

Paediatric Renal Network Steering Group
Friday 22nd March 2013

Present: Martin Christian, Shelley Jepson, Judith Hayes, Simon Rhodes, Mona Aslam

Apologies: Gail Moss

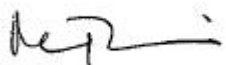
	Item	Discussion	Action
1.	Minutes of last meeting	These were discussed and agreed.	
2.	Terms of reference	Martin circulated the draft Terms of Reference for discussion. He has spoken with Manoj but we still have no urology representative on the steering group as ideally we would like this to be a combined nephrology and urology network. Other suggested members are: Michelle Rippin – new commissioner from April 1 Parent representative – suggest Julie Gibbs. It was also suggested that parents should be invited – possibly see who is active on Facebook. Psychosocial – Heidi/Suzanne/Kat/Claire Continence Advisor Pharmacist would be important – to ask Andrew Wignall It was agreed that we should take advice from Michelle about other roles. The terms of reference were passed as a provisional document and will be put on the website.	Martin to approach Shelley to approach Judith
3.	Branding of network	We have surveyed a few members of staff and it has been agreed that the network should be called EMEESY (East Midlands, East of England and South Yorkshire). We have a design for the logo and this will be circulated to members of the steering group for approval.	
4.	Feedback from Glasgow	Martin will produce a report at the end of the first 5 months secondment which will include feedback from	Martin

		Glasgow and the focus group.	
5.	Review of service specification	A network conference has been organised which will take place in Nottingham on 17 th May to which steering group members are invited. There will be videoconferencing available for those unable to attend in person.	
6.	Website development	The website is now available. It has been combined with the unit website and we do have some constraints on what we are allowed to put on it. It is being added to gradually. There was a suggestion that we could link to the BPSU website.	Judith/Martin
7.	Patient parent involvement	a. Focus groups. A focus group was held on 31st January with parents from 4 families being involved. They reported that they are happy with their care being at Nottingham but they are all families who have been with us a while. It was agreed that it would be useful to have further focus groups in other centres with families who have not yet reached dialysis/transplantation. b. Monique Burgin, staff nurse from Nottingham, has been put forward to do patient stories through the University of Nottingham. They would also like her to do more focus groups. c. Facebook. The Facebook page is still not running. Once it is we will hand out a flyer in all clinics with details of this and the website. d. Surveys. Poor response to SurveyMonkey but once Facebook is running we will link to this and give a deadline for completion. Once the surveys have been finalised they will be analysed.	Shelley Shelley
8.	Job descriptions	a. Link nurse. It was agreed that the job description should be e-mailed around link nurses. It was suggested that a reference should be made to e-learning training for nurses and that they should	Shelley

		be encouraged to participate in such training. It was also agreed that we need to ask what support nurses get in DGHs. b. Link doctor – Simon has drafted a job description. There was discussion re PAs and it was agreed this should be a minimum of 0.125 to a maximum of 2. Link doctors to be contacted and asked to review with a deadline. To be put on website.	Simon/Judith
9.	Quality standards for existing shared care clinics	Mona has reviewed SPIN doctors survey and developed guidelines for SPINs. The local paediatrician should be the gatekeeper for clinics. It would be important for referral letters to be sent to the visiting nephrologist prior to the clinic so that they have some knowledge of the patient but it would be the link paediatrician's responsibility to add the patients to the clinic. Timing for patients – 15 mins for follow ups. 20 mins for new patients if the link paediatrician is also in clinic and 30 mins if no link paediatrician in attendance. The visiting nephrologist would normally dictate the letter. It should be the responsibility of the link paediatrician to check results. Mona has checked with her IT dept who suggested that Citrix should be accessible externally and that other hospitals should have similar systems. It was also suggested that there should be a designated timeframe for discussing results with the visiting nephrologist. Ideally there should be a dietitian and nurse with an interest available for each clinic.	Mona to create document to be put on website.
10.	New shared care clinics	We have now had positive clinics at both Barnsley and West Suffolk where shared care clinics will commence once management have agreed contracts and dates have been set up.	

		A clinic has also been held at Hinchingsbrooke but their management do not support regular clinics being set up. Martin has contacted the specialist commissioners about this and is waiting to hear back from them. The clinic itself went well. Jonathan is to do a clinic at James Paget Hospital on 12th April. Doncaster and Bassetlaw Hospitals have only agreed to a meeting at present on 17th April.	
11.	Communication	EMED – Simon has not yet contacted Catherine Byrne but will do so in the near future.	.
12.	Multi-professional education day	Verbal feedback from today has been positive.	
13.	Pathways	No progress yet. To start looking at these in the next 12 months.	Martin/Shelley
14.	Any other business	RCPCH document. This was discussed and agreed it is a very good document.	Martin to reproduce 20 proposals with 4 th column for Progress for EMEESY.
15.	Date of next meeting	Suggested dates either 24 th or 28 th June 2013.	

These minutes accepted as a true record.



24 June 2013