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

The PICANet team consists of the following people:

- The Principal Investigator, Senior Research Fellow, database manager and clerical officer at the University of Leeds
- The Principal Investigator and the Research Nurse 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 last two reports, however, (the most recent published in June 2007) have 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. All requests for national/regional data relating to research are forwarded to the chair of the Paediatric Intensive Care Society Study Group for comment and advice. This ensures that different research groups are not replicating studies and that expertise within the whole PIC community can be exploited.

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 senior research fellow 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 senior research fellow.



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## **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 senior research fellow to respond to the request within their normal working hours.
- An e-mail will be sent to the senior research fellow, 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 senior 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 senior 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 senior 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 senior 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 be 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 senior 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



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## **Procedure for requests for information from PICANet**

To request any information 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:  
"URGENT, 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. 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 senior 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 senior research fellow to respond to the request within their normal working hours.
- An e-mail will be sent to the senior research fellow 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 senior research fellow based in Leeds will attend to the matter directly.
- The PICANet clerical officer will be informed as to which research fellow (when applicable) is taking the lead with the request.

- The senior research fellow may liaise with their PI for advice and support.
- All requests for information will be discussed in full by the PICANet management team.
- The Chairs of the PICANet Steering Group and Clinical Advisory Group may be involved in decisions regarding the release of information.
- The applicant will be informed by the senior 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 senior 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).
- Information will then be 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 senior 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