

Paediatric Renal Network Steering Group
Friday 4th January 2013

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

Apologies: Gail Moss

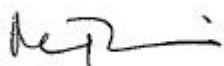
	Item	Discussion	Action
1.	Terms of reference	It was agreed that we need a steering group and it is hoped that this will evolve into a more formal group for which we need terms of reference. Martin showed the Glasgow template to Simon and Mona. It was agreed that we need a member from each area – East of England (Mona), East Midlands (Simon) and South Yorkshire (Gail). Ideally the steering group needs to include both nephrology and urology as many of the management problems are enuresis, etc. We will invite a Nottingham urologist to attend the next meeting. Simon asked whether there was any scope to include neonatologists. Martin said there probably wasn't a need for this at the moment but it is important to draw up standards for neonatology referral etc. Mona suggested that we have a study day with a neonatal slant in the future. A formal infrastructure of communication is needed and pathways are required for this.	Martin to draft terms of reference. Martin to speak with Manoj
2	Branding of network	It was discussed that we need a logo and name for the website and Facebook page. 2 names were suggested – EMEESY (East Midlands, East of England, South Yorkshire) or simply East of England Network as that describes the area broadly. It was agreed that a logo should be designed and sent out to lead consultants for agreement.	Shelley to speak to Jonathan (teaching assistant) about designing logo

3	Feedback from Glasgow	Martin explained how the Glasgow network was set up. They now call their outreach clinics shared care clinics and this is something we should adopt. There is a need to define a level of time for nephrology for consultants in each centre along with dedicated nurse and dietitian time. Glasgow have a full time coordinator/administrator. They also do a lot of videoconferencing and Martin mentioned that we have started to do this with Cambridge for x-ray meetings. He felt it would be good to establish this with other centres as well. Kings Mill have established nephrourology x-ray meetings which are held on the same day as the shared care clinics. The vision for the end of March is to take some elements of the Glasgow network and do what is possible with the limited resources we have. There is a need for central administration for coordination of meetings, clinics etc.	
4	Review of service specification	The national plans are that each tertiary centre will receive money to fund local clinics but there is uncertainty as to how this will work yet. Would we be able to top slice this for administration and local nursing? We would need a network lead consultant, lead nurse and central administrator to sustain the network. Martin and Shelley are hoping to be on the national committee discussing these issues. Martin mentioned the possibility of extra local funds being available to extend the secondment for a further year. If this is possible then by the end of the year we should be able to make a business case on how the network infrastructure looks and what we need to resource it effectively.	

5	Website development	We will be developing a website which will be an essential tool for communication. Martin encouraged Simon and Mona to look at the SPRUN website (www.sprun.scot.nhs.uk)	
6	Patient parent involvement	a. Focus groups. We originally thought about having focus groups in each area but with the time restraint have decided to hold one in Nottingham after the Thursday clinic. It was agreed that someone who does not work in Nottingham should chair this meeting and Simon agreed to do this. A date of 31st January was suggested but Simon was unsure of his commitments for that day. At the focus group we will ask families about difficulties in travelling to Nottingham, costs involved, what needs to be in place locally etc. b. Facebook. Martin said that we are going to have a dedicated Facebook page for which we have permission. c. Surveys. Following on from discussions at the focus group we plan to survey patients attending shared care clinics as well as the Nottingham clinic.	Simon to let us know whether 31 st January convenient
7	Job descriptions	a. Link nurse – a draft has been circulated b. Link doctor – Simon agreed to draft this.	Simon
8	Quality standards for existing shared care clinics	It was agreed that standards and guidelines need writing. It should include issues such as who decides who is added to shared care clinics and who should overall responsibility for them. Following this a dashboard for each centre can be prepared so each centre can see how they compare to the network average standards.	Mona Martin
9	New shared care clinics	Martin explained that we are planning to hold new one-off shared care clinics at Doncaster, Bassetlaw, Barnsley, Hinchingbrooke, West Suffolk and James	

		Paget. We already have a link paediatrician in each centre and each clinic will be followed by a clinical discussion meeting.	
10	Communication	The website will be the main focus of communication. Notes from meetings etc will be put there. Martin is producing a regular update for Stakeholders and lead clinicians on our progress with the Network. The importance of a good IT infrastructure was discussed. Martin mentioned the launch of EMED and the hope that it can eventually be set up in other centres. Kings Mill will also be launching this at the same time.	Simon to contact Catherine Byrne to see if he and Kerrie (his secretary) can have access to EMED.
11	Multi-professional education day	The details of the next nephrourology meeting to be held on 22 March were outlined; nurses and dietitians are to have meetings at the same time as the main meeting with nurses joining in a plenary session. There should be the opportunity for everyone to talk at lunchtime as well.	
12.	Any other business	a. Mona suggested having study days for GPs locally. b. Pathways. Shelley said that we were working on some pathways and that these would be put on the website. Simon mentioned a GP website that already has some good pathways.	Simon to e-mail name of website
13.	Date of next meeting	It was agreed to hold the next meeting following the nephrourology meeting on 22nd March 2013.	

These minutes accepted as a true record.



22 March 2013