

**BAPN Audit and Registry Committee Meeting
UK Transplant, Bristol, from 11am-3pm on 10/06/08**

Attendees:

David Ansell (DA), Hilary Doxford (HD), Sue Shaw (SS) Matthew Brealey (MB),
Charlie Thomson (CT), Carol Inward (CI), Manish Sinha (MS), Farida Hussain (FH),
Shazia Adalat (SA)

Apologies:

Malcolm Lewis (ML), Moin Saleem , Chris Maggs

Welcome

Review of previous meetings minutes from 23/3/09

Re-iteration of aims of committee

To transfer paediatric registry to Bristol under auspices of Renal Registry.

To move from paper- based to electronic data entry for paediatric registry.

To obtain the benefits of strategic UK Renal Registry expertise and links with Adult Renal Registry.

Progress on Consent forms

To correct previous minutes. Instead of stating there are only 3 units with forms pending, the minutes should state five units. This includes Manchester and Southampton, as well as the previously reported GOSH, Belfast and Leeds.

Manchester currently exempt due to encrypted data sent to Registry.

CI has received some forms from Leeds.

GOSH have only returned 53/174 forms.

Southampton report that they are aiming to achieve electronic submission.

Forms and posters are being sent out to units using Proton

CI has emailed units a covering letter for the consent forms to individual units

Units were informed of the census data of 31/12/08 at the last AGM of BAPN.

HD would like to obtain an up to date patient counts from all paediatric units to calculate accurate capitation fees.

Previously held paediatric registry data from ML

ML reports that he will send this to DA by end of day today. The data will include all information held to 01/04/08.

DA reported from the UKRR that this is the last date that they will accept this information. It is unclear in what format the data will be submitted by ML.

There is currently no SASS code for paediatric data.

Progress on Annual data returns

Current situation is as below:-

Units reported to be electronically transferring data

Bristol
Cardiff
Birmingham
Nottingham
Newcastle
Leeds

No units using Proton have reported back any technical/ data entry issues apart from Bristol. CI has sent out query asking for any issues to be reported from all units.

Cardiff- MB has emailed the IT department but had no reply as yet. Are reported to using Proton and will use this next year.

Nottingham - MB reported regular monthly expiry of his password on Nottingham system. Fault to be reported back to unit to be rectified.

Leeds- Have been sent Proton screens and are currently in the process of inputting data.

ECH- 70% of paper returns already submitted to ML. Overwhelming majority also completed on paper and will be submitted to ML. Now also have a Proton screen to facilitate electronic data submission in the future. ECH needs to sort out some technical issues with transfer of laboratory data from ECH to Bristol.

Southampton are aiming to achieve electronic submissions. DA has been in contact with the IT department and has sent them the UKRR data specifications and NRD dataset. It appears they already collate a lot of this information in their own database.

Manchester- Have been using a database operated by MI rather than Proton. Will be using Clinical Vision from this month.

Liverpool- Have completed paper returns. It is anticipated Cybernius will not be in place for next year.

Newcastle- Are awaiting upgrade to ClinicalVision 4. This years returns on paper and will be complete by Monday

Glasgow- New system operational soon with paediatric data. Direct export from Yorkhill

Liverpool, GOSH and Belfast are anticipated to use paper returns next year.

As there are only three units expected to use paper returns, it was agreed that the Renal Registry will receive these and will be able to input them directly from next year, rather

than the previous system where returns were sent to ML and Jo Shaw. The A&R committee wished to thank both for their invaluable input over the years. Another individual will need to be identified by the Renal Registry to fulfil Jo's role when she finishes in her post and this will be addressed on an annual basis, as the eventual expectation is that all returns will be electronic.

This year's paper returns to continue to go to Malcolm Lewis & Jo Shaw in Manchester.

The UKRR expect all information by the deadline of 30/6/09 but anticipate the deadline for next year will be 30/04/10.

Actions agreed –

MB- Fault with email access to be reported back to Nottingham to be rectified.

CI to contact Cardiff to clarify submission CI to ask Brian Judd if continued paper returns next year

MS, MB, DA to liaise to correct technical issues with transfer of laboratory data from ECH to Bristol.

Progress on National Renal Dataset

Amendment/removal of data items still on to do list

Actions agreed- *CI to liaise with Alan Watson & Chris Reid as to who will become involved in clarifying definitions*

Screens for electronic data Returns

Issue of drug recording on Proton not perceived to be a governance problem. CT has discussed this particular issue with Nottingham, the unit raising the issue at last meeting.

Growth Hormone and EPO will be added to Proton.

Co-morbidity items not relevant to paediatric practice. CI still needs to liaise with Chris Reid to remove/rename items highlighted at last meeting.

CT reported that EDTA/ERA have a new set of definitions (including all paediatric kidney disease diagnoses) appearing on their website in the next week, as a series of codes. There will need to be a (?lengthy) transition process in adopting the new codes.

Existing co-morbidity groups listed in NRD do not distinguish between paediatric and adult patients.

There are some changes e.g. no collection of antihypertensive treatment. BAPN A&R committee would like to see this item re-instated. Paediatrics works with a more limited formulary and this information is already entered into Proton.

Actions agreed- CI to contact Chris Reid (on European working group for coding and definitions), Alan Watson and Jane Tizard to work together on behalf of BAPN to make progress on this

DA to send spreadsheet of dropped items off NRD list

MB to add Growth hormone and EPO to proton and to reinstate antihypertensive treatment

Admission/discharge data transfer

Action- CI yet to liaise with Andrew Hopper.

Many sites have a way of recording this information already. For example, Birmingham records on timeline.

Matters arising

UK Renal Registry/BAPN paediatric registry and information governance

BAPN just voted to be division of Renal Association.

Control of paediatric data and analyses involving data of previous/present paediatric patients will stay under the control of the BAPN A&R committee.

Access to data held will continue to be decided on an ad hoc basis and be referred to the A&R committee for decision making.

Data will be transferred to the European Registry in an anonymised way.

UK Renal Registry will need to refer to BAPN A&R committee before using information from data collated from paediatric units.

Writing of Paediatric Chapter for 2009

Deadline for chapter is 30th September.

Will focus on

Demography (ML)

Laboratory indices (FH)

International comparisons (MS)

Methodological changes in data collation (CI)

Renal Replacement Therapy in young adults to be published separately.

Future analyses will be performed on the database at Renal Registry.

Actions- Individuals responsible for topics for next chapter - See initials above

Proposals For Paediatric Analyses

Biochemical indices.

Lipids-MS has liaised with local metabolic consultant re: lipids. No guidance except for NICE on hyperlipidaemia in familial hypercholesterolaemia.

Estimated GFR- Still to find out which constant is used to calculate GFR in each unit.

Actions agreed-FH to contact individual units to identify factor used in each unit to calculate eGFR

RRT in young adults and long term outcomes

CI has liaised with Paul Harden (Oxford). He will discuss with UK transplant and inform CI of results of his discussions.

AUDIT

Renal biopsy audit

As yet not published. Re-submitted to NDT and reviewers comments being addressed.

Recommendations will be available by next meeting

Suggestion was to re-audit in 2 years.

Actions agreed- FH to submit recommendations to be discussed next meeting

Hypertension audit

As yet not published

Action agreed-Recommendations to be emailed out to audit contacts and Standards and Guidelines committee (MS)

Manuscript for publication should be prepared before end of next meeting

Anaemia Audit

Since last meeting, anaemia audit proforma modified as per comments. Amended form sent to Clinical Standards and Guidelines Committee and then to audit leads of individual units. It was assumed that units are happy with proposal as we have not heard otherwise. Once ML has sent data to registry, it should be possible to identify patients at each unit for time period specified. Will initially contact individual units with this list to identify how much of laboratory data can be extracted electronically. Deadline to extract this data will be end August.

Actions agreed- Will need to clarify with individual units whether honorary contracts are required (CI). Also need to identify contact at Human Resources ECH(SA)

HQIP funding drive for multisite audits announced therefore CI not contacted D

Trompeter/M Taylor re funding from BAPN.

Application submitted to recent round of HQIP multisite audit fund call.

