BAPN Audit & Registry Committee Meeting  
10:00 - 15:00 18 June 2015  
Winford Room, Brunel Building, Southmead Hospital, Bristol BS10 5NB

Attendees:  
Fiona Braddon (UKRR, Clinical Informatics Manager)  
Anna Casula (UKRR, Senior Statistician)  
Ron Cullen (UKRR, Chief Executive)  
Alex Hamilton (UKRR, Tony Wing Registrar)  
Carol Inward (Member, Bristol Children’s Hospital)  
Malcolm Lewis (Member, Royal Manchester Children’s Hospital)  
Tamara Mallett (Member, Bristol Children’s Hospital)  
Manish Sinha (Chair, Evelina London Children’s Hospital)  
Yincent Tse (Member, Royal Victoria Infirmary)

Apologies:  
Hilary Doxford (UKRR, Head of Business Development & Support)  
Shaun Mannings (UKRR, Clinical Informatics Assistant)  
Heather Maxwell (Member, Royal Hospital for Sick Children, Glasgow) – unable to join as no teleconferencing facilities

List of action points:  
1. To discuss with colleagues at Birmingham regarding ‘planned’ delay in providing data extract to the UKRR; also to discuss with Cardiff and Belfast – Manish (DONE)  
2. To write Framework for Contract for Registry Returns – Manish, Alex and Ron to prepare initial draft  
3. To prepare lists of recent 5-year patients with missing comorbidity and disability data – to be circulated to each centre and request for updating - Alex  
4. To prepare document regarding diagnostic codes and request for comments/feedback as in 2.2 below - Alex  
5. To email Alex previous list of PRO’s as published in other Registry reports – Manish (DONE)  
6. To compile list of diagnoses which are not currently codeable with plans to highlight this to the ERA-EDTA coding group – Alex and Manish  
7. Discuss possible change to capitation fees with BAPN Exec. – Manish (DONE)  
8. To discuss with RIGB regarding proposed changes to capitation fee structure following discussion at BAPN Exec - Manish and Ron (DONE)  
9. Inform the BAPN Exec with the Access audit plans and timelines – Manish (DONE)  
10. To finalise online Access audit details and inform A&R sub-committee – Yincent and Malcolm  
11. To present an outline of “Growth in RRT patients” project for discussion next meeting - Heather

Registry: Agenda Topics  
1. Data returns for 2014  
1.1 Progress on 2014 data returns – FB, AH  
   o Awaiting full data from 3 centres – Belfast, Birmingham and Cardiff.  
   o Belfast – continuing issues with difficulties in change to electronic systems. In the future we hope that the template for Nottingham written by Mediqal could be adapted. Two thirds of patients will also need updating manually to complete.  
   o Cardiff – No paediatric specific screens on Vitaldata probably because there is no specific funding. Some data will be possible from adult extract.  
   o Birmingham – RR informed that Vitaldata will not do extract until August, as separate from adult hospital extract. Issue is with supplier. Have asked IT Renal Manager to discuss with Vitaldata.  

Action Point: Manish to discuss with Catherine to ensure she is aware of ‘planned’ delay in providing data.
1.2 Discussion around planned framework for Contract for Registry Returns
   - Contract must be accessible for everyone to read. Document to highlight best practice, from the Registry to all the Units to offer help and provide support locally as well as making it clear that it is mandatory. Important that it takes them through the steps of what is expected. Specify what the Registry is, the obligations and the role of the Registry.
   **Action Point:** Manish, Alex and Ron to prepare document.

1.3 Discussion around process – All
   - Discussed issues with data if not received by deadline. A strategy discussed included to analyse data end of June to identify what is missing.
   **Action Point:** Manish to talk to Birmingham clinicians to make them aware of extraction date problem, and also to Cardiff and Belfast.

2. Data quality improvement projects
   2.1 Send tables of comorbidity and disability to centres for checking
      - Currently data returns do not differentiate between ‘blank’ entries as missing data or no comorbidity and disability. Plan to send request to centres for missing data (focused on previous 5-years). Further discussions if this data should be included in Annual Report or be reported as stand-alone data.
   **Action Point:** Alex to circulate request sheets to group.

   2.2 Issue around PRDs with no new ERA-EDTA codes
      - The meeting discussed the issue of too many codes for the same diagnosis but also that some diagnosis do not have a code. Alex had prepared a summary of impact of different coding methods on patient groupings (e.g. mapped adult diagnosis to paeds EDTA codes). This would loose relevant detail from current paediatric reports.
   **Action Points:** (i) Alex to circulate list for comments/feedback. (ii) Manish, to email Alex previous list of PRD’s as published in other Registry reports; (iii) To compile list of diagnoses which are not currently codeable with plans to highlight this to the ERA-EDTA coding group.

   2.3 Transition and transfer
      - Alex not heard back from Rachel Gair (who is taking over new role in UKRR) and who is taking over doing survey in units regarding this.
      - Need to improve reporting from database on age at transfer to adult renal services. Clarification of definition of ‘transfer out’ date needed. Francis report shows transfer date should be when primary responsibility for patient moves to adult nephrologist. Plan to add definition to Annual Report in the future.

3. 2014 report summary of changes and discussion – AH
   - The meeting was informed regarding planned changes to the chapters – key were to include data regarding 16-18 year olds and to display quarterly data. The discussion in the Demography report too will be improved.

4. Merger of adult and Paediatric RR dataset – FB & AH
   - Aim is to get quarterly paeds data in “gold standard” - this will facilitate data upload to adult registry. Excellent progress has been made. When new ADULT dataset is in, there will be a place to put paediatric data.
   - The meeting also discussed data on transplantation in children less than 5 years old. It was decided that we would aim to publish a short report separately initially.

5. Discussion around Paediatric UKRR day - All
BAPN AGM is early December. Discussed possible dates and agreed that spring 2016, when returns are due, would appear to be best time. IT colleagues at each centre would be key attendees. It was decided a team including - 1 consultant, 1 trainee and 1 IT representative from each centre would ideally be invited.

6. Capitation fees
- The meeting discussed at length the ongoing issues relating to delayed returns despite timelines being advertised in advance with subsequent reminders. The meeting discussed possible changes to capitation fees with one standard band and one “support” band, which would cost for additional support from registry. Specifically, this extra cost would be applied for retrieval of data (and not for collection of data). It was likely that this would result in doubling the standard fee for such centres – thus 40 instead of 20 pounds per patient. Any changes to the current arrangements would need to go to RIGB.

Action Point: (i) Manish to discuss this issue at the BAPN Exec meeting 19 June; and (ii) Ron to discuss this with RIGB following feedback from BAPN Exec.

7. ERA-EDTA related matters – MS
- Data has been submitted for last year. No update since December 2014. Are working through their list, and will contact the relevant person for each topic.
- The meeting also discussed the limited input in ESPN/ERA-EDTA Registry output the UK has despite submitting substantial data (nearly 1/5th of current ESPN/ERA-EDTA Registry).

8. Terms in office – MS
- Next year in 2016 MS to step down as chair and to continue as member for next 3 years in Carol’s current role. Malcolm will stay as permanent member of the A&R sub-committee. Catherine O’Brien has now stepped down; Carol Inward will step down after last meeting in November 2015, Yincent and Heather will be step down in 2016.
- There will be election for chair and for 2-3 new members over the next 12 months - this will be staggered/timed to ensure smooth transition of work.

9. Audits for 2015
9.1 AKI national audit update – MS
- 3 teaching hospitals and 3 district general centres. Data has been collected electronically from 5 of 6, and case note reviews from 4 of 6. Abstract for ESPN accepted as oral. Hoping to wrap up by later this year. Manish is assisting David Milford, lead for this project with plans for a formal write up subsequently.

9.2 Audit on dialysis access and complications – finalise
- Discussed dialysis access document sent out by Yincent. Need proforma of how data will be collected. Yincent and Malcolm to help set up secure website for data entry. Agreed to collect data for 1 year. All patients in a unit to start on same date, with new patients added in when commence chronic dialysis. Data to be collected monthly. Yincent and Malcolm to discuss further and update sub-committee.

Action Point: Manish to inform the BAPN Exec with the audit plans and timelines.

10. Update regarding ongoing projects – MS
1. Updates renal biopsy re-audit report – MS
   - Completed and submitted in April.
2. Late presenters report – MS
   - Preparing final manuscript. This is also the basis for a new project for Paediatric Renal trainee Lucy Plumb.
3. Infant dialysis report
   - Presented 2 years ago. Carol, Heather, Malcolm and Manish to set time aside to write up.
4. Anaemia audit report
   - Identified someone to work on this (Caroline Platt) – lots of analysis has been performed and now needs to be written up. Early findings highlight current lack of consistency regarding approach to anaemia management.
5  Analysis of patients starting RRT in paediatric centres at age <16 years, between 1995 and 2013 – TM
   o Tamara presented update to group. Analysis has been performed on 19 years data including nearly 2000 patients. It had been accepted for oral and poster presentation at ESPN. Plan to submit brief report to Archives. Will prepare presentation and report to include 2014 data.

6  Headlines from Young Adult Demography Report – AH
   o Alex presented preliminary results to group. Have looked at incident patients between 1999 and 2008, and split into 4 age groups. Data on just over 3000 patients. Less than 1% are still in paediatrics. Currently looking at discordant data items. Once the extract has been refined, full data will be pulled and analysed to report on this high risk group. The meeting discussed if this should be presented at the 2015 BAPN AGM.

11. Proposals for future projects and audits
   o Graft outcome post-transplantation based on longitudinal eGFR changes – previously agreed by RR
   o Analyses of causes of death in children with ERF over a 3-year period – to be discussed
   o Growth in ERF - planned
   *Action point: HM to present an outline of this project for discussion next meeting*

12. Dates for next meeting
   o Post meeting note – next meeting confirmed – Monday 30 November 10:30 to 14:30 – Seminar Room 16, L&R Building, Southmead Hospital, Bristol.

13. AOB: The meeting also discussed the following
   o Key achievements for 2014 were Alex starting, annual data returns went paperless and new paediatric data set got merged with young adult data set.
   o Key tasks for 2015 are to do 2 presentations and complete 2 publications.