BAPN Audit & Registry Committee Meeting

Held on 11th Nov 2014, 10:00AM – 3:30 PM @ Glenside room, Level 3, Gate 7, New Hospital Brunel Building, Southmead Hospital, Bristol BS10 5NB

**Attendees:**
Manish Sinha (Chair, Evlina Children’s Hospital)
Vincent Tse (Member, Royal Victoria Infirmary)
Ron Cullen (UKRR, Director)
Carol Inward (Member, Bristol Children’s Hospital)
Alex Hamilton (UKRR, Tony Wing Registrar)
Catherine O’Brien (Member, Birmingham Children’s Hospital)
Malcolm Lewis (Member, Royal Manchester Children’s Hospital)
Fiona Braddon (UKRR, Clinical Infomatics Manager)
Heather Maxwell (Member, Royal Hospital for Sick Children, Glasgow)
Sarika Dahiya (UKRR, Business and Project Support Coordinator)

**Apologies:**
Damian Fogarty (UKRR, Past Chairman)
Hilary Doxford (UKRR, Head of Business Development Support)
Rishi Pruthi (UKRR, Registrar)
Shaun Mannings (UKRR, Clinical Infomatics Assistant)
Moin Saleem (Member, Bristol Children’s Hospital)
Jelena Stojanovic, (Member, Evelina Children’s Hospital)

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<tr>
<th>Reference to Agenda</th>
<th>Action Items</th>
<th>Responsible Person</th>
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<tr>
<td>2.3</td>
<td>Email reminders for submission of data – Mid December. Re-send reminders highlighting centres that have not provided the data – Mid January. Discuss at BAPN AGM importance of data submission deadlines and a mention in the BAPN e-news. Email Registry Leads and Service Managers of renal centres highlighting that not submitting data equals breach of Service Agreement entered with NHS England. Email all inviting ideas for an educational day.</td>
<td>FB &amp; MS</td>
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<td>4.0</td>
<td>Issue timeline for 2015 data returns. Belfast - Arrange to meet with Mediqal Birmingham – Arrange to meet with VitalData Cardiff – Arrange to see Analyst Newcastle – liaise with IT and medical staff Communicate to every unit the spec of what is required to meet publication deadline. Glasgow – Discuss with Keith Simpson to have patients registered on PV Check with units that they have patient consent to be on</td>
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<td>PVLiverpool – Arrange to meet them with RC</td>
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<td>GS to attend next meeting to talk about RaDaR</td>
<td>FB</td>
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<td>Email link to all ref. EDTA codes</td>
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5.0 Email start dates to MS ALL

6.0 Provide Debtors list, issues with recovering fees HD/SC

8.1 In the Feb/March meeting, HM to give a short brief on what aspect of growth would be interesting to include. MS to provide inputs to this. Thought to recording and improving collection of co-morbidity data. ALL

9.0 Suggest four names of people with specialist interest to participate in a working group ALL

12.1 Email CI infant Dialysis report MS

12.2 Anaemia Audit report – CI to discuss with AH & AC CI

13.0 Email to agree on which Audits to take forward for 2015 MS

**Agenda Topics:**

1. Data returns for 2013
   1.1 Summary of data returns in 2013 – FB and AH
   
   *All data has eventually been received but some units were very late, there were particular problems with Nottingham and Birmingham where extracting had to be done by Matthew Brealey on a private contract with the renal Units.*

2. Data returns for 2014
   2.1 Update on electronic systems in use at Paediatric Centres for 2014 - FB
   2.2 Data extraction for 2014 – FB, SM
   2.3 Agreed timelines for 2014 data returns – FB, AH and MS
       - FB and MS to send email reminders for submission of data – Mid December. Numbers, new, prevalent and transferred patients must be received by RR by 31.1.15
       - Re-send reminders highlighting centres that have not provided the data – Mid January (Quarterly returns will be requested from Paediatric Units, this should be possible for all units with electronic systems.) All data returns (quarterly/annual) must be received by 31.3.15.
       - MS to stress importance of receiving data on time at the BAPN AGM and a mention in the BAPN e-news.
       - RC to email UK Renal Registry Leads and Service Managers of Renal centres highlighting that not submitting data equals breach of Service Agreement entered with NHS England. Furthermore, it will result in exclusion from the annual report to be published.
       - MS to email all inviting ideas for an educational day with a view to highlight the importance of receiving quality data within the set timeframe.
2.4 Data entry – use of old or NEW paediatric dataset – FB, SM and AH
All units should be using V10 dataset. New EDTA PRD codes for new patients.
2.5 Discussion around process – All

3. Merger of adult and Paediatric RR dataset – FB & AH
3.1 Paediatric specific items in planned New ADULT Dataset
There is a copy of the new RR dataset version 4.0 with two specific Paediatric pages on the website. Units who share a Renal IT system with Adults will use the return for both.
https://www.renalreg.org/datasets/the-uk-renal-registry-dataset/

3.2 Workplan from the Registry

4. Quarterly data returns – FB
- Time line to follow for Q1 2015 adult data:
  - Data to be received by 31st March
  - Summary to be returned to centres by 30th May for agreement
  - Analysis and write up of report from July onwards.
- Table which centres are providing data quarterly. Good for FB to meet with centres, (needs an IT contact to communicate issues with).
- Centre updates/actions:
  - Bristol – not updated to the new V10 dataset. Personal difficulty in completing extraction of data.
  - Belfast – FB to arrange to meet with Mediqal, to get them involved in resolving issues as not feasible to keep visiting Belfast and collecting data manually. Also issues around inputting data and missing special diagnostics for children.
  - Birmingham – extraction is missing 1-2 variables. MS to communicate to every unit a spec of what is required by when to meet publication deadline. FB to meet with VitalData to sort out extraction but overall great improvement.
  - Cardiff – good IT extraction needs a bit more work for next year. Feedback to them for completeness of missing heights. FB to visit to help their Analyst with reporting the data.
  - Evelina – tested data via Excel sheets this year, have a roadmap of what’s missing and IT will assist with sorting issues. Drugs will be put in manually.
  - Glasgow – Main problem in Glasgow is patients attending follow-up clinic in East and North of Scotland where they do not have VitalData system running as in the West of Scotland. MS to have conversation with Keith Simpson to have patients registered on PV so data can be extracted from data warehouse.
  - GOSH – backdata loaded on to VitalData, will be up and running by end of the year. FB liaising with VitalData regarding extracts for 2015.
Liverpool – Still no solution with Liverpool Cyberren system (CB) as special Paeds data items not on CB. Also not all children are on CB. MS to arrange to meet with them with RC.
Leeds – no issues with Data.
Manchester – using last year’s data on CV5 to test and move forward into using it.
Nottingham – Problems over private extraction in 2013, but should be Mediqal for 2014.
Newcastle – missing height and other data. Possible to send quarterly data going forward. FB to liaise with IT and medical staff.
Southampton – excellent, no issues due to FB working with Shuman Haq and IT in Southampton.

- Check with units if they have patient consent to be on PV
- GS to come along to next meeting talk about RaDaR
- All to use new EDTA codes for new patients.

5. Term in office for A&R sub-committee members – MS
- There is a 3 year period in office for the chair. MS will continue for 1 additional year i.e. until 2016. Position will be advertised for in 2015.
- All to email MS their start dates. Suggested to stagger leaving dates between present members so that new colleagues joining get an understanding of how the group operates.

6. Capitation fees
- There is an intention to increase the fee by £1 per annum for each patient on RRT for adults, the UKRR will send out a one year notice for this.
- SC to provide a debtors list and any issues with receiving fees.

7. 2013 report highlights and discussion – AH & MS

8. Summary of proposals for change to the 2014 report – AH, all

8.1 Discussion around proposals and preparation of 2014 report format
- In the Feb/March meeting, HM to give a short brief on what aspect of growth would be interesting to include. MS to provide inputs to this. Quarterly data will improve quality of anthropometric data.
- All to think about how to record or improve the collection co-morbidity data.
- Consider collection of other data – Severity outcome measures, attendance at a special school, causes of death.

8.2 Authorship - formalising process – MS, all
- It was thought all current authors made contributions so status quo applies for 2015.

9. ERA-EDTA related matters - MS
Suggestion of 4 names with specialist interest to be involved in participating in a working group.

10. Audits
10.1 AKI audit project – JS and MS
   To go live on 9th March. It was promised to consult with RR on Adult AKI project.
10.2 Updates renal biopsy re-audit report – MS
   Meeta will be sending this out via email.

11. Late presenters report – RP/MS/CI
   Planned to be finished by 24th November.

12. Update regarding ongoing projects – MS, CI
   Reports out by Feb/March 2015.
   12.1 infant dialysis report
   MS to forward to CI, it needs a bit of work.
   12.2 Anaemia audit report
   Need assistance to finish the project. CI to have a chat with AC & AH if we can contact people to get missing data. Any thoughts feedback to AC & AH.

13. 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
   - Audit on dialysis access complications
     Agreed to use UKRR dialysis access model which has been tested and refined.
     MS will email to agree on which Audits to take forward for 2015.

Dates for two further meetings in 2015 - all
February/March 2015 – 19th March, confirmed via doodle poll.
May/June 2015 – doodle poll to follow.

AOB - No