BAPN Audit & Registry Committee Meeting
10:00 - 15:00 19th Mar 2015
Seminar room 2, Learning & Research building, Southmead Hospital, Bristol BS10 5NB

Attendees:
Manish Sinha (Chair, Evelina Children’s Hospital)
Fiona Braddon (UKRR, Clinical Informatics Manager)
Carol Inward (Member, Bristol Children’s Hospital)
Vincent Tse (Member, Royal Victoria Infirmary)
Anna Casula (UKRR, Senior Statistician)
Alex Hamilton (UKRR, Tony Wing Registrar)
Heather Maxwell (Member, Royal Hospital for Sick Children, Glasgow)

Apologies:
Catherine O’Brien (Member, Birmingham Children’s Hospital)
Ron Cullen (UKRR, Director)
Hilary Doxford (UKRR, Head of Business Development & Support)
Malcolm Lewis (Member, Royal Manchester Children’s Hospital)
Moin Saleem (Member, Bristol Children’s Hospital)
Jelena Stojanovic (Member, Evelina Children’s Hospital)
Shaun Mannings (UKRR, Clinical Informatics Assistant)

<table>
<thead>
<tr>
<th>Reference to Agenda</th>
<th>Action Items</th>
<th>Responsible Person</th>
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<tbody>
<tr>
<td>1.1</td>
<td>Liverpool paper turns. Ensure data is entered locally and then accept the electronics from them.</td>
<td>FB</td>
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<td>4.0</td>
<td>Details (location/date) to be discussed via email for the Paediatric UKRR day</td>
<td>MS &amp; AH</td>
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<td>7.1</td>
<td>Structure a definition on 'Transfer' and 'Transition’</td>
<td>AH</td>
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Registry: Agenda Topics

1. Data returns for 2014
   1.1 Summary of data returns in 2014 – FB and AH
   Checking of data is mainly consultant lead currently. Registry to send something to all; in order mandate what is required. Work on getting a document together with ‘gold standard’.  
   ➢ **Belfast:** only one consultant is entering data into the Mediqal system. FB has an IT lead from Northern Ireland to chase. Part only end of year summary/incidents and prevalence received 30 January.  
   ➢ **Birmingham:** only went to Vitaldata part way through last year – no data coming in currently however to be extracted. Have not received Quarterly Data Returns. End of year summary/incidents and prevalence received 28 January.  
   ➢ **Bristol:** All patients are on the Proton system and mainly in the adult submission. All data is in the system and is coming through for the adult returns. End of year summary/incidents and prevalence received 10 March.  
   ➢ **Cardiff:** Vitaldata Extraction. Good Data Manager. End of year summary/incidents and prevalence received 30 January.  
   ➢ **Glasgow:** Now electronic. Vitaldata is bespoke so unable to extract as it’s not always the same. End of year summary/incidents and prevalence received 6 January.  
   ➢ **GOSH:** Going to Vitaldata soon – not yet live. No data entry for 2014/2015. Nobody to do data entry. Deadline is 30 April. Steve Marks is chasing.  
   ➢ **GUES:** Bespoke system. End of year summary/incidents and prevalence received 13 January.  
   ➢ **Leeds:** have a good system running – getting quarterly returns and Vitaldata coming through. End of year summary/incidents and prevalence received 14 January.
Liverp *ool: All data received bar 5 patients. All inputted - paper returns. FB to ensure their data is entered locally and we accept the electronics from them. Unable to send quarterly returns. End of year summary/incidents and prevalence received 5 January. Full 2014 data received 1 March.

Manchester: No data / no communication / no end of year returns. Submitted data in 2012 via file maker – moving on to Clinical Vision. Update required from ML.

Newcastle: All patients received. Full return and coming back in the Adult Data Return. Quarterly Data Returns received. Since November they are adding in heights. Timelines and bloods are updated live. End of year summary/incidents and prevalence received 5 January.

Nottingham: Sending Proton returns along with the Adults – changing to Mediqal. No quarterly Data Returns, but should have this year for bloods. End of year summary/incidents and prevalence received 13 January.

Southampton: No Data Quarterly returns from last year.

3 Units (Manchester, GOSH & Belfast) have submitted Incidents and prevalences and 6 Units have submitted blood quarterly.

2. Data returns for 2014

2.1 Update on electronic systems and data extraction for 2014 – FB, AH

Request data by the 31st March. Last week full data request was sent out. Anna has fed back they need data to be back by May at the very latest. Benefits need to be shown on the electronic system.

2.2 Agreed timelines for 2014 data returns – FB, AH and MS

2.3 Discuss framework for Contract for Registry Returns – C’OB, MS, AH

Contract must be accessible for everyone to read – shy away from calling it a ‘contract’. 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 expected. Specify what the Registry is, the obligations and the role of the Registry. Need to show the benefits of providing the data and benchmarking. RC to send Breach of Service Agreement to Manish.

2.4 Discussion around process – All

3. Merger of adult and Paediatric RR dataset – FB & AH

3.1 Workplan from the Registry

Important to prioritise quarterly returns and focus on the immediate problems with extraction and quarterly returns in order to be in the best position to move forward with the merger. Need something in writing and also a rebranding.

4. Discussion around Paediatric UKRR day - All

People from each unit, from IT and from clinical to attend. Also beneficial to have trainees. Venue/Location is important. Separate day to AGM. Before or after the summer holidays. To look at an initial section on the report – good practise on data sending and how it is used clinically. Areas that are being explored. Use it as an opportunity to engage. Details are to be discussed via email.

5. Capitation fees

Lunch

6. 2014 report highlights and discussion – AH & MS

7. Summary of proposals for change to the 2014 report – AH

7.1 Discussion around proposals and preparation of 2014 report format

Need to look at restructuring as it can be repetitive. Include table of the different IT systems that are used. Detailed information of what we understand by transaction and what units
understand transfer. Need to consider an online supplement for diagnostics codes with breakdowns etc. Include data for 16-18 years old. Include percentages and growth.

8. ERA-EDTA related matters – MS
8.1 Collaborations and data to send for 2013

9. Terms in office – MS

   ➢ Next year MS to step down. Second half of this year approach people to see if they are interested in stepping up / out. Advertise for some posts. Key points from meetings to be sent out.

10. Audits for 2015

10.1 AKI national audit update – MS

   ➢ Feedback provided at Renal Association Meeting.

10.2 Audit on dialysis access complications – discuss and finalise

   ➢ Audit 6 month data (July – December) Asking for Data Entry monthly.

10.3 AKI plasma exchange in paediatrics

   ➢ To be collected from 2016. FB to send data set to MS.

10.4 Proposal to present paper at RR Annual Audit meeting on paediatric audit

11. Update regarding ongoing projects – MS, CI

   (i) Updates renal biopsy re-audit report – MS

   ➢ Done and submitted.

   (ii) Late presenters report – MS

   ➢ Late however near final version done.

   (iii) Infant dialysis report

   ➢ Drafted.

   (iv) Anaemia audit report

   ➢ Identified someone to work on this (Caroline Platt). Just needs to be written up. Current lack of consistency about approach to anaemia management.

   (v) NIDA Study (Newcastle Infant Dialysis Machine Study)

12. Proposals for future projects and audits

   • Graft outcome post-transplantation based on longitudinal eGFR changes

   • Growth in ERF

   • Analyses of causes of death in children with ERF over a 3-year period

   • Grant Applications.

   • Anyone interested in project work to assist.

   • Study on age at transplant and weight of children

   • Transition Study – AH doing survey as part of MD. AC currently following up transferred out dates in adult data set.

Dates for two further meetings in 2015 – all

   ➢ Thursday 18 June, 10:00 – 15:00, Winford Room, Level 2, Brunel Building, Southmead Hospital, Bristol

   ➢ WC 05th October – Doodle Poll to follow

AOB

   ➢ AKI – to be included in the registry returns quarterly.

   ➢ ESPN – deadline in 2 weeks. Something required showcasing work – something from the AKI.

   ➢ New EDTA codes – HM to provide list of conditions without suitable EDTA codes.