

British Association for Paediatric Nephrology

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BAPN Minutes Business meeting minutes

Friday Dec 7th 2007

Birmingham Children's Hospital Education Centre

Present: Mark Taylor (President), Jane Tizard (Secretary) Jonathan Evans, Simon Waller, Nadeem Moghal, Catherine O'Brien, Heather Lambert, Chris Reid, Dick Trompeter, V Ganesan, Farida Hussain, Jane Deal, Carol Inward, Shivram Hegde, Mary O'Connor, Maggie Fitzpatrick, Sally Hulton, Shuman Haq, Andy Lunn, Larissa Kerecuk, Sally Johnson, Kate Verrier-Jones, Moin Saleem, Mark Bradbury, William van't Hoff,

Apologies: Sally Feather, Lesley Rees, Jan Dudley, Peter Houtman, Jean Smellie, Judy Taylor, Robert Kleta, Sandra Irragori, Steven Marks, Robert Jones, Alan Watson, Nick Webb, Mary McGraw, Eric Finlay, Sue Rigden, Maurice Savage, Malcolm Lewis, Malcolm Coulthard, Milosh Ognjanovic

1. **Minutes of the last meeting** at York, March 2007 were accepted as a true record.

2. Reconfiguration and Services Committee Update

- a. Mark Taylor introduced "Foundation for Change" a document under construction that is designed to be an internal reference statement for the BAPN, and the first step towards a strategy for the next 5 years. This is being prepared to include the following areas:
 - o Equality of access to services, matching services to populations
 - o Education and development of the workforce
 - o Manpower, team structure and critical mass
 - o Research, development and audit
 - o Adolescents and the interface with adult services
 - o Specific issues of healthcare delivery and infrastructure; chronic care, dialysis, transplantation, acute renal failure, and rare diseases

The drafted paper will be reviewed by the Executive in February and circulated to the Association before the next General meeting in May.

b. Nadeem Moghal gave an overview of the current state of PbR and Commissioning. The BAPN briefing paper had been influential with Sheila Shribman in taking forward these issues. NM has attended the PbR children's specialist services working group at the DoH. This included Ian Rutter Clinical lead for implementing PbR for England. The DoH now acknowledges the difficulties posed to specialties by PbR, but PbR is here to stay. The structure is being altered with time but there is concern that the more complex it becomes the more likely it is to fail. A "Year of Care" model has been suggested. There is debate as to whether to use HRG 3.5 or 4.

NM to request examples of failure of PbR, for example, integrated care, to take to meeting at end of January. Action NM and all members.

There is a plan to test PbR tariffs against standardised clinical cases, and to assess HRGs and relation to tariff calculations. This is because clinical record data which determine costs may vary between units. NM to send out standardised scenarios to determine variation in HRGs. JE reported that variation in coding is already established. **Action NM**

The BAPN is interested in asking the NAO whether an audit of cost effectiveness of PbR is or will be considered. **Action NEM & CMT**

Commissioning: There is currently planning blight because of PbR. Improvements in service can now only be obtained by addressing quality issues that attract funding. Quality issues need to be defined. There is a benchmarking group with 12 trusts involved, assessing e.g. OP activity v PAs.

The West Midlands renal commissioning group is analysing the range of costs of HD in 14 adult units. There was consensus that the BAPN should participate with this process. NEM to draw a team together. **Action NM**

The NE will be a pilot site for PbR for nephrology. RT suggested employing a Health economist to work with BAPN –this was supported. MS suggested that the academic process could be involved in this assessment. It was agreed that it is important to work with other similar groups with same problems eg PICU and oncology. Involvement of a patient organisation should be sought to give more support to the process. All these will be discussed at next Exec meeting.

c. JT reported on the responses to the "Modelling the future" document and BAPN questionnaire. All 9 Units that responded were using the "Model 1" ie 24/7 on call for nephrology only, giving advice to region, with no cross cover from other specialties. There was a variation in responses but it was thought that 3-6 consultant WTEs were needed per centre but 6 were necessary to be EWTD compliant while continuing to provide a 24/7 specialty on-call rota. For nephrology, telephone advice alone was not a sufficient on call service. Most believed specialists should be released from general paediatric on-call. There was support for academic posts that would generally be in addition to the service requirement of a department. The amalgamated response will be sent to the RCPCH.

JT also reported from the “Specialised paediatric services-Commissioning safe and sustainable services”. The main focus of this work has been on co-dependencies between services and factors affecting service configuration. A co-dependency matrix has been developed and was demonstrated. A draft report is being written and this will be reviewed by members of the BAPN for comment. The final document will be circulated to the BAPN.

3. Research

- a. MS reported good progress and thanks to all involved. There are Research Leads, in each centre, who have now met. There is greater clarity over new funding streams such as Health Technology Assessment programme, NIHR-research for patient benefit programme, MRC, NIHR programme
- b. KRUK and KKR have provided a matched total of £150,000 for project grants for research specific to renal disease in children. This will be advertised as the KKR/KRUK paediatric renal research award.
- c. The Nephrotic trial is progressing well. Plan to increase numbers to 80 as recruitment is good. In process of costing the full study. Need full time trial coordinator/secretarial support. Ethnicity may affect recruitment as lack of understanding of “trials”. Therefore possibly losing Asian families. MCRN has been very helpful with the study.
- d. ARB/ACEi study protocol being developed
- e. Taurolock study-Plan to have outline protocol by April. Need to know how many units will participate. Currently need 50 in each arm. However if Alteplase arm included will need longer to develop as not licensed and also will need 3rd arm and more patients so will take another 12 months + to develop. **Action all to let EF/ know if participating.**
- f. UTI- Sally Feather and Jan Dudley proposal being developed
- g. NICE guideline proposal-A Lunn proposed study of all 1st UTI under the age 5. US and DMSA in all and compare finding with investigation as per NICE guidelines. There was general support for the proposal. WvH suggested working with The Primary Care Network. KvJ pointed out that they would identify more scarring if DMSAs in all but questioned the significance in terms of outcome. Short term outcomes of eGFR/ BP/ Proteinuria should be assessed. Long term outcome study should be considered.
- h. RA –UK Kidney Research Consortium includes BAPN, led by Caroline Savage
- i. Rare diseases registry. There are plans to map to the Renal Registry via a web portal.
- j. MCGN proposal has been sent by CMT, S Marks and S Johnson to the Research leads. COREC approval obtained. Funding being sought .

4. MCRN

WvH proposed to create a BAPN/MCRN clinical study group. This will enable access to UK Clinical Research Network resources. It will also link to the UK Kidney Research Consortium (see above) It will require £10,000 pa from BAPN to support infrastructure (the BAPN will ask KKR for further funding). It will be responsible for

protocol development & peer review. There would be an open election to chair and representative membership. It was suggested that there should be urological input possibly including 1/2 urologists. A patient /family representative should also be recruited. Group members may include nursing or other multidisciplinary team members. In the event of the proposal being agreed the elected chair would be the BAPN research officer ex officio, requiring a minor amendment to the constitution. The proposal was strongly supported, there being only one vote against.

5. NICE UTI guidelines

Jan Dudley had collated a survey of responses to the UTI guideline. Eleven responses were obtained from 10 Units (7 tertiary). 27/66 (41%) statements were agreed by all. 7/66 statements generated 'non-yes' responses from >30% of units 2/66 statements generated 'non-yes' responses from >50% of units (1.5.1.6 and 1.3.1.3). Heather Lambert thought that the report should highlight the diversity of opinion and the lack of evidence base. She was concerned regarding a recent incident in which paediatricians were being pressured into "complying" with the guidelines. She proposed a statement to be used in a response to NICE.

"As the professional organisation responsible for continuing education and maintaining standards in paediatric nephrology, the BAPN encourages its membership to read the guideline, learn from it and modify practice as appropriate. The BAPN would encourage its membership to follow evidence based medicine where possible.

NICE's own published summary clearly states that substantial parts of the document are not evidence based. The BAPN notes this and observes that there is no substantiation of consensus sought, certainly none from the BAPN or RCPCH membership. Therefore the BAPN is not in a position to endorse the guideline as a whole and would strongly resist any imposition of the guideline by Trusts or other organisations to limit or restrict the clinical practice of clinicians."

KvJ reported that there had been consensus within the NICE group.

The proposed statement was in part supported. It was agreed that the final deadline for submission of responses to JD would be extended to the end of the year. Once feedback was complete and discussed within the Standards and Guideline subcommittee the executive would decide whether there was a consensus view from the BAPN which could be released.

6. York

At the RCPCH meeting to address the future of the Annual Meeting in York it was agreed that there were too many subspecialty sessions and that these no longer provided a platform for leading edge research and that attendance by clinical scientists and specialists was declining. A plan to reduce specialty sessions by amalgamating specialties for cross interest, and expanding plenary sessions was likely. There would be more emphasis on CPD and education. These changes will not be effected until 2009. (The BAPN will continue to make the joint meeting with the RA its main base for clinical and scientific exposure, and members were strongly encouraged to attend the RA in Glasgow in May 2008)

7. Registry

Jonathan Evans gave an update on the registry. There are currently two vacancies on the registry committee. One of these should have a particular interest in Audit. These will be advertised before the end of the year. **Action JT**

Last year there were 3 chapters in the registry report. In future the report will be published in an NDT supplement. The BAPN is not able to contribute this year as data not available in time. A paper on transitioning to adult care is in progress. Very poor returns by Units last year.

There is still little progress in transferring data electronically to the Renal Registry in Bristol. The BAPN does not fulfil DoH requirements for anonymised data in manual returns and urgently need to get consent from all patients. JE will circulate consent form by end December. **Action JE**

The DoH now acknowledges that CfH will not be suitable for all renal systems and support the continuing use of specialty systems. There is no point in waiting for DoH systems. Donal O'Donoghue and John Feehally are willing to write to Trusts in support of Units trying to obtain suitable IT systems. JE outlined a plan for transferring data to Bristol including Malcolm Lewis visiting Units to collect data to complete collection for 2008

There was a long debate on how the BAPN should progress with the Registry. There were strong views that all efforts should be concentrated on developing the electronic connections to the Registry and to stop paper reporting and to achieve the transfer of the database to Bristol.

- It was agreed that the BAPN should not lose the current data.
- There should be timeline for developing the direct system.
- There should be 3 monthly meetings of the Registry group in Bristol.
- The BAPN should consider utilising (or asking for specific) KKR funds to support the Units to access proton or similar.
- Commissioners should be aware of the NSF requirements and funding issues. There should be a patient representative on the Registry group. **Action JE**

8. Standards and Guidelines

Lesley Rees was unable to attend and a briefing was given by JT. A meeting of the guideline committee has been set for the 7th Feb 2008. The haemodialysis and peritoneal dialysis guidelines are on the website. Others are still in progress and will be discussed in Feb. Authors of guidelines are requested to inform LR of progress. Patient information will also be discussed at this meeting. It was agreed that there should be an effective framework linking the S&G and audit and registry committees.

Larissa Kerecuk gave a presentation of the MPGN guideline. This will go forward for review by the committee.

It was agreed that the committee should set out the structure for guidelines based on the RCPCH structure. Trainees need comprehensive guidance from the guidelines committee. **Action LR**

9. Renal Information Exchange Group (RIXG)

Chris Reid gave an overview of RIXG. The 3 main elements are information for direct patient care, information needed for secondary purposes eg audit, and a

knowledge base for patients and professionals. There was a demonstration of Renal Patient View (RPV). Two units currently use RPV with positive feedback from users. A formal evaluation is underway. There is an important issue of patient information accessible from RPV. CR asked whether the GOS site should be linked. It was agreed this should be discussed at the guideline group meeting on Feb 7th.

10. Treasurer

Dick Trompeter reported that there is £32,000 in the current account and £80,000 in the treasury A/C. KKR is donating £300,000 over 3 years. This can be used as the BAPN wishes. £100,000 will be used for a KRUK/KKR grant for early 2008. KRUK have offered a further £50,000. Need to plan how to spend subsequent funds eg Health Economist or for Registry.

Members requested to pay by standing order and not Paypal.

11. Training and Trainees

Sally Hulton gave an update on training. The responsibilities of all are as follows:

- **Deanery:** local quality control
- **RCPCH:** ensure specialists + trainees fit for purpose, recertification
- **Trust:** ensure trainees have sufficient clinical experience, supervisors are trained and have time to supervise
- **Trainer:** maintain educator skills, CPD-must be in good standing
- **Trainee:** meet regularly with supervisor + enter results in portfolio

We were reminded of the current assessment structure, which includes the MRCPCH exam, the work place assessment (including Mini CEX, DOPS, case based discussion, e SPRAT, SAIL, SHEFFPAT), the portfolio and trainers report

The Grid interviews are on 4th February. It has been decided to limit to 2 posts this year due to the current number of trainees. Suitable candidates can defer the start of the Grid post of registered for higher degree.

There are now 8 trainees with CCT with further 3 due next year. There are 3 consultant vacancies in Cardiff, Manchester and Nottingham. Eva Simkova was appointed to Belfast.

The following educational events are recommended for all Grid trainees

- GOS Nephrology Week: once
- CPC at GOS June: annually
- Training days: Leeds 10-11 January 08
- Training days attached to adult SpR club: annually
- Renal Association: once
- Renal U/S training Liverpool: start of grid (this has been developed with radiology CSAC)

The CSAC is keen to promote training in dual centres. There is currently one rotation between GOS and Guys. There is one ad hominem post between Newcastle and GOS.

Trainees

Sally Johnson reported on behalf of the trainees. There are 15 trainees in 9 centres

All BAPN trials have a trainee allocated to them. Rukshana Shroff was awarded the first of the new Travel bursaries-Congratulations to Rukshana. There is trainee representation for the Registry, Website, Service delivery and the Clinical Standards and Guidelines group.

There was a survey of the use of CSAC by the trainees. Generally, very positive views. All trainees who responded have educational supervisors. The training page of the website was noted to be useful.

There is concern about erosion of specialty training due to the “hospital at night” rota. Approximately 45 sessions per 6 months is lost-equivalent to 4 weeks of training. There is concern that with loss of visits there is no voice to the RCPCH except via the CSAC.

There was discussion about training outside the Grid and whether non Grid trainees could gain enough experience to be “trained”. Although the current training emphasises competency outcomes it was thought that for rarities time in post is important experience to allow exposure to such cases. The trainees are keen to have more clinical experience.

SH thanked Sally Johnson for her hard work in the role of the trainees lead for the past year and welcomed Leah Krischock to the post for this year.

12. Membership

Eva Simkova-Consultant Paediatric Nephrologist, Belfast

Simon Frazer-Consultant paediatrician with an interest in PN, Bradford

Lucy Robin-SpR Leeds

These were welcomed to the Association

Two resignations from the Association were noted from Dr Chris Nelson and Dr Graham Smith

13. Kidney Advisory Group

a) JT reported that the Kidney Advisory Group had proposed a separate Paediatric Subgroup. This would included

- Representative from each paediatric unit (50% should be surgeons)
- Statistician
- Tissue typing rep
- Chair
- Paediatric link to KAG (BAPN rep)
- It is suggested that there should be a 3 year term of office.

- Annual meeting with E mail discussion in between

The proposal was supported and this will be taken forward by JT. **Action JT**

b) JT reported from the feed back from the new kidney allocation system. The total number of transplants has been equivalent to before the new scheme

- 1/1/05-31/12/ 05 (12months) 71Tx
- 03/06-10/07 (18 months) 103Tx
- Waiting list Dec 05 112, Oct 07 106 ie stable
- Offers have decreased significantly but there is increased acceptance in most but not all units-This is to be investigated as to the reason why?
- There is improved matching but Tier E difficult to access and therefore the difficult to match are waiting a long time

- From April 2008-this should improve significantly for those waiting 2 years as they will receive significant number of extra points to enable paediatric patients to be top or near top of Tier E.
- It has been proposed to maintain the benefit of being paediatric into early adult life to prevent the problem of reducing access to kidneys at age 18.

14. Meetings

Guideline group Feb 7th 2008

BAPN Exec Bristol Feb 29th 2008

BAPN Research Meeting 6th March-venue to be confirmed

CSAC Friday 14th March Birmingham

BAPN general meeting Wed May 14th Glasgow (JT to confirm venue)

CPC Thursday 12th June GOS

BAPN Exec Friday 13th June GOS

CSAC Friday 13th June(pm) GOS

BAPN AGM Dec 5th 2008 Venue to be confirmed