

**BAPN Audit and Registry Committee Meeting
Southmead Hospital from 11.00am to 4.00pm on 16/10/08**

Attendees

Shazia Adalat (SA), David Ansell (DA), Carol Bosworth (CB), Matthew Brealey (MB), Hilary Doxford (HD), Farida Hussain (FH), Carol Inward (CI), Malcolm Lewis (ML), Manish Sinha (MS) and Charlie Thomson (CT)

Apologies: Dick Trompeter, Moin Saleem

Welcome

Review of previous meeting minutes from 25th June

- CI confirmed that all points of section from previous minutes on 'terms of reference for BAPN Audit and Registry Committee' had been agreed with following previously agreed actions outstanding
 - 1) *ML was yet to confirm date of end of current term so that date for review could be agreed*
 - 2) *MS to check if minutes of previous meeting were on BAPN website*

(1) REGISTRY

Progress of 2007- 8 Paediatric Renal Registry report

- CI reported that data from 5 centres was still outstanding. These were Cardiff, Glasgow Liverpool, Newcastle and Southampton. CI had had assurances from Cardiff, Glasgow, Liverpool and Newcastle that relevant data for the 2007-8 registry report would be submitted before the end of October. Discussions with Southampton were ongoing and hopefully they too will be able to submit their data in time for the report this year.
- The committee agreed that the final date for submission of data from individual centres would be 31st October. If individual centres failed to submit their data before this then the paediatric report would be published without these centres.
- It was pointed out once again by DA and MB that by April 2009 it would be mandatory for all paediatric and adult units to enable electronic data collection as part of the national agenda of the NSF. The committee agreed that for centres that failed to submit data a letter from the BAPN president to the centre would be appropriate.

Actions agreed

CI will e-mail outstanding centres requesting submission of data before deadline

1) Progress on electronic transfer of data (report by individual unit) by CI

Glasgow – already have the PROTON system at present but do not use it to submit data. It is expected this to be in place by April 09. There are fairly advanced plans for a new system to be used in Scotland that would hopefully not affect the registry.

Newcastle – use 'Clinical Vision' version 3. Planning to upgrade to version 4. No progress has so far been made in exploring the possibility to export data from Clinical Vision onto Southmead PROTON. Basic laboratory data is presently transferred.

Leeds - already have the PROTON system at present but do not use it to submit data. It is expected this to be in place by April 09.

Liverpool – planning to use 'Cybernius'. The team does not wish to use PROTON. Overall electronic submission of data needs further discussion. ML suggested that he might be able to submit data for Liverpool from Manchester but the committee agreed that this was not a long-term viable option.

Manchester - PROTON is presently available to ML and has used these to submit data recently. The plans for the future though are for installation of 'Clinical Vision' although probably a newer version 4. As for Newcastle issues around electronic data transfer to the Renal Registry need to be discussed.

Nottingham - PROTON is available but at present only used to transfer laboratory data. There are plans to start using PROTON for submission of other registry related data.

Birmingham - already have the PROTON system and could use it for submission of data to the Renal Registry.

Bristol - already have the PROTON system and could use it for submission of data to the Renal Registry.

GOSH - as per previous discussions there is at present no electronic data transfer. GOSH does not use PROTON and details of its present IT system were not known.

Evelina/Guy's – MS updated with progress of 'EPR' system in use there. MS informed of the likelihood of having the ability to submit registry data sometime next year using EPR.

Cardiff - already have the PROTON system and could use it for submission of data to the Renal Registry.

Southampton - CI informed that Southampton was in the process of adopting new software. Previous discussion suggests that this new system will enable electronic submission of data. PROTON system is in use at Portsmouth with laboratory links between Southampton and Portsmouth. This will allow at least laboratory data collection for Southampton.

Belfast – Colleagues in paediatric unit presently were not being allowed to access software used by adult teams on the same site. Further clarification regarding this was needed.

There were some centres (Nottingham, Bristol, Cardiff) where adult teams were discussing possible new software for their IT needs and it was felt that it would be important for the paediatric teams locally to liaise with the adults.

HD provided a breakdown of money spent from a previously awarded grant to facilitate electronic data collection to the registry. The grant was for £28,200 and so far £10,442 had been spent dealing with software licenses, problems at individual centres and payment for IT time. Approximately £17,750 was still left to utilise.

DA informed that as a general rule it would cost £1,000 per centre plus additional costs for IT time to the Registry to enable individual centres to have access to a PROTON terminal so that electronic data transfer could take place.

Actions agreed

FH to liaise with Dr Trompeter at GOSH requesting for an update regarding in-house software and ability to facilitate electronic transfer of data to the registry

CT to write to Northern Ireland Registry representative for clarification on points raised regarding Belfast above

2) Further discussion around the provision of PROTON and paediatrics specific screens

- MB has created the majority of the 'Paediatric screens' (screens that are specific for the paediatric dataset for the Renal Registry). They will be ready to roll-out to PROTON users in 6 weeks. Separate screens will need to be devised for non-PROTON users in due course.
- They will still need IT linking by Andrew Webb to enable installation locally and ensure transfer of data.
- The cost implications for IT time were equivalent of ½-1 day per site of Andrew's time (approximately) £700-£800 per day. As PROTON is available at Birmingham, Cardiff,

Nottingham and Leeds this is likely to cost £3,200. This spend of £3,200 was agreed by the committee.

- As Glasgow is likely to change its IT systems in the near future it was felt it would not be appropriate to spend money on updating the proton system there.
- It was felt that all PROTON users need instruction manuals to help use the new paediatric data screens.

Actions agreed

HD to investigate likely time scale needed for Andrew to install Paediatric screens at all centres

MB will provide instruction manuals for PROTON users

3) Comparison of data items on ML's registry database with the renal registry database

- The committee spent 2 hours discussing each data item presently included in the paediatric renal registry data set. Each item was examined for its usefulness from a national renal registry report perspective. MB made changes to the dataset during the course of the discussion.
- Several data fields were modified in the paediatric electronic data set with some additions made to the adult registry fields too. The details of this with MB and a copy provided to ML.
- Specific changes were made to category "causes of transplant loss" with additions also made to "renal registry mortality time line list".

Actions agreed

DA will write to British Transplant Society to request addition of donor EBV details to their present dataset

CI to provide definition of "single carer" to allow accurate recording of data

Discussion of outline of chapter for Paediatric component of renal registry for 2007-8

- DA informed that the renal registry is wanting to report all descriptive registry data as per STROBE guidelines published recently in the Lancet and BMJ
- ML and CI briefed that the content of the chapter would be an abbreviated version along the lines of the report from 2006.
- DA suggested a further extension of this report could be a section including comparison with data published in the ERA/EDTA registries.

Action point

HD to send pdf of STROBE guidelines to all committee members

ML to circulate version of chapter to committee members before final submission

HD will send capitation invoices following submission of chapter

(2) Audit

- CI discussed the need for a process to determine priority areas for future audits by this committee. CI reported that at the recent BAPN executive committee meeting, the need for clarity about which group was responsible for determining the BAPNs priorities for audit projects was discussed as both the standards committee and the audit & registry committees had expressed an interest in deciding future projects. It was not possible to resolve this matter as Dr Rees was unable to attend. It was felt this registry subcommittee would establish a consultation process in liaison with the standards & guidelines committee and would be in the best position to determine which projects would be taken forward.

- CI reported that ML had recently found some information on the NIHR website that made it possible to access patient case records as part of national audits without resorting to the need for CRB checks and/or honorary contracts.
- Costs for future audit projects - Possible agencies to help with the cost implications could be HQIP
- CI observed that future audits do not necessarily need to be performed by only by doctors and should be multi professional eg involving audit nurses in the project where appropriate.
- The next BAPN audit is an 'audit of anaemia in transplant patients through dialysis and post transplantation'. Brief review of the guidelines on this subject was provided by SA with a review of published data including data previously published in the Paediatric chapter of the Renal Registry report in 2006.
- An audit proforma sheet for the project was presented and discussed. CI suggested the need to complete an audit proposal form to help formulate audit questions and help from Renal Registry statisticians.
- DA agreed continuing statistical support would be provided from the Renal Registry for this project similar to previous BAPN audit on blood pressure control by MS.
- SA expects to identify renal trainees who will be happy to help with collection of data. If unable to identify, CI to find appropriate individuals to help with data collation.

Action point

*It was decided that CI would send an email to all centres to identify patients with CKD stage 4 (eGFR 30-59) at each centre to allow planning of future projects in this area
SA to formalise audit proposal form, data collection sheets and discussions with Registry statisticians*

Feedback from renal patients meeting by FH. This agenda items was not discussed because of shortage of time. However a summary is attached to the minutes.

The next BAPN registry committee meeting is planned for January'09 but the final date needs to be confirmed