

BAPN Audit and Registry Committee Meeting

Learning & Research Building, South mead Hospital, Bristol

Meeting on the 16th July 2010

Attendees:

Carol Inward (CI), Malcolm Lewis (ML), Manish Sinha (MS), Matthew Brealey (MB), Damian Fogarty (DF), David Ansell (DA),

Attended 1st part of meeting (am): Sue Shaw (SS), Dirk van Schalkwyk (DvS), Hilary Doxford (HD)

Apologies: Farida Hussain (FH), Helen Jones (HJ), Claire Castledine (CC), Fiona B (FB)

1. Minutes from previous meeting

The following information in the 'Paediatric Project Mandate' section should be included in the previous minutes and agreed for minor amendment:

1. Paediatric project mandate: Planning to keep all data initially in a 'holding table (database)'. This 'holding database will initially i) allow merger of all previous years BAPN data (transferred from ML) and UKRR data (for registry reports 2008 and 2009); ii) The data needs evaluation for any missing key data variables; iii) 'cleaning and sorting' with assignment of unique ID to ensure data not already available before iv) request from centres for missing data. Once completed the 'holding database' will be merged with the UKRR database.
2. Current year (2009) data returns were discussed. All centres have now submitted data.
 - o Electronic returns: all proton users-Birmingham, Bristol, Cardiff, Nottingham, GOSH and Leeds.
 - o Non proton users- Manchester submitted recently; Southampton have also sent a file and that is being looked through at the moment.
 - o Paper based returns: remaining centres and they have all submitted

Action Point:

- *To aim towards having analyses of paediatric data including completeness of returns ready for presentation to the AGM of the BAPN in December 2010.*

- *Timelines for 'holding database' not formalized today but SS re-assured work is ongoing.*

Agenda for meeting on 16th July

Paediatric Project Mandate

- CI expressed concern that as phrased currently “Data will be capable of extraction by the Paediatric Renal Centres...” needs rephrasing as not all paediatric centres have an electronic system to submit data to the UKRR currently. It was agreed that this should be rephrased to include “Centres that currently have paper based return centres will make active steps to move towards electronic return.”
- To ensure electronic returns from all centres MB asked “what is stopping the paper centres from using Malcolm’s database system?” This move though was considered to have a net retrograde effect on the current drive to assist individual centre IT departments to facilitate electronic returns. It would probably also not help with current registry plans for more frequent reporting.
- The current situation in adult nephrology where all centres now submit RR data electronically has resulted from a mix of drivers including improving physician realization that it improves clinical effectiveness but also centres wanting to ensure that they comply with national guidelines by submission of data to UKRR.
- Discussion around electronic submission from the Evelina Children’s Hospital. Two possible methods (i) satellite proton user and downloading intermittently of labs or (ii) Link with adult renal at Guy’s by putting all paediatric subjects in that file. MS felt the latter was more difficult given his previous discussions at GSTT.
- DF suggested emailing all current paper based centres 1-month prior to each meeting of the Paediatric Registry sub-committee meeting for an update of their IT system. CI informed the meeting that she has already been doing this informally. DF also highlighted the contents of the recent Government White paper regarding this issue that has highlighted the need for more ‘information’ to inform patients and policy . We should continue to engage with and encourage all centres to set up electronic registry reporting as soon as possible.
- Further, brief discussion regarding all current paper based centres.
 - Newcastle: **Clinical Vision** (CCL) no update
 - Liverpool: **Cybernius** no change from previous state
 - Cardiff and Glasgow: **Vitalpulse** system (as is Birmingham Children’s Hospital by end of 2010 and Leeds). It was noted that If the implementation is successful in BCH this would assist implementation in the other paediatric units.

- Belfast: DF reported that discussions have been continuing regarding access to the Adult renal IT system (**Mediqal**) for use by the paediatric nephrologists. The outstanding issue is to identify funds for the system to be adapted and progress is being made. It is likely that electronic system will be in place before the end of the year.
- Budget: need to change the wording in the mandate from current statement as the paediatric capitation fees from the ERF population are not going to cover the costs. It was pointed out that by making all returns electronic the costs would be reduced further.
- ML inquired about plans within the UKRR to expand reporting of patients to pre-dialysis CKD 5 as this would increase paediatric patient numbers. It was agreed that this would be an aim in the future once electronic returns for children receiving RRT was universal.

Action Point:

1. To make suggested changes to the Paediatric Project Mandate (SS)

2. MB and MS to test after re-establishing of the Proton links again. MB to perform site visit to train up local team at ECH to work with Proton.

2. Finances

Update provided by HD.

i) Overspent by -£1800 from projected costings. Nottingham had not paid capitation fees in 2006 but has paid all since. CI suggested checking the billing address for that year. BCH, Glasgow, Belfast not paid 2009 capitation fees as yet but it was noted that the contact list for invoices needed updating.

ii) Have £2800 left from the original DoH grant. Monies from previous update have been spent appropriately on setting up of electronic returns from various centres so far.

iii) CI commented that so far there has been no income to the account from donations/grants but funds are being sought..

iv) Budget as presented passed and HD thought she did not have any concerns.

3. National renal dataset

i) IC Database: DA informed the meeting of ongoing discussion to set up a national database (IC database) for an analysis to be performed funded by the 'NHS Kidney Care'. The data to be provided for the IC data by linking three existing databases (NHS-BT; UKRR and HES)

ii) Hospital Episode Statistics (HES) Database: The HES analysis from the 'HES database' is designed to look at the burden of in-patient and out-patient visits to the hospital for kidney patients.

iii) UKRR and HES database study together: Project with the Research and Capability Programme (RCP) to perform a 'one-off' linkage to merge the data together from these two databases. The analysis for a detailed project looking to analyse the data (currently adult only). If paediatric patients are to be included this will need ethical approval and funding. Current timelines are (a) ethical approval not through for the one off linkage before Sep 2010; (b) database management to be in place by October 2010.

4. KKR research funding for Paediatric RR project looking at long term outcomes in young adults with childhood onset of ERF.

Recent application for monies to KKR/KRUK was successful in the preliminary 'expression of interest' round. This has been invited to submit a full application for 1-year costing. UKRR will support this application.

Audit projects and updates:

1. Vascular access audit SS discussed if paediatric patients are to be included in this access audit (only haemodialysis patients). The committee are aware that GOSH is contributing to the pilot project but felt there was little benefit in performing a nationwide study following discussion around the audit objectives.

2. Hypertension audit: One manuscript submitted to peer reviewed journal in June 2010. Another related manuscript is due for submission in Aug 2010. MS will update the 'recommendations from the hypertension audit' document and email to CI for presentation at the BAPN Guidelines, Standards and Guidelines committees.

3. Anaemia audit: Shazia is currently organising site visits. Funding is currently being reviewed in an application to 'NHS Kidney Care'.

4. Infant dialysis: Funding for the audit secured from 'NHS Kidney Care'.

5. Report on the longitudinal trends of BMI following renal transplantation in the UK Accepted for oral poster presentation at IPNA, New York 2010.

- BAPN Audit for 2011 looking at growth in RRT or CKD stage 4/5 paediatric patients. Details of the audit to be decided by members of the Paediatric sub-committee.
- Brief discussion regarding dissemination and publications from the Paediatric UKRR. The consensus was that the improving output from the Audit and Registry sub-committee will likely address the current perception that the Registry reports are not

widely read or referenced. This will in turn improve the impact of the Paediatric Renal Registry.

- Young Adult Patients 16-25 year olds. Work to allocate unique identifiers will allow this work to move forward.

Action Points:

i) Both the 'Anaemia audit' and the 'infant dialysis' audit results will aim to present data at the AGM of the BAPN towards the end of the year.

ii) MS to email CI revised version of the recommendations from Hypertension audit' document.

iii) This year we plan to report 'completeness of data' so that we are able to report key projects that aim to report next year.

iv) CI to lead on an executive report from the registry aimed as a short report for publication in peer reviewed journal. This could be in the format of an 'editorial' summarizing the registry's work over the past 3 years and the exciting projects over the coming years; also to highlight the difficulties/barriers encountered in reaching current state as this will improve the readers understanding of the dataset from RR.

Important future dates:

1. Renal Patient View meeting on the 7th of September, Manchester
2. RR annual audit day on the 30th of September, Birmingham
3. Next meeting of the Paediatric RR Sub-committee to be decided