

**BAPN Audit and Registry Committee Meeting
South mead Hospital Bristol from 11 am to 3 pm on the 5th October**

Minutes of Renal Registry Meeting 5 October 2009

Attendees:

Shazia Adalat (SA), Matthew Brealey (MB), Hilary Doxford (HD), Farida Hussain (FH), Carol Inward (CI), Malcolm Lewis (ML), Manish Sinha (MS), Charlie Tomson (CT), Dirk vS (DvS) Sue Shaw (SS) Chris Maggs (CM)

Attended part of meeting: Moin Saleem (MSa).

Apologies: David Ansell (DA)

Welcome

Review of previous meeting minutes from the 10th June 09

1. Previous Paediatric Registry data and returns for 2008
 - CI reported that all previous Paediatric renal registry data had been transferred from Manchester to the Renal Registry at Bristol now.
 - This year a number of centres had transferred the 2008 data electronically to Manchester. A few centre's had made paper submissions to Manchester following which all data had been entered on the electronic data base are per previous years by ML before being transferred down to the Renal Registry at Bristol.
2. CI reported that the work on coding and definitions remained out standing from the previous minutes.

Action Point: CI to complete the coding and definition related work.

Congratulations on behalf of the BAPN Audit & Registry Committee

CI extended congratulations to Charlie Tomson for his recent appointment as the Chair of the Renal Association (RA) and to Damian Fogarty for his appointment as the Chair of the Renal Registry.

Finance and Paediatric Renal Registry

- HD presented the 2009 budget for the paediatric registry. The 2009 budget was tabled with projected costing's based on annual income from previous years. Additionally a draft budget plan for 2010– 2014 was also presented. The projected budget plans were estimates based on completed time sheets from previous years. In summary the projected 2009 budget suggested spending of £22,350 with a surplus of just over £8,800.00 at the end of 2009.
- The projected annual budget for 2010-2014 ranged from spends from between £28,000 to £29,900. This would lead to deficits in the Paediatric Renal Registry budget of £8,000 to £12,000 per year.
- CT informed us that at a recent meeting of the Registry Management of the Renal Association it had been agreed that the Renal Association would subsidise the

Paediatric Renal Registry. The RA would continue to subsidise the funding of the Paediatric dataset as it was recognized that the capitation fee raised as a result of the smaller number of Paediatric patients would fall short of the required sum.

- CT also reminded the meeting that the Paediatric Registry has approximately £12,000 available from a previous Department of Health grant. These funds are available to facilitate IT infrastructures support for Paediatric Renal Units.
- *Action Point* HD to meet with CI re finances

Progress report on Management of data from existing BAPN data bases presented by MB, ML & DS.

- DS highlighted gaps in the recently transferred data set that is being used to prepare the 2008 Paediatric registry report. Important missing data included information such as ‘*start dates of renal replacement therapy*’ that would make it difficult to perform survival analysis of patients who have end stage renal failure. It was felt that this would probably be better once electronic submission was done by all the centres.
- CT suggested that some of these missing data points could be found by interrogating the existing Renal Registry database by looking for subjects who have had a pre-emptive transplant for example.
- It was also highlighted that patients who had RRT (dialysis or transplantation) for less than 90 days within a reported year were unlikely to be captured in the present dataset.
- To facilitate tracking of patients who sometimes move between paediatric renal units for example between Southampton and Evelina or Cardiff and Bristol it was felt that NHS number for all patients should be used as a unique identifier in future submissions. This would also help in tracking these patients as they transfer to adult services.
- CT suggested that there was a recent national recommendation to report individual renal unit participation in electronic collection of data by means of “league tables”. He pointed out that such reporting would help in improving quality of registry returns but also provide support to colleagues who have been participating actively in renal registry data collections in the past.
- *Action Point* CI to remind units of importance of new NHS number prior to 2009 census. Strategies to retrieve missing data to be discussed at next meeting.

Progress report on data analysis from 31st December 2008 census and managing this data

- The writing of the 12th Report from the paediatric registry.

HD informed us that the renal registry was looking at a 4-week turnaround as the **deadline for the completed chapter is the 16th November**. The authors for the various sections of the chapter are i) introduction on methods: CI ii) demographics: MAL and iii) report on laboratory results: FH. The Renal Registry have nominated Dr Claire Castledine, Research Registrar who would act as ‘point of contact’ to facilitate this process.

Visit to GOSH on the 1st October by DA and CI

CI reported that CI and DA had travelled to GOSH and met relevant managers including those from IT Department along with colleague Dr Steve Marks, Consultant Paediatric Nephrologist at GOSH.

- It has been agreed that a single screen of PROTON will be made available for data entry by one user before the end of November 09.
- We will not have any electronic “lab links” at the moment.
- HD will send posters and information leaflets regarding the Renal Registry for patients and families to be displayed at the renal unit at GOSH.

Plans for managing paper returns until the remaining renal units have an electronic system in place

- As of October 09 the following centres are going to make electronic submissions: Glasgow (their data is sent via the Scottish Renal Registry), Leeds, Nottingham, Birmingham, Bristol, Manchester, Evelina and Cardiff. GOSH will have electronic links before the end of the year. Electronic test files are awaited from Newcastle and Southampton. Paper based returns will continue from Liverpool and Belfast.
- There was discussion within the committee on how electronic information being sent in and out of the renal registry is made via secure links. CI requested HD for details of previously agreed guidelines from the Renal Registry.
- ML suggested setting up an Excel based electronic system to help with data entry for units that have no electronic system as yet and are likely to continue with paper based systems.
- There was further discussion around the need for a unique identifier for paediatric patients. Presently all patients within the renal registry have a unique identifier but this does not identify them as paediatrics or adults. It was felt having a unique Paediatric Renal Registry identifier would help in future reports that wish to report on survival analyses of paediatric end stage renal failure patients.
- *Action Point* HD & colleagues at UKRR to advise re security of electronic data being sent to & from UKRR.

Paediatric research registrar at Renal Registry presented by MSa

- Similar to adult leagues it was felt that the creation of a paediatric research registrar post at the Renal Registry would help in developing expertise in epidemiology within UK Paediatric Nephrology. MSa reported that a recent application for funding such a post had failed although the application had received very supportive comments following peer review. It was felt that an ideal candidate for this post would be somebody in the middle of their training.
- Presently, research registrars for the adult subjects of the Renal Registry have so far been getting their salaries from on-call commitments at Southmead Hospital, Bristol. This is likely to change in the near future with the adult registry also having to make bids for 3-year fellowships for up to £250,000.
- *Action Point* MSa & CI to discuss options for funding a paediatric research registrar to be based at UKRR with BAPN executive

Location of paediatric registry data within UKRR

- MB raised the question regarding the merging of the database as yet this has not been done.
- *Action Point* DA & MB to establish permanent location for paediatric data.

Audit Committee Meeting

1. Results of National Audit on transport for haemodialysis patients presented by FH

- The audit reported differences between adult and paediatric patients CI to write a couple of lines regarding this and circulate within the BAPN.
- CI commented that it was frustrating not to have individual unit data as this information was likely to be more useful and powerful for negotiating change at individual unit level. CT offered to enquire if individual units data could be obtained.
- The important findings from the audit include
 - i) Families should not have to pay for transport for dialysis. For paediatric patients this was less than the national average but still present in approx 10 % of patients
 - ii) Strategy to have an alternative escort for every dialysis patient if the designated escort became unavailable suddenly
 - iii) Units will need to discuss improvements needed to transport arrangements with commissioners.CT suggested writing to Beverly Matthews in NHS Kidney Care to request for help with negotiation if difficulties arise.

Action Point:

CT to enquire if individual unit data from the transport unit could be available.
CI to circulate findings of transport audit amongst BAPN colleagues and
CI to write to Beverley Matthews in NHS Kidney Care.

2. Renal Biopsy Audit

CI extended congratulations to FH and colleagues for publishing the renal biopsy audit and National report on the Paediatric Registry recently in Nephrology Dialysis and Transplantation 2009.

Action Point CI to take recommendations for adopting new standards to BAPN standards & guidelines committee meeting.

3. Recommendations from hypertension audit presented by MS.

- These were discussed in detail with draft version of recommendations tabled. It was planned that a final version would be submitted via this Audit Committee to the 'Standards and Guidelines committee of the BAPN'.

- ML suggested a web-based calculator for calculation of height and blood pressure z-scores to improve management of hypertension. It was suggested that this calculator could be placed on the BAPN website and be readily available to BAPN members.

Action Point:

ML to contact Leah Krischock regarding web-based calculator on the BAPN website

4. Update on anaemia audit covering Jan' 03 to Dec'07 presented by SA.

- Over the period there are 1400 subjects who could potentially be included in the audit. As this cohort would be too large to consider collecting data from, it was felt that a subset analysis could be selected to make the audit feasible.
- SA has recently sent out Excel sheets with patient details to individual Paediatric renal units requesting for laboratory data that could be retrieved electronically. These had been sent out in early September with a 6 week time period for responses until end of October.
- CI informed that honorary contracts would be needed for each centre.
- Funding application to HQIP has been unsuccessful this year. Funding for the project would therefore be discussed with interested pharmaceutical companies.

Action Points:

MS to email CI with details of previous point of contact at each centre.

MS to approach pharmaceutical companies for monies to fund the project.

5. Discussion around plans for next audit on dialysis therapy in infants and neonates.

The details of this project have been forwarded to Helen Jones, paediatric nephrology trainee at Evelina Children's Hospital. We are awaiting proposal details from Helen regarding the audit presently.

Action Points CI to ask for an update prior to next meeting