

Paediatric Renal Network Steering Group **Thursday 3rd October 2013**

Present: Martin Christian, Michelle West, Shelley Jepson, Pearl Pugh, Judith Hayes, Simon Rhodes, Mona Aslam, Andy Robb

Apologies: Gail Moss, Alun Williams

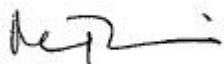
	Item	Discussion	Action
1.	Minutes of meeting 24 th June 2013	These were accepted as a true record.	
2.	Matters arising	The secondment report was sent to Sue Dryden and there has since been a meeting with her. Michelle queried whether the CRG should be paediatric or renal. It was felt that it should be paediatric but that paediatric representation on the renal CRG might be helpful. It was felt that we now need another meeting with Sue. No meetings have yet been set up with either Sheffield or Leicester. We now have a new AGM, Jenni Twinn, so in the first instance it would be a good idea to have a meeting with her. Victoria Barry, contract manager, should also be involved. We need to be clear on where NUH stands before having meetings with Sheffield and Leicester. Martin and Michelle are due to do a presentation to the Nottingham Children's Hospital Management Team shortly.	Martin to discuss with adult nephrologists about this and propose suitable paed rep if necessary.
3.	Update on shared care clinics	These have now happened in Doncaster, West Suffolk, James Paget and Grantham. However, no SLAs have been agreed as yet. NUH hope to operate a system whereby they take the tariff for the clinics. NUH also hopes that all the shared care clinics will eventually be run in this way but it has to be agreed through specialist commissioning. Jenni Twinn be asked to look at these issues. We are still experiencing problems contacting the	Martin to write to

		relevant managers at Hinchingsbrooke but will be contacted again. The urology team at Addenbrookes are currently trying to set up clinics at Hinchingsbrooke and this is a good opportunity to try to see if they could be on the same day as a renal clinic from Nottingham. West Suffolk clinic is running but the financial agreement still needs sorting. James Paget is on hold until agreement can be sorted out. Grantham has evolved as both the Lincoln and Boston clinics are very full but no on-going commitment to Grantham clinics at present.	Hinchingsbrooke management again Martin to write to Dr Babu to put the case for expansion of Lincolnshire clinics.
4.	Nephrology support for integrated children's hospitals.	Sheffield are hoping to advance things and Andy Lunn represented NUH at a recent meeting there. They are committed to allowing existing nephrology PAs to be used to fund a future post in Nottingham and they would also like to appoint a SPIN paediatrician in the nearer future. The paediatric nephrologist would also look after most of the South Yorkshire shared care clinics. Leicester has not yet progressed. Cambridge is more difficult because it is not within a commutable distance and it is felt that a SPIN doctor would be the best way forward. Andy Robb welcomed this but acknowledged there may be funding issues.	
5.	Peer Review	EMEESY is to pilot a peer review of paediatric nephrology networks along with GOS from London and Southampton as a unit without transplant facilities. Peer review has improved networked cancer services. The diabetes network standards were discussed to look at what they have audited against, eg hospital standards, clinics.	
6	Constitution of steering group	It was also felt that we need to clearly define the membership of our steering group along with definite	

		terms of reference for the patient/parent representative. It was suggested that they have a 2 year term of contract. It was also suggested that there could be more than one patient/parent representative to make it less daunting for them. We still need a local nurse from outside Nottingham, a pharmacist, dietitian and psychosocial input. We could also include a urology nurse at a later date.	
7	Annual General Meeting	Martin went through the agenda for the AGM to be held on 4 th October. He suggested that next year's education meeting/AGM should be held on 10 th October 2014 with acute kidney injury as the topic. It was suggested that we propose an audit of UTI and Simon Rhodes will take the lead on this.	Martin Simon
8	Website	Martin showed a mock up of our proposed new website. We still need to check whether we can use www.emeesy.nhs.uk and to check NHS branding. Michelle offered to enquire with NHS England but also suggested we look at www.nhsnetworks.uk website	All
9.	Review of paediatric renal service specification	Specialist commissioning have developed these and we have been asked to carry out a self assessment against them. They have been developed through clinical reference groups and come into contracts from October. Antenatal counselling – well covered in Nottingham but not sure about in other centres; Transition is patchy – we need to aspire to a transition clinic for each centre Home haemodialysis – not compliant. Mona asked whose responsibility it is to chase blood results which have been requested by the Nottingham team but to be done locally. It was agreed that this was the responsibility of the person who has asked for the tests to be done. Andy Robb suggested having a	

		white board or similar to keep a check on these. There was some discussion about nephrology support for other children's hospitals and whether non-compliance in these areas meant that it should be registered as a network risk.	
10.	Governance	Risk assessment was discussed. It was agreed that this needs defining more and will be discussed at the next meeting.	Shelley/Martin
11.	Patient pathways	The nephrotic syndrome pathway was looked at. All were happy with the format and it was agreed that it should be published on the website once it has been finalised.	
12.	Any other business	Andy was asked if he could put together details of urology services within our area by finding out what each centre has in terms of clinics and nurses.	Andy
10.	Date of next meetings	16 th December 2013 at 3.00 pm. NUH 20 th March 2014	

These minutes accepted as a true record of the meeting.



16 December 2013