Morris (2006- ).

Clinical Advisory Group members

Dr Paul Baines (2002 - present), Ms Corenna Bowers (2002 - Sept 2004), Dr Peter Davis (2006 - present), Dr Andrew Durward (2002 - present), Ms Georgina Gymer (2005 - 2006), Dr James Fraser (2002 - October 2005), Dr Hilary Klonin (2002 - present), Ms Christine Mackerness (2002 - present), Dr Jillian McFadzean (2005 - present), Ms Victoria McLaughlin, (2002 - present), Dr Roddy O'Donnell (2002 - present), Ms Geralyn Oldham (2002 - present), Dr Gale Pearson (Chair; 2002 - present), Dr Damian Pryor (2002 - Sept 2004), Dr Allan Wardhaugh (Sept 2004 - present), Ms Debbie White (2002 - present), Ms Tina McClelland (2006-present).

**Contributors and sources:** ESD and PAM (and formerly GJP) are principle investigators for PICANet. RCT is a consultant paediatric intensivist and chair of the Paediatric Intensive Care Society Study Group. RCP and KT (and formerly ND, SJ and TC) are co-workers in PICANet. RCP, GJP, PAM and ESD initiated the project. RCP conducted the statistical analysis and wrote the first draft. GJP provided additional statistical advice. Thereafter PAM, RCT, GJP, ESD, ND, KT, SJ and TC critically revised the manuscript. PAM is the guarantor.

**Funding:** PICANet is funded by the Department of Health and by Health Commission Wales Specialised Services. The views expressed are those of the authors.

**Conflict of interest statement**

We declare that we have no conflict of interest

## *Appendix K PICANet policy on PICUs lying outside the control limits of the mortality ration funnel plots*

### **Background – mortality ratios and funnel plots**

PICANet is required by the Department of Health to report on the mortality outcomes of all children admitted for paediatric intensive care. The PICANet Clinical Advisory Group and Steering Group recommended that the mortality outcomes from each PICU be adjusted for the illness severity of the child at admission using Paediatric Index of Mortality (PIM) (Shann et al, 1997). PICANet reports the unadjusted mortality outcome from all PICUs and a mortality ratio based on the ratio of observed mortality in each PICU to the expected mortality calculated using PIM. The 2005 Annual report used the algorithm derived from the recently completed United Kingdom Paediatric Intensive Care Outcome Study. In future years, PIM 2 will be used for risk-adjustment (Shann et al, 2003).

Earlier work published by members of PICANet team (Parry et al, 1998) has highlighted the problems of attempting to rank PICUs on their annual mortality, whether unadjusted or adjusted. PICANet however, has also recognised the need to identify units which appear to have outcomes very different to other units. Consequently, in the 2004 and 2005 reports PICANet published a funnel plot of the observed to expected mortality ratio of individual PICUs. The funnel plots are constructed in such a way that there is an approximately 5% chance of a PICU falling outside the control limits if the distribution of the mortality ratios is random.

The mortality ratio is calculated for each PICU by dividing the expected number of deaths calculated using the published PIM algorithm by the observed number of deaths for each PICU. The mortality ratio is then plotted on the y-axis against the number of admissions to the PICU on the x-axis. In order to satisfy the condition that if the overall distribution of the mortality ratios is random there exists an approximately 5% chance of a PICU falling outside the control limits, then the upper and lower control limits constructed at an individual PICU level must represent not 95% confidence intervals, but 99.9% confidence intervals around a mortality ratio of 1 by number of admissions (Spiegelhalter, 2002). This is analogous to increasing the confidence interval (or significance level) when correcting for multiple comparisons in data containing numerous groups.

### **Data outliers**

- A PICU whose mortality ratio lies outside of these control limits will be identified as having returned data that is markedly different to the other PICUs.
- It is important to note that a PICU lying outside the control limits is not sufficient evidence to suggest a PICU has either markedly higher or markedly lower mortality than the other PICUs, it merely indicates that the data they have returned is different to that of other PICUs.
- For those PICUs that do lie outside the control limits the principals of clinical governance should apply:
  - PICANet will raise the issue with the lead clinician of the PICU and the Trust Chief Executive
  - PICANet will work with the PICU and the Trust, following the plan below until the issue is resolved.

In these circumstances, PICANet will:

- i) Review the data to investigate whether there are data driven reasons for a PICU lying outside of the control limits (it is known that risk-adjustment tools can be unreliable when a PICU has a particularly high proportion of patients at either end of the bounds of the tool.)
- ii) Review the data quality of the PICU. The quality of the data is the PICUs' responsibility. PICANet will provide feedback from PICU visits and central validation procedures. PICUs will be expected to check the quality of individual data items.

- iii) Plot the data quality indicators over time to identify whether the anomaly can be traced to a certain data collection period.
- iv) Plot the mortality ratio over time to identify whether the anomaly can be traced to a certain data collection period.
- v) Plot the observed mortality over time to identify whether the anomaly can be traced to a certain data collection period.
- vi) Plot the expected mortality over time to identify whether the anomaly can be traced to a certain data collection period.
- vii) Investigate the primary reason for admission to the PICU. If the PICU has a markedly high proportion of some primary reason of admission to the PICU compared with other PICUs this may suggest further refinements to the risk-adjustment method are required.
- viii) Produce a brief summary report of the above to be forwarded to the lead clinician and Chief Executive at the PICU concerned together with an invitation to meet in person to review the data with the PICANet team.

Where reference is made to the Chief Executive it is accepted that they may be represented by their clinical governance lead.

**NOTE:** Excess mortality in particular sub-groups of patients or associated with other aspects of service provision may be identified using different statistical methods. The process outlined above will be implemented wherever anomalous results/outliers are identified.

**References:**

Parry GJ, Gould CR, McCabe CJ, Tarnow-Mordi WO. Annual league tables of hospital mortality in neonatal intensive care: A longitudinal study. *BMJ* 1998; 316:1931-1935.

Shann F, Slater A, Pearson G. PIM 2: a revised version of the Paediatric Index of mortality. *Intensive Care Med* 2003; 29:278-285

Shann F, Pearson G, Slater A, Wilkinson K, Paediatric index of mortality (PIM): a mortality prediction model for children in intensive care. *Intensive Care Med* 1997; 23:201-207

Spiegelhalter D. Funnel plots for institutional comparison. *Qual. Saf. Health Care*, Dec 2002; 11: 390-a - 391.

**PICANet November 2005**