BAPN Audit and Registry Committee Meeting Minutes 15 May 2012

Learning and Research Building, Southmead Hospital, Bristol BS10 5NB

Attendees:

Carol Inward (CI) – Chair, consultant paediatric nephrologist, Bristol Children’s Hospital
Ron Cullen (RC) - Chair UKRR
Sue Shaw (SS) - Project manager, Registry
Hilary Doxford (HD) - Renal registry Business manager
Matthew Brealey (MB) - Analysis / programmer
Manish Sinha (MS) – consultant paediatric nephrologist, Evelina Hospital
Heather Maxwell (HM) – consultant paediatric nephrologist, Glasgow Children’s Hospital
Rishi Pruthi (RP) – SpR registry
David Bull (DB) - Systems manager, registry
Anna Casula (AC) – Statistician registry
Fiona Braddon (FB) - Clinical informatics registry
Catherine O’Brien (COB) – consultant paediatric nephrologist, Birmingham Children’s Hospital
Catriona Shaw (CS) – SpR registry
Yinents Tse (YT) – consultant paediatric nephrologist, Newcastle Children’s Hospital
Malcolm Lewis (ML) – consultant paediatric nephrologist, Manchester Children’s Hospital

Apologies: Damian Fogarty

1. Minutes of previous meeting 18 January 2012 agreed, discussed, and action points reviewed.
   The meeting agreed these were an accurate reflection of discussions
   o No consent forms have been received for the 2 units submitting paper returns (Liverpool and Belfast).
   HM to clarify
   o 2011 data submission

   Anticipate Liverpool will submit paper returns, Belfast may submit electronically  CI to clarify

   CI has informed all units that data needs to be submitted by end June 2012 and requested each unit establishes a secure means of electronic communication eg nhs.net account.

2. Data submission to the European paediatric registry.

   A request for this data to be submitted by the end of May has been made. A more complete data set than was sent last year has been collated and AC confirmed that this will be submitted by 31 May. The possibility of sending more complete data from previous years was also discussed AC
3. Review of process of data extraction and validation 2010 data – learning points for 2011?

We discussed the document produced by David Bull (DB will e mail to group). The numerous difficulties were discussed. It was felt that problems for 2010 data submission included:

- Communication issues - need clarity of the routes of communication i.e. a nominated person from each centre to submit the data and an appropriate contact person from the registry. MS and DB will have further discussions regarding enhancing the communication pathway and clarifying responsibilities. CI highlighted that it was essential that secure electronic means of communication ie nhs. e mail account be set up in each unit. This process is ongoing.

- Urgent need for an agreed data set for 2013 data. FB will email ML the current data set for comment. It will then be forwarded to this registry group for review. The proposed data set will then be placed on the BAPN website with a 1 month deadline for comments from the BAPN. The final data set will be agreed at our next registry meeting in July. This will be forwarded to each unit, the software data extraction companies and will be available on the BAPN website. It was highlighted that extraction routines were critical to this process. As 2012 data is already being received it was felt unrealistic to try to use the new data set for 2012. As well as the new data set each unit will receive from the registry details of exactly how the data needs to be presented.

DB, FB, ML, all

4. Progress with paediatric reports of 2010 data

RP updated the meeting with current progress. The demography data is thought to be more accurate this year. The first version of the demography chapter has been drafted and will be sent to CI week beginning 28 May. There has been a new analysis of late referral rates (children over 3 months of age who have not been seen by paediatric nephrologist within 3 months of starting RRT. There is data over a 15 year period 1996 – 2010 with breakdown that included ethnicity, centre and disease. It was agreed that this data should be published as a separate article rather than being integrated with in the registry report.

The biochemistry data is in progress. There are many more parameters within this year report and also more missing data, particularly from Newcastle, Southampton and Liverpool. There are problems with data from GOS, results without names. It is hoped the first draft of the biochemistry chapter will be ready to be forwarded to HM by 22 May.

5. Proposals for analysis of 2011 data

New analysis to be considered included a young adult report, survival data and pre-emptive transplantation. AC requested that as much notice as possible be given for the figures and tables that will be required.
6. Registry projects

BP audit: MS was congratulated on the publication of this audit.

Anaemia audit: Maraid and Shazia continue to work on this project. They have collected data from all but 1 of the 5 or 6 units.

Infant dialysis audit: Helen and Jo have submitted abstracts to ESPN and have 2 oral presentations at the Renal Association meeting. They have sent data to AC. It was agreed that this was an important cohort group to continue to follow up.

Renal biopsy audit: this project is ongoing with data from all units currently being collected.

A registrar from Birmingham met with CI to discuss potential projects. CI suggested the late referral data may be a suitable subject.

Potential future projects might be an audit of peritonitis, renal bone disease and growth.

7. BKPA Tony Wing Fellow post.

BKPA are considering funding a paediatric registry fellow post to work alongside the adult renal registry fellows. Academic supervision would be via the University of Bristol with clinical supervision from CI.

8. Registry fees

Still some outstanding payments:

2010 Southampton

2011 Birmingham, Manchester, Nottingham, Southampton

9. Chair of paediatric renal registry

Carol Inward was warmly congratulated by all for her huge contribution to the paediatric renal registry and all that have been achieved whilst she has been chair. Manish Sinha was welcomed as the new chair of the committee.

10. Date for next meeting

July date. MS will doodle.

Catherine O’Brien 23.5.2012