

BAPN Audit and Registry Committee Meeting
Learning & Research Building, Southmead Hospital
Bristol BS34 8RR

Meeting on the 19th September 2011

Attendees:

Catherine O'Brien (CB), Fiona Braddon (FB), Matthew Brierley (MB), Anna Casula (AC), Hilary Doxford (HD), Terry Feest (TF), Carol Inward (CI), JJ Kim (JJ), Malcolm Lewis (ML), Heather Maxwell (HM), Sue Shaw (SS), Manish Sinha (MS), Yincent Tse (YT)

Apologies: Damian Fogarty (DF), Claire Castledine (CC)

1. Minutes from previous meeting on the 25th May'11 discussed and action points reviewed. The meeting today agreed that they were a true reflection of discussions.

Discussion regarding the UKRR reports from 2009.

Action Points: (i) To review the 2009 report for any changes in the format of the Paediatric UKRR report. This will need to be done over the next 4-weeks.

(ii) TF suggested making small changes to the previous report format to help maintain comparisons with previous reports

(iii) Discussion regarding some of the missing parts of the current dataset such as 'dates for commencements of modality and treatment'. In addition it was important that height, weight and creatinine corresponding with these dates is recorded.

- ML commented that the lack of these in the past had been related to the initial aims of the paediatric registry to produce reports regarding cross-sectional data

(iv) Discussion regarding planned 'Young adults report' – an important 'timeline' detail that has not been uniformly recorded in the available dataset is regarding the dates of transfer and name of the unit the child is transferred to

- Current identifiers in the UKRR are: name, dob, hospital number, NHS/ Chi number, once in the dataset Registry database number
- Concluded that date of transfer and patient identifiers should allow identification of patient in an adult unit. There are too many options for it to be practical to record unit transferred to in the dataset.

2. ERA-EDTA registry. Thanks to FB and AC for submitting the data to the ERA-EDTA registry.

3. Specifications of the electronic dataset for the 'National Renal Dataset':

The meeting agreed that this is urgent and important because (i) UKRR needs to know device the dataset and (ii) providers of electronic platforms to renal units can incorporate this. The main points requiring decisions relate to whether to continue to collect information on use of medications as for the foreseeable future this data would need manual entry by most teams.

- Discussion regarding immunosuppression drugs to be included in the dataset. It was commented that this is already collected by UKT. As an initial plan we will enquire from UKT whether they are able to provide data regarding the immunosuppression drug data.
- Discussion regarding the implementation of 'Vitaldata' electronic platforms at Birmingham, Glasgow and Leeds paediatric renal units. TF pointed out that it is the responsibility of the units to provide data from their systems for analysis at UKRR although staff at UKRR will offer advice and support.
- The meeting agreed there was a need to include the following in the NRD (i) modality at start of RRT (ii) date of start of RRT (iii) definition of ERF as per registry is if the patients are on dialysis/transplantation and not if the eGFR is $<15\text{ml}/\text{min}/1.73\text{m}^2$. FB pointed out that there has been some discrepancy in the interpretation of ESRD/ERF with some returns including patients not on RRT but with eGFR $<15\text{ml}/\text{min}/1.73\text{m}^2$. (iv) BP level and anti-hypertensive medications: level of BP; Yes/No are you on anti-hypertensive medications; if so which ones ACEi/other (v) co-morbidities at ERF Yes/No (vi) need timeline entries for any change in the modality or transfer out dates.
- Discussion regarding the new diagnostic codes that have been proposed by ERA-EDTA. ML informed the meeting that he has looked through this to make them more paediatric specific. It was suggested that he should produce a document and present them at the BAPN exec meeting on the 30th of September. This should then be opened for discussion within the BAPN before being finalised. It was thought that it would be useful to have all these diagnoses 'mapped' to UKRR database

Action Points:

- CI to delegate task of contacting UKT to request for available data regarding immunosuppressant medications.
- ML to produce a document regarding ERA-EDTA diagnostic codes and present it at the BAPN exec meeting on the 30th of September.

4. Merger of Paediatric and UKRR main database (TF)

TF informed the meeting regarding the 'merger of paediatric dataset on filemaker to the main UKRR database'. He suggested this was planned after the 2010 paediatric dataset had been checked and details to be included confirmed. The RR plan is to merge the databases about 3-months following the submission of 2010 dataset to the RR statisticians in December 2011.

5. Tasks & Timeline to complete merger of adult & paediatric registries (CI, SS)

- 2010 returns will be the last year when any centres will be allowed to submit paper based returns.
- 2011 data returns:
 - (i) Glasgow has entered data on Filemaker in 2010 and will submit similarly in 2011;
 - (ii) Liverpool will do the same as Glasgow submitting returns via Filemaker in 2011 They have submitted paper returns in 2010;
 - (iii) Belfast is likely to have MediCal up and running by 2011 but this needs to be confirmed.

6. Progress with 2010 returns (SS MB)

- 2010 returns that have not yet arrived: **Belfast** awaited (Mary O'Connor), **Newcastle** awaited and need it before 15th October 2011 (YT), **Manchester** (No data returns yet and none entered onto FileMaker; Manchester is unlikely to submit any returns this year), **Nottingham** - not performed an 'data download' yet but concerns that there may be no detailed data (MB), **GOSH** data awaited,
- The following 2010 returns have been submitted but are currently awaiting processing by the UKRR: Glasgow (awaiting response to queries); Birmingham- data received/ final checks ongoing; Cardiff- PROTON extraction ongoing/planned, Evelina data received, Liverpool- paper 2010 and Filemaker 2011
- Plan to start looking at the extraction/data checks in October 2011.
- It was also requested that a preliminary report regarding incidence/prevalence and some initial checks of the 2010 data centre are 'fed back' to the individual units
- Deadline for the last date of return on the 15th of October 2011.

Action Points:

- UKRR - ?MB to perform 'data downloads' of centres that have submitted data but also to check regarding Nottingham

- CI to chase data from outstanding centres: Belfast and GOSH
- YT to submit Newcastle data before 15th October 2011
- Deadline for the last date of return on the 15th of October 2011.

7. Progress with extraction 2010 data (MB, FB)

- All 2009 patients will have their timelines checked. All data will be uploaded and sent to the UKRR paediatric committee and individual units. This data should be checked and returned by all the units by the 1st of November.
- The chapter proposals for 2011 report should be submitted to the UKRR before the end of October 2011.
- Validated data will be submitted to the statistician before the 25th of December and the analysed data will be returned to the Paediatric UKRR before the end of January 2012 with 3-months to write the chapter.

Action Points:

- SS to send 2010 data for each centre as it becomes available through October-November to the UKRR Paediatric committee.
- CI to and members of paediatric sub-committee to check data before forwarding to individual units.
- The chapter proposals for 2011 report should be submitted to the UKRR before the end of October 2011.

8. Timeline for young adult project (TF)

- Chasing up **initially** the current PREVALENT ERF patients. This has been discussed previously and agreed that the RR should work backwards in 5-year time-intervals updating the database.

9. Audit project updates

- Hypertension: To submit the revisions to NDT in October 2011 (MS)
- Obesity: First version to submitted before the committee by the 1st of November (YT)

- Infant dialysis: Now nearly done n=80 subjects and likely to complete data collection by the end of the year. Proposal for statistical analysis awaited.
- Anaemia: data collection proceeding slowly. Data collection completed in Bristol. Visit to Leeds planned for October.
- Renal biopsy: plan to re-audit renal biopsy has been agreed. This project will be lead by trainees in Nottingham with support from Dr Meeta Mallick.
- Audit of CKD in Children: allocation of tasks to be discussed by paediatric subcommittee

10. AOB: (i) Claire Castlefield (CC) was thanked by the paediatric UKRR committee for her efforts. She is moving on from the registry.

(ii) Application submitted to the Bristol University for PhD studentships for a paediatric registry trainee.

(iii) Capitation fees outstanding: 2009 from Birmingham, Liverpool and Southampton from 2010, and Nottingham from 2006.

(iv) Invite Ron Cullen to the next meeting planned in December 2011

11. Date for next meeting to be confirmed