

BAPN Audit and Registry Committee Meeting
UK Transplant, Fox Den Road, Bristol BS34 8RR

Meeting on the 25th May 2011

Attendees:

Claire Castledine (CC), Fiona Braddon (FB), Matthew Brierley (MB), Carol Inward (CI), Dirk van Schalkwyk (DvS), Sue Shaw (SS), Manish Sinha (MS)

Apologies: Terry Feest (TF), Hilary Doxford (HD), Damian Fogarty (DF), Malcolm Lewis (ML), Heather Maxwell (HM), Catherine O'Brien (CB), Yincen Tse (YT), JJ Kim (JJ)

1. Minutes from previous meeting in Jan 11 and action points were reviewed. The meeting agreed that they were a true reflection of discussions.

Action points from that meeting:

(i) To set up a meeting with nurse specialist and clinical team at GOSH to help with electronic data returns:

CI visited GOSH and had a fruitful meeting with colleagues. She noted that 'personnel change' over the past few months has led to a delay in the data returns for 2010 but that they are now almost ready for submission.

(ii) MB will help with extracting timelines for all patients from units who have submitted electronic data returns to the RR
Action MB

The meeting had an in-depth discussion regarding paediatric data currently being held in different databases within the UK Renal Registry (e.g. filemaker database from MAL, registry database with FB, paper based returns awaiting entry in to electronic databases and SAS databases with DvS). It was observed that the UKRR plans to map all these various databases initially into a single 'Filemaker programme' and subsequently be transferred into the main UKRR database. 'Mapping' of these data has been planned for some time and some progress has been made. FB estimated that the complete amalgamation of these databases would take about 3-weeks and a formal plan needs to be made imminently to ensure this important task is completed as part of previously agreed project planning.

(iii) MB and FB will help to populate all timelines and static demographics' for Evelina_London and GOSH_London before data entry for 2010 is commenced. Action MB FB

This is work in progress and at the meeting further plans were made to complete this.

(iv) Evelina_London to discuss with Cormac Breen about how adult GSTT subjects returns are currently submitted Not made any progress with this. Action MS

(v) MB plans to investigate further into why timelines are not coming up from units doing electronic returning
Action **MB**

The meeting discussed this in some detail along with 'Action Point' (ii) above. The meeting agreed that there was an urgent need to complete the 'mapping exercise' described above. As there are several hundred patients within the Paediatric cohort it was decided that we should initially focus efforts on completing the mapping exercise for the current 'prevalent' cohort of ERF patients. We defined this 'Current cohort' including all ERF patients who are currently being treated in Paediatric Nephrology units in the UK. Once this is completed we will identify cohort of patients in 5-year time intervals starting from the most recent 5-year period and work our way backwards to complete data mapping. This would mean initially completing mapping of the 'current cohort' followed by 2009-2005, then 2000-2004 and finally 1995-1999.

(vi) To finalise paediatric dataset at future meetings of the Paediatric RR

This needs to be done as a matter of priority. Action FB CI

(vii) finalise details regarding administration of BKPA grant (CI, HD and TF)

This has now been finalised

(viii) CI to chase outstanding data returns for 2010 with individual units

This was done with details discussed later

(ix) RR will perform an internal review to ensure there is no data extraction issue Action SS

As discussed earlier this remains to be done and clearly needs to be performed urgently.

(x) CI to email other unit leads for suggestions regarding future national audits

To be done Action CI

Further agenda items discussed at the meeting

2. Registry:

i). Timescale for completion of paediatric chapters discussed by CC, DvS, CI and MS

- The paediatric demography chapter is progressing well.

The issue of re-categorising of diagnoses of all ERF patients was discussed. It was agreed that there was a need to discuss the mapping of diagnostic groups from 'Filemaker' format to the new EDTA diagnostic codes. Action DF TF CI

- The 'labs chapter' would follow on once the demography chapter was finalised with MAL as lead author.

2. Timescales for publication 13th report (discussed by all)

- Data issues to be completed by Dirk over the next couple of days with an aim to put a draft version of the demographic chapter for the RA-BRS meeting.
- To finalise biochemistry chapter by the 17th of June. The UKKRR had aimed to submit all chapters (adult and paediatric) before the end of June

3. Specifications of paediatric data set

- Sue Shaw, Terry Feest, Fiona Braddon and David Bull are due to meet up soon clean up the paediatric data that is currently held in various databases and agree method of transfer data to UKRR database.
- Long discussion regarding need to progress with above such that these are in place before extraction of data for the registry report for 2010.

4. Timescales for extraction 2010 data (MB, FB) and data validation process for 2010 data (FB). There was an in-depth discussion regarding these issues at the meeting. Points discussed included:

- Checking of all data entered as a two step process i) combine PROTON and Filemaker lists for all patients at each centre and post these out to each centre to confirm that these patients are at that centre and ii) Once this was confirmed by each centre Matthew B to check that data has been entered for the agreed patient lists.
- Following timelines were agreed upon: to complete point i) by the end of June and look for missing data point ii) before the end of July 2011
- Discussion regarding the timelines and 'transfer out' information when sending data electronically as it currently does not allow specifying which unit they have been transferred out.

5. Analyses for 14th report (MS CI)

- The demography and labs chapter would be reported in a similar format to the 13th report. The increasing electronic data returns and data checks and mapping as discussed previously were likely to improve the data richness.
- Young adults dataset – discussion about how to make this happen
 - a. data validation as discussed in point 4 previously
 - b. include over 18 patients with childhood onset ERF
 - c. need for formalising statistical support for this project especially as Dirk is now retiring
- Other topics discussed: Project looking at dialysis efficacy in children

6. Review of individual centres plans across the UK for electronic data return.

It was estimated that there have been about 150 paper based returns from 2010. Data returns for 2011 from various centres were discussed.

- a. **Cardiff** has now moved to Vitapulse from PROTON and we need to identify what systems are in place to have data returns for next year. **Birmingham** and **Glasgow** are also likely to move to Vitapulse in 2011
- b. PROTON centres are: **Bristol, Nottingham, ECH, GOSH** and **Leeds**
- c. **Belfast** expected to submit **via Mediqal**
- d. Filemaker programme: **Manchester** & also **Liverpool** in 2011
- e. **Southampton** on bespoke electronic platform
- f. Clinical Vision – Newcastle & possibly also Manchester in 2011.

Need to establish extraction routines for paediatric data from centres using Clinical Vision, Mediqal & Vitaldata urgently as soon as paediatric dataset is agreed Action SS.

7. Data for EDTA-ERA registry – ML, FB

Karlijn from the EDTA-ERA registry has contacted the UKRR for 2009 data. Spreadsheet to be sent once paediatric demography chapter has been finalised

8. Audit:

Hypertension: Two reports have been submitted to NDT in March/April 2011 and awaiting peer review. CJASN declined the reports after 5-months of editorial review.

Management of hypertension guidelines in paediatric renal transplant patients have been submitted to the BAPN Guidelines and Standards Committee.

Anaemia: Shazia visiting some centres; no recent update

Infant dialysis: Helen Jones and Jo Clothier are working through this and have made significant progress.

Re-audit of renal biopsy: Wesley Hayes due to commence this prospectively over next 6-months

9. Audit of CKD in Children – allocation of tasks to be discussed in more detail at the next meeting.

10. AOB: Date for next meeting to be confirmed