



## **1. The purpose of this document**

This document sets out the information governance policies that apply to the provision and use of data supplied by the Paediatric Intensive Care Audit network (PICANet) including the publication and dissemination of analyses in the form of reports and peer-review journal articles.

It also provides guidelines on how authorship is determined and how the contribution of all those involved in the collection, validation and analysis of data are acknowledged.

It supersedes the following documents:

PICANet Publication Procedures Version 1.2 July 2006

Policy / procedure for the release of PICANet data July 2006

Request procedures July 2006

## **2. The PICANet dataset and routine reporting**

PICANet collects demographic and clinical data on all children admitted to designated Paediatric Intensive Care Units (PICUs) in the UK and Eire.

Each admission constitutes an episode, and an individual may have a number of episodes within the database. Episodes may be aggregated by individual PICU or by census/administrative geographies using standard postcode lookup tables (the National Statistics Postcode Directory).

Annual reports are produced that include a large amount data on activity and outcome for contributing PICUs. Individual PICUs also receive calendar and financial year reports detailing activity.

The proposed PICANet Web Access Reporting Tool will provide dynamic access to reports and enable PICUs to query their own data.

### 3. Information governance

Demographic details from Eire are anonymised in accordance with the requirements of the Irish Data Protection Officer. PICANet has permission to collect patient identifiable data under section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001).

#### 1.1 Release of data

Any data released to a third party will be anonymised in accordance with strict policy guidelines [*Centre for Epidemiology and Biostatistics. Security Policies and Procedures, November 2009, University of Leeds*] such that no personally identifiable material will be released in any form and data that produce low cell counts that may result potential identification of individuals will be further aggregated or anonymised.

EXCEPTIONS to this requirement for data to be anonymised are given below:

- i. Researchers who obtain specific ethics permission to do so, may submit patient identifiers to PICANet for linkage on the server. Subject to approval by the PICANet Principle Investigators and independent approval from the PICANet Steering Group Chair, these identifiers will be returned with the associated PICANet data items requested.
- ii. Individual PICU leads may request identifiable data from their own unit for the purposes of local audit and research, or to rectify catastrophic and irreversible destruction of their own local dataset. PICANet recommend that this kind of data request is limited and security procedures (encryption, data transfer methods) should comply with current data protection legislation.
- iii. In some special cases, with appropriate ethics approval, identifiable data may be released to allow data linkage to be carried out either in a third party safe haven or within an organisation that has suitable security and data protection standards to process PICANet data. It is envisaged that such an organisation would be managed by the government or NHS.

In addition, no individual unit or Trust will be identified in a data release to third parties without the express permission of the clinical lead/Trust CEO or their representative.

#### 4. Data/information request procedures

- All data and information requests must be sent to the PICANet team email using the appropriate form. These are available at [www.picanet.org.uk](http://www.picanet.org.uk).
- Data requests should specify what variables are required and include date ranges/calculated fields as necessary. Specific requests are much easier to deal with. The purpose of the data request must be clearly stated.
- Information requests also need to be specific and with a clear purpose for the information stated on the form.
- **All requests for data or information relating to research or clinical trials will be forwarded to the chair of the Paediatric Intensive Care Society Study Group (PICS SG) for consideration and recommendation for approval to allow co-ordination of research in the paediatric intensive care community.**
- Note that information or data requests that require a significant amount of data processing may incur a fee. Charges will be determined according to the level of data processing/analysis required.
- Commercial organisations requesting data or information will be charged for this service. The level of fee will be determined by the complexity of the request in addition to a flat rate charge.
- Data and information requests are logged on receipt and an acknowledgement sent as soon as possible. Further contact will be made by a member of the PICANet team to confirm how long the request will take to complete and to clarify any queries.
- **It should be noted that not all data/information requests can be turned around quickly – this is dependent on the complexity of the request and the workload of the PICANet team.**
- In some circumstances, requests for information or data may be referred to the Chairs of the Clinical Advisory Group or Steering Group for approval. Their decision is final.
- **All individuals or organisations must agree to provide information on the use made the information or data requested. PICANet will actively follow up all requests.**
- **Individuals requesting data or information relating to research or clinical trials may be required to present their results at meetings of the Paediatric Intensive Care Society Study Group.**
- **All individuals or organisations requesting information or data must confirm their agreement to the terms and conditions detailed in this document.**

## 5. Publication using PICANet data: involvement, authorship and acknowledgment

- PICANet has expertise in the manipulation and analysis of the data it collects.
- Where data is requested with a view to publication as research or regional/national reports, it is expected that an appropriate member of the PICANet team should be involved in writing/analysis and interpretation of results. In most circumstances, this would qualify them as an author on any work submitted for publication/circulation.
- 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).
- PICANet has an undertaking with PICS SG to ensure there is a clinical lead on any publication initiated and carried out by the team to ensure we have good clinical support and interpretation.
- ***All research submissions to academic peer-review journals based on or involving PICANet data must be submitted to the Department of Health at least one month prior to publication. This is a contractual obligation and non-negotiable.***

### 1.2 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)**

### 1.3 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.'

### 1.4 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.

**6. Acknowledging the use of PICANet data, funding sources, the contribution of the Steering Group and Clinical Advisory Group members and the contribution of the staff in individual PICUs.**

- A huge amount of good will and hard work supports the operation of PICANet and this, along with the funding sources must be acknowledged in any publication.
- Standard acknowledgments are available from PICANet.
- Where space is at a premium, funding must be acknowledged and other contributions (participating Trusts, Clinical and Steering Group members) can be referenced on the PICANet website.



## **7. Variation to the terms and conditions set out in this document**

The terms and conditions in this document have been agreed by the Principle Investigators of PICANet and the PICANet Steering Group but are subject to change at any time in accordance with changes in UK legislation.