

Progress

Steering group: meeting scheduled for 23rd May in Sheffield.

Clinical Advisory Group: meeting scheduled for 20th May in Leicester.

IT survey: a questionnaire has been sent out to 34 clinicians in 23 Units and to the heads of IT in 23 trusts asking for information on hardware and software used in PICUs, as well as details of current datasets being collected.

We would like to welcome Nicola Davey to the PICANet team from 29th April 2002. Nicola is joining us from QMC Nottingham where she is currently the PIC retrieval co-ordinator and will take the role of Research Nurse based in Leicester.

Steering Group

The Steering Group will oversee the implementation and management of PICANet. Representatives from the following organisations/areas of expertise have been invited to join the Steering Group and attend its inaugural meeting in Sheffield on 23rd May:

- Statistics / Health Services Research
- Public Health
- ICNARC
- Royal College of Anaesthetists
- Royal College of Paediatrics & Child Health
- Paediatric Intensive Care Society
- Royal College of Nursing
- NHSIA
- Clinical Advisory Group (to be

nominated by the CAG on 20th May)

- ONS (data protection)
- Regional Health Authority
- Department of Health
- Clinical IT specialist

Clinical Advisory Group

The Clinical Advisory group will provide clinical advice and support to both the Steering Group and the management team. We have stratified PICUs into small, medium, large and very large (in respect to their yearly admissions) and a Doctor and Nurse representative from each category have been invited to sit on the Clinical Advisory Group, together with representation from Wales. The clinical advisory group will have its inaugural meeting in Leicester on 20th May.

Included centres

The following units have been identified to us as providing paediatric intensive care in England and Wales. If you think that intensive care is being provided in any other centre not listed please let us know.

- Addenbrooke's (Cambridge)
- Alder Hey (Liverpool)
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- City General Hospital (Stoke)
- Frenchay Hospital (Bristol)
- Great Ormond Street Hospital for Children (London)
- Guy's Hospital (London)
- Hull Royal Infirmary
- King's College Hospital (London)
- Leeds General Infirmary

- University Hospitals of Leicester
- Middlesbrough General Hospital
- Newcastle General Hospital
- Queen's Medical Centre (Nottingham)
- Royal Alexandra Hospital for Sick Children (Brighton)
- Royal Brompton Hospital (London)
- Royal Manchester Children's Hospital
- Sheffield Children's Hospital
- Southampton General Hospital
- St Georges Healthcare NHS Trust (London)
- St Mary's NHS Trust (London)
- The John Radcliffe Hospital (Oxford)
- University Hospital Lewisham (London)
- University Hospital of Wales (Cardiff)

Dataset specification

The full dataset specification will be discussed at the Clinical Advisory Group meeting on the 20th May and their recommendations and comments brought to the Steering Group meeting on 23rd May. An updated draft data collection sheet will be distributed to members of the Clinical Advisory Group prior to their meeting.

If you would like the opportunity to comment on this draft please contact Sam Jones or Roger Parslow (contact details overleaf). We will send you a copy together with an appraisal sheet to be returned to us. Your comments will be forwarded to the Clinical Advisory Group.

IT survey results

We have had 14 replies from 23 units but only 2 from the IT departments of the 23 Trusts (who were surveyed independently).

Thank you to those of you who have responded. It is clear from your replies that there is a significant variation in IT support available to the units:

- Less than half the units who replied have dedicated IT staff, some of whom are data clerks, while others have no support.
- The majority of units who replied have some sort of departmental database system and.....
-these regularly collect data for other research/audit projects, in some cases more than one.
- File backup procedures vary from regularly backed-up servers, to zip drives, floppy drives or none.

We have also received very enthusiastic comments from several units who are keen to incorporate the PICANet dataset into the data they currently collect.

This information is extremely useful to us as we need to devise an IT implementation strategy that accommodates the variation between units and makes best use of existing infrastructure and data collection processes.

We have included another copy of the IT survey form together with a pre-paid envelope. We would be very grateful if you could check whether a response has been sent out from your unit. If not, or if you don't know, please take the time to complete the questions and return the form to us.

Health and Social Care Bill

Elizabeth Draper is currently taking the lead in producing an application for class support under this Bill for BINOCAR (the British Isle Network of Congenital Anomalies Registers) that is to be submitted to the Patient Information Advisory Group (PIAG) in June. This application will form the template for a PICANet application. The Steering Group will decide whether to submit this to the June meeting of the PIAG or to wait for the outcome of the BINOCAR submission and submit to their next meeting in September.

Sir John Pattison has replied to our letter detailing the case for exempting the National Paediatric Intensive Care Audit database from the anonymisation and consent requirements of the Data Protection Act, 1998. In his reply, Sir John has asked for permission for ministers to cite our response to the consultation exercise.

While progress has been slow we are hopeful that our application will be successful. We will keep everyone informed of any progress via the PICANet newsletters.

Circulation List

Currently this newsletter is distributed to those we have identified as lead clinicians in PICUs. If you would like more copies or know of someone who should have a copy mailed directly to them please let

us know. We aim to include anyone who will be involved, directly or indirectly with the PICANet database.

Thank you

Thank you for your ongoing support.

In time we will be visiting all the included units to provide software and training and to discuss issues raised by the data collection process and we look forward to meeting you in person

Contact Info

We now have a team email address: email sent to:

picanet@sheffield.ac.uk

will reach all of us. Our individual contact details are given below:

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...to be advised

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