

**BAPN Audit and Registry Committee meeting  
Southmead Hospital, Bristol, from 10am to 3pm on 9/1/09**

**Attendees:**

**David Ansell (DA), Hilary Doxford (HD), Matthew Brealey (MB), Malcolm Lewis (ML), Charlie Tomson (CT), Carol Inward (CI), Shazia Adalat (SA) and Farida Hussain (FH).**

**Apologies:**

**Dr Trompeter, Moin Saleem, Manish Sinha**

**Welcome**

**Review of previous meeting minutes from 16<sup>th</sup> Oct 08'.**

- Progress of 2007-8 Paediatric Renal Registry report
  - ML reported that the data collection for demographic details is complete except for 1 centre.
  - The ongoing patient activity data, however, was not complete, as 3 centres did not provide full datasets.
  
  - CI had liaised with Southampton who will submit the 08' and 09' data together.
  
  - There will be mandatory collection by May 09', all units were informed of this at the recent BAPN AGM, however the penalties for units not providing data are not yet clear. A 'name & shame' policy is thought to be the most effective at present.
  
- Progress on electronic transfer of data (DA & CI)
  - Glasgow** – in advanced stages of implementing a new system. Need to ensure that it contains the paediatric dataset. CI has previously written to Heather Maxwell about this, but as she is now off on maternity leave need to remind other consultants.
  - Leeds** – no change.
  - Nottingham** – no change
  - Birmingham** – no change
  - Bristol** – no change
  - Liverpool** – the transition to 'Cybernius' is likely to take a couple of years, therefore need to discuss with them what their plans for electronic submission prior to this are.
  - Manchester** – likely to move over to Clinical Vision when they move to the new hospital in June. To continue with PROTON until then.
  - GOSH** – still no method of electronic data transfer at present. Their nearest adult renal unit (Royal Free) is unlikely to have a system in place until much later this year. Therefore need to discuss the options of either becoming a satellite unit of Bristol, or continuing with paper returns for this year.

**Evelina/Guy's** – no change from last meeting, therefore likely to continue with paper returns for this year. Should be given the option of using the adult PROTON system or becoming a Bristol satellite also.

**Cardiff** – they have agreed to move over to a new system. Need to ensure correct paediatric dataset is installed on this.

**Southampton** – new system hopefully in place for 2009. Need to liaise with consultants to ensure data return by some means this year.

**Belfast** – ongoing problems, with paediatricians not having access to software used by adult teams. A quote was obtained for creating paediatric dataset, but was unreasonably large. Unfortunately, Northern Ireland is not part of the area covered by statement mandating returns from May 09'.

It was agreed that in order to make progress, a letter should be written to the Chief Medical Officer, backed by CI, CT, and the presidents of both the RA and BAPN explaining the situation and need for a solution.

*Actions agreed*

*CI – to write to David Hughes (Glasgow) regarding the need for the addition of paediatric screens to the new system.*

- to write to Liverpool, GOSH and Southampton to ask how they intend to return data for this year.*
- To draft letter to Chief Medical Officer re: Belfast*

*SA – to liaise with Manish Sinha / Chris Reid to discuss the preferred option on returns for Evelina.*

*DA – to liaise with Andy Webb re: paediatric datasets on new systems in Cardiff and Glasgow*

## **Consent**

- HD reported that so far only 3 centres (Bristol, Glasgow & Birmingham) have sent consent forms back to her.
- Concern that the originals are being sent – so will photocopy them and send originals back to the units for records.
- Unsure as to how complete the returns are – so to check numbers against numbers of patients from those centres on the registry list.
- It was noted that the patients name is not on the document anywhere, if a carer signs the form on their behalf, therefore future forms will need to be altered for this.
- It was discussed that as soon as electronic transfer of data occurs, individual consent will not be needed, but presumed consent with an opt-out option given. Posters explaining this should be placed in each of those centres, and forms for opting out available. These were both reviewed by all at the meeting and felt to be appropriate for a paediatric population without needing any changes.

*Actions agreed*

*HD – to photocopy originals that are sent to her, and return originals to units*

*To post out forms and posters to those units using PROTON.*

*To compare numbers sent back vs. numbers from these centres on the registry*

*CI to write covering letter for packs (poster & forms)*

*To chase other units for consent returns*

**Registry**

- Census date –

Previously this has been 1<sup>st</sup> April, whereas adult data is collected by calendar year. Agreement that we should move to this also. It was agreed that this year we should set a deadline of returns for 30/6/09 for returns for last 8 months of 2008, and to then switch to 31<sup>st</sup> Dec thereafter.

*Action*

*CI to write to units informing them of this change and the deadline of 30<sup>th</sup> June for this year.*

- Progress on implementation of electronic data returns

MB stated he has forwarded the agreed paediatric screens to Andy Webb, but is waiting to hear back about timing of implementation of these. Concerns raised about time-pressure on Andy, especially given new Healthcare Commission projects being set-up and the priority that these have to be given.

Suggestion that for those units using PROTON (Birmingham, Nottingham & Leeds), MB may be able to go to each individual unit to set these screens up. Given the complexity of the task and the need to work with live systems, this process may take up to 3 days at each centre. The funding to be provided from the paediatric budget held at the registry.

Newcastle – the CCL link to registry does not provide complete data, so they will either need to request to add paediatric data items to their system, or to revert to paper returns or to become a Bristol satellite unit, and use PROTON system to fill in missing data.

Glasgow, Liverpool, Belfast, London – to continue with paper returns for now

- Comparison of data items

DA stated that this was almost complete.

- Process for data validation  
DA stated that a point of contact for each centre would be required so that missing data can be retrieved.

Concern that at present adult and paediatric patients combined, so would need a way of separating out paediatric patients. Suggestion and agreement by the group of adding site of prescription of dialysis or transplantation so as to identify paediatric patients.

Would also need to provide a set of validation rules for each item (e.g standard deviation values for height, weight, BP etc.etc.) to allow the registry to identify patients who fall outside these values and require verification of values sent.

*Action*

*DA to add treatment centre data item to screens in units where adult & paediatric renal patients are co-located.*

- Paediatric analyses for 2009 and timings  
Data from 1/4/08 to 31/12/08 to be collected by 30/6/09  
To specify analyses within the next 3 months  
Analysis results returned to authors by September

BAPN database to be downloaded to the UKRR to allow UKRR statisticians to undertake analyses this year

*Action ML DA*

Suggestions for analyses:

Demography and cause of renal failure in patients aged 16 -20 (ML)

Look at patients diagnosed with renal failure in childhood who are now in their 20's & 30's, to see where they are now (ML)

Under 4 yr old population (CI)

Basic demography (DA)

Biochem values e.g Hb, PTH & phosphate control etc. (DA)

*Action: agree topics & provide specifications for analyses (BAPN A&R Committee Members)*

- Communication  
It was communicated at the meeting by CT and DA that the Healthcare Commission has mandated national audit projects that include paediatric patients. The current one is a vascular access audit. All units are due to receive information, although this was not found to be the case amongst the units represented at the meeting to date. GOSH have volunteered themselves as an early adopter to complete this information (? On behalf of all

paediatric units). There was some concern that GOSH had not communicated with all UK units with regards to this yet.

A future project is intended to look at all CKD 4/5 patients

*Action*

*CI to liaise with HQIP to ensure effective communication with paediatric units for any future projects*

**Audit**

- Anaemia audit proposal (SA)

The detailed proposal was reviewed and the following suggestions agreed:

In order to decide on which standards to audit against, SA to liaise with the standards and guidelines group.

Within the Aims and objectives (page 5) – to delete ‘and explore the causes for this’ in point 3. To omit point 5, as this is implied within point 4.

Funding – It was suggested that the Health Quality improvement Partnership (HQIP) may provide some funding. It was also agreed that if pharmaceutical companies were to be approached, then both those providing i.v iron and EPO should be approached, rather than favouring one above the other.

Stats – SA to liaise with ML to obtain rough numbers of patients, to enable discussions with statisticians to start.

MB may be able to help with extraction of a lot of the lab data required

It was agreed that we should consider including those long-term dialysis patients who have not been transplanted, within the analysis. To look at values 6 months prior to dialysis and 3 monthly thereafter for these patients?.

SA will contact units to confirm PTH units, and she will perform the conversion if necessary to ng/L.

Mairead Condery (SPR based in Glasgow) will be helping SA with the data collection, particularly in the northern units.

*Actions agreed*

*CI to write to HQIP re:possibility for funding*

*SA to liaise with ML (re:numbers)and MB (re:extraction of lab data)*

*SA to make amendments to aims and objectives as discussed*

*SA to liaise with standards and guidelines group*

- Renal biopsy audit  
FH announced that the final draft of the biopsy paper had been sent to Pediatric Nephrology that day.

It was suggested that a re-audit should be planned and started as soon as possible.

*Action agreed*

*FH to liaise with local SpR /colleagues re: re-audit*

**Next meeting.**

It was agreed the next meeting will be in 3 months.

Dates to be circulated by CI. CT suggested a doodle survey to decide.

It was also agreed that dates for the remaining meetings for this year should be decided