Minutes of BAPN Audit & Registry Committee Meeting

10:30am – 3:30pm 29th May 2014

Venue: Learning & Research building, Southmead Hospital, Bristol

Attendees:
Fiona Braddon (infomatics RR)
Sharece Charles (Renal Registry – admin)
Hilary Doxford (Manager, Renal Registry)
Carol Inward (Member, Bristol)
Heather Maxwell (Member, Glasgow)
Vincent Tse (Member, Newcastle)
Manish Sinha (Chair, Evelina)

Apologies:
Anna Casula (Registry statistician)
Fergus Caskey
Ron Cullen
Malcolm Lewis (Member, Manchester)
Shaun Mannings (infomatics RR)
Catherine O’Brien (Member, Birmingham)
Rishi Pruthi (Renal Registrar)
Jelena Stojanovic (Trainee representative)

Ref | Action | Who
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1.0 | Meeting agreed that the timelines for 2014 Registry returns will be 31st Jan 2015 - Incidence & prevalence data from each centre 30th April 2015 - All data returns in from centres 30th May 2015 - Date before all centres should verify data and return to UKRR Month of July onwards - Analysis and write up of chapters | ALL

2.0 | FB and MS on behalf of the Registry will send email reminders in December 2014 to all centres. This will be followed by a reminder mid-January email regarding closing date 31/1/15 | FB/MS

3.0 | The meeting agreed that the reminder mid-January email in January will include a ‘benchmarking’ element informing centres that have already submitted and those that have not. | ALL

4.0 | FB to update list of IT contacts and Registry lead contacts at each centre and circulate to meeting. FB will email MS with the changes to further versions of new adult dataset v3.3 | FB

5.0 | FB to design data collection form and send out to all Paediatric units for minimum data set for CKD stages 3-5 patients. | FB

6.0 | MS to inform BAPN regarding plans for data collection for pre-dialysis CKD stages. | MS

7.0 | MS to discuss merger of databases with AH | MS

8.0 | Discussion around final height in adults with childhood onset ERF - FB to run query on adults in the RR database to check in how many is this available | FB

9.0 | FB to request NHSBT for data on immunosuppression on induction | FB

10.0 | Request AC to produce completeness for all paediatric data items especially ferritin, IV iron and haemoglobin | AC

11.0 | MS to email all units for their normal range of bicarbonate values | MS

12.0 | MS to liaise with RP and update regarding the changes discussed at the meeting | MS

13.0 | MS to contact Helen J regarding dialysis audit report | MS

14.0 | MS to contact Rishi regarding the Late presenter report | MS
Previous Meeting Minutes & Review of Action Points

1. Update regarding activities following meeting at Bristol in October 2013
   i. teleconference early December regarding second chapter
   ii. meeting with Shaun at Bristol – merger with adult dataset of new paediatric dataset
   iii. AKI audit meeting 24.2.14
   iv. Changes to 2nd chapter of the Paediatric Annual report (meeting in London 8/5/14)
2. It was agreed that the final version of Registry Report Paediatric chapters would be sent to sub-committee chair (MS) as a word document so that changes could be tracked and returned to Hilary within 1-week; ‘pdf’ versions of proofs would also be sent to chair but will have 24-48 hour turnaround deadline.
3. An update of the AKI national audit was provided by MS – 6 centres participating (3 DGH and 3 teaching hospitals); sub-set of notes (n=30) at each centre to be reviewed.
4. Alexander Hamilton appointed as Tony Wing Fellow (March 2014) - commencing August 2014; inform BAPN of appointment via eNews

Data returns for 2013– FB, MS
- Timelines agreed previously: (i) Each centre should inform RR of incident and prevalent patient details by 31/1/13; (ii) RR data to be submitted by 28/4/13; (iii) Data returned for checking to individual centres by 1/8/13; and (iv) analysis and publication of report all before end of 2013
- There were significant delays this year with (i) & (ii) above being achieved by only 50% of centres and this has delayed (iii) but plans for (iv) remain on track.
- A significant this year has been that nearly 2/3rds of Paediatric Nephrology units moved to new IT platforms this has resulted in delays extracting data from old platforms – although this should not affect task (i) above.
- At least three PROTON based units (Birmingham, Nottingham and Bristol) have had difficulty in extracting their RR data this year. This was because some PROTON centres previously had informal and ad-hoc support from the RR to help with data extraction from their PROTON systems. Following recent changes in RR staff this capability has now become unavailable.
- MS informed the meeting that although there were differences between individual centres regarding issues highlighted above, as regards Data returns to the RR, this has not been possible from these 3 centres – the specific issue being of collected data not being extractable locally.
- MS informed the meeting that he has helped facilitate negotiations to allow data returns to happen in time for inclusion in this year’s annual report.
- Individual units have had to negotiate contracts at additional costs to help with data extraction. MS informed the meeting that this has been difficult for local teams and unit registry and clinical leads have expressed their frustration regarding this situation. MS expressed his thanks to registry and clinical leads at these centres for their understanding and help.
- The meeting agreed that if the data was not returned in time from outstanding centres then the Annual report would not include their data.
- Returns from Manchester were delayed and only received today.
- FB visited centres to facilitate electronic data returns. Centres visited included Belfast, Cardiff, Liverpool and Southampton. MS thanked FB for all her efforts with data collection.
- The meeting thought that data returns for 2014 cohort are likely to be easier now that the majority of centres have moved to new IT systems.

Review of individual Unit IT systems and annual Registry returns for 2013 and 2014
Bristol – PROTON – issues around extraction of 2013 data; similar issues in 2014
Belfast – Mediqua – data obtained by visiting locally; 2014 likely similar scenario in 2014
Birmingham – PROTON→ moved to VitalData – 2014 returns using this
Cardiff – moved to VitalData – FB informed meeting 2014 paediatric data issues now been resolved
Evelina – excel based – MS informed meeting returns using bioinformatic support in 2013; Ongoing discussions to facilitate RR specific data collection and extraction using iSoft EPR and local resources.
Glasgow → VitalData for future returns

| 15.0 | CI to contact Shazia for update regarding anaemia audit | CI |
| 16.0 | MS to email worklist from ERA-EDTA to sib-committee | MS |
GOSH → VitalData for future returns
Liverpool – Filemaker based returns in 2013 and likely in 2014. Cybernius - new IT system
Leeds – PROTON → moved to VitalData – 2014 returns using this
Manchester - CV5 – ML previously informed meeting collecting data on both CV5 and Filemaker
Nottingham – Proton 2013 → eMed→ 2014 returns using this
Newcastle – CV5 - problem with extraction routine in 2013; YT monitoring data issues locally
Southampton – bespoke IT system → 2013 data return complete and no issues likely in future

Discussion about New paediatric dataset v10, new adult dataset v3.3 and how to introduce it
i. Previously agreed that ‘New Paediatric dataset v10’ will be introduced when new IT systems are set up and running. The timelines for implementation of these new IT systems have not been agreed.
ii. The items of the ‘New Paediatric dataset v10’ have been integrated in the new adult dataset v3.3. The final version of the adult dataset is being discussed, currently awaiting some items from the dialysis sub-group.
iii. The meeting was informed that it was likely that the new adult dataset would be available across centres in the UK over the next 2-3 years with different centres adopting the new dataset at different time points dependent on local/IT factors.
iv. The New Paediatric Dataset v10 items have been adopted at the following Paediatric centres - Birmingham, Cardiff, ELCH, Glasgow, GOSH, Leeds, Manchester, Nottingham, Newcastle and Southampton. It is likely that data returns for the cohort of 2013 onwards will include these data.
v. In the interim period, until new datasets become universally available, Paediatric centres will continue to collect RR data annually using their current systems. Plans for a New Filemaker version of the New Paediatric Dataset have been cancelled as this is not needed anymore.
vi. FB informed meeting that it would be helpful for the RR to know about CKD stages 3-5 patients and this is part of planned new adult dataset. A brief set of data will help improve data collection regarding presentation and outcome evaluation of ERF patients eventually.
vii. The meeting also discussed merger of the Paediatric and Adult Registry database. The meeting agreed that as this has not happened as yet it would be ideal for Alexander Hamilton to lead this project. This would be in keeping with his fellowship objectives.
viii. The merger of both databases is also an objective of the Renal Data Warehouse project.

Tony Wing Fellowship Post – CI, MS
• Alexander Hamilton appointed as Tony Wing Fellow (March 2014)- commencing August 2014
• Project will involve the medical, social, psychological and educational issues in young adults with childhood/teenage onset CKD. Work with renal registry
• Alex will work as member of the Audit & Registry sub-committee and take over as the first author of the annual report chapters from Rishi Pruthi

Changes to 2013 report – MS
MS summarised the outcome of the discussions so far – teleconference in December 2013 and data meeting (AC, RP and MS) in May 2014
• Anthropometry – meeting discussed it would be interesting to investigate this further in the annual report; last years inclusions and exclusions to be kept; the meeting reviewed longitudinal growth analyses prepared by AC and RP but were unable to comment on it in detail. Overall, would be helpful to have growth analysed along recent ERA-EDTA report investigating final height in children with ERF – including age at start of ERF, final height and steroid (yes/no)
• Anaemia - the meeting felt no new changes except review data completion for ferritin and IV iron; do we have any data regarding blood transfusion and await report of the anaemia audit
• Bicarbonate – need to display data as ‘below and within range of bicarbonate as per individual centre reference values’
• Cardiovascular risk factors – a summary of the report was tabled for discussion - the meeting agreed to show as sub-section cross-section CV risk factors by age, gender, ethnicity and modality
Future projects were also discussed in brief. It was felt that these would be of interest to the BAPN including:

- Graft outcome post-transplantation based on longitudinal eGFR changes over time
- Growth in ERF patients
- Detailed analyses of causes of death in children with ERF over a 3-year period
- An audit of children on Peritoneal dialysis

**Audits**

(i) Updates regarding renal biopsy re-audit – MS
- Preliminary data was presented at the 2013 BAPN Winter meeting – final report nearly ready for submission. Lead author Meeta Malik at Nottingham

(ii) Retrospective audit of AKI in children – MS
- A retrospective audit lead David Milford at Birmingham on behalf of BAPN
- 6 centres participating (3 DGH and 3 teaching hospitals); sub-set of notes (n=30) at each centre to be reviewed.
- Audit to be performed via A&R sub-committee – proforma and plan agreed at AKI audit group meeting on the 24/02/14. MS will keep committee updated with progress.
- Trainee lead Jelena Stojanovic will review case notes along with two other trainees

(iii) Discussion around outstanding project reports
1. Infant dialysis report - MS informed this is still awaited from Helen Jones who is currently away on maternity leave.
   - Meeting expressed concern that reports were delayed and that similar reports likely to be published from other cohorts will reduce its novelty
   - Important to publish these in time to show the sponsors of timely completion of projects

2. Late presenters report – MS, CI - no new update although all statistical analyses has been completed
3. Anaemia audit report – CI – not heard anything recently from Shazia; concern around timelines

Once again it was agreed that in future that the A&R committee would define the roles, responsibilities and publication strategy before commencing with project.

**ERA-EDTA related matters - MS**

(i) Several high quality publications coming through and list of planned publications to be emailed later by MS (previously tabled in October 2013) – A&R committee to agree/propose UK authors
(ii) The meeting discussed possibilities of linking part of Tony Wing fellowship work with ERA-EDTA

**AOB** - none

**Dates of next meeting**

Planned August 2014 but postponed to Tuesday 9th Sep, Monday 22nd Sep, Thursday 25th September

November meeting: Thursday 6th Nov, Tuesday 11th Nov or Friday 14th November