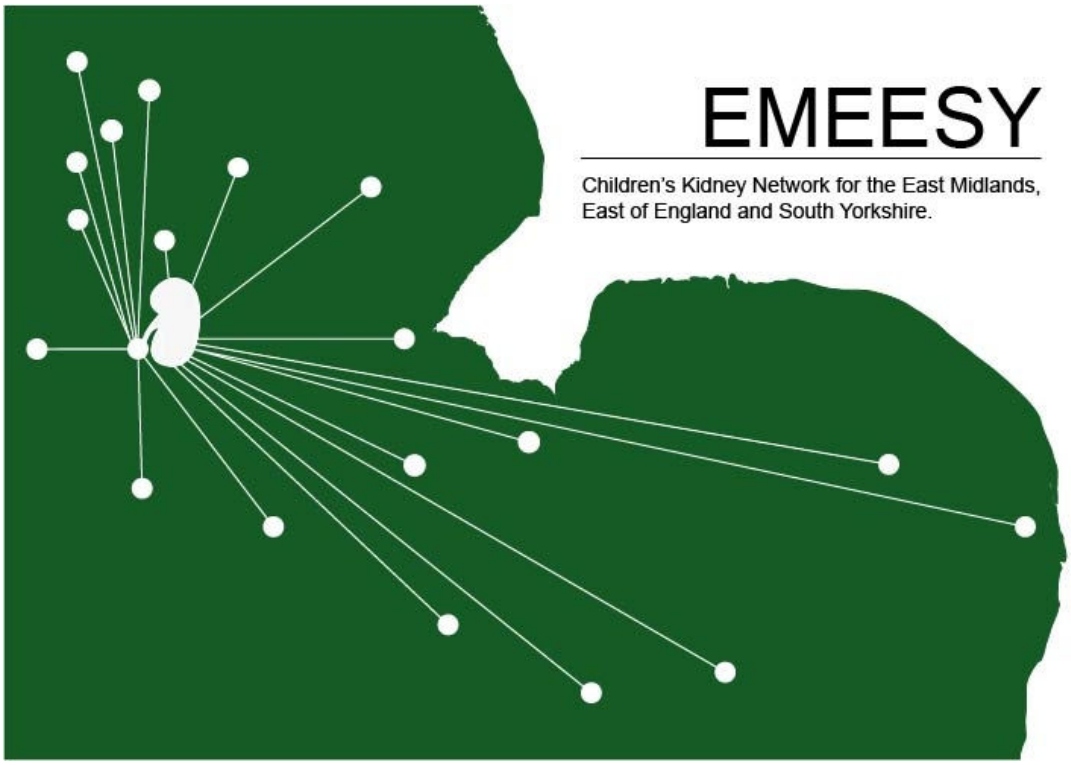


Secondment project

November 2012 – March 2013

Children's Kidney Network for the East Midlands, East of England and South Yorkshire.

Report of a 5-month secondment from November 2012 to March 2013.

Author:
Martin Christian
Consultant Paediatric Nephrologist
Nottingham Children's Hospital

With contributions from:
Shelley Jepson, Lead Nurse, Paediatric Nephrology, Nottingham Children's Hospital
Pearl Pugh, Senior Paediatric Renal Dietitian, Nottingham Children's Hospital

Contents

Date of report: May 2013

1. Executive summary

Background

A resilience grant of £30k was awarded to the renal team at Nottingham Children's Hospital to undertake part-time secondments over a 5-month period from November 2012 to March 2013 to develop networked services. The main aims of the secondment were to conduct a health needs analysis of the network and build basic network infrastructure.

Main findings of the health needs analysis

- Half of the patients seen in Nottingham clinics are from outside the immediate Nottingham area.
- A significant number of children seen in local shared-care clinics warrant dietetic input which is currently not available universally.
- There are considerable differences in the organisation of local clinics, affecting the nature of the shared-care.
- Significant time is spent centrally dealing with clinical advice to local colleagues which is not included in commissioning.
- The weekly nephrourology x-ray MDT is a clinically effective meeting which is well-utilised by paediatricians from the more local centres and deserves formal development through quality and potential cost-saving.
- Views of families have been sought through various means. Travelling time and costs to Nottingham are repeatedly cited as issues and this is supported in surveys of local professionals.
- The Scottish Paediatric Renal and Urology Network (SPRUN) offers a template of networked care for a part of the UK which is similar in geography and variety of local centres to EMEESY.
- Clinical discussion at the time of shared-care clinics has the potential to provide cost-savings through confident discharge to primary care and reduction in further investigations.
- Clinical discussion during shared-care clinics also highlighted unmet need, thus providing measurable improved quality of care.

Main achievements of the secondment

- A bank of network resources on the hospital intranet shared area available to Nottingham Children's Hospital renal team staff.
- Identification of a dietetic contact for all local centres.
- From a baseline of zero, identification of a nursing contact for 14 out of 19 local centres.
- Agreement to commence new shared-care clinics in 5 out of 6 local centres that currently have no clinic.

- Launch of new network website (www.childrenskidneynottingham.nhs.uk)
- Launch of Facebook page (www.facebook.com/Emeesynuh) to develop patients/parent involvement and support
- Set-up of provisional network steering group meeting 3-monthly
- A new multi-disciplinary education meeting that was well-attended by nurses and dietitians, representing 12 centres between them (with representatives from 3 other centres registered but unable to attend due to weather).

Recommendations for sustainable networked services

- The secondments have been able to continue for a further 12 months funded charitably.
- Within the next 12 months, EMEESY aims to
    - consolidate the work of the initial secondment
    - build stronger network links
    - consolidate newly established clinics
    - formally constitute a network steering group to develop clear network vision
    - develop measurable outcomes
    - use this experience to influence national commissioning of paediatric renal services.
- Network links thus far have been built upon long-term good working relationships; the investment required to develop networks when building on such existing structures may not be as considerable as was used to establish the SPRUN network in Scotland.
- Beyond 2014, there is a need for investment in core infrastructure and network leadership for EMEESY to be a sustainable network.
- The British paediatric renal community need to work together to develop acceptable and valid measurable clinical outcomes.
- Experience gained through this secondment should be used to develop a national framework for commissioning paediatric renal services.

2. Introduction

Background

Improving the standard of care of children with kidney disease through paediatric nephrology networks[1] was published by the Royal College of Paediatrics and Child Health (RCPCH) in August 2011 and was the result of a working party between the RCPCH, the British Association of Paediatric Nephrology (BAPN) and NHS Kidney Care.

The report is in line with other recent RCPCH strategy to promote good specialised paediatric clinical care via networks. The current provision of paediatric renal services across the UK is reviewed. Recommendations are made for service improvement in line with principles within the Kennedy Report of 2010 for children to receive "the best possible quality of care as close to where they live as possible". General principles for commissioning paediatric networks are followed by paediatric nephrology-specific recommendation standards for providers and then commissioners.

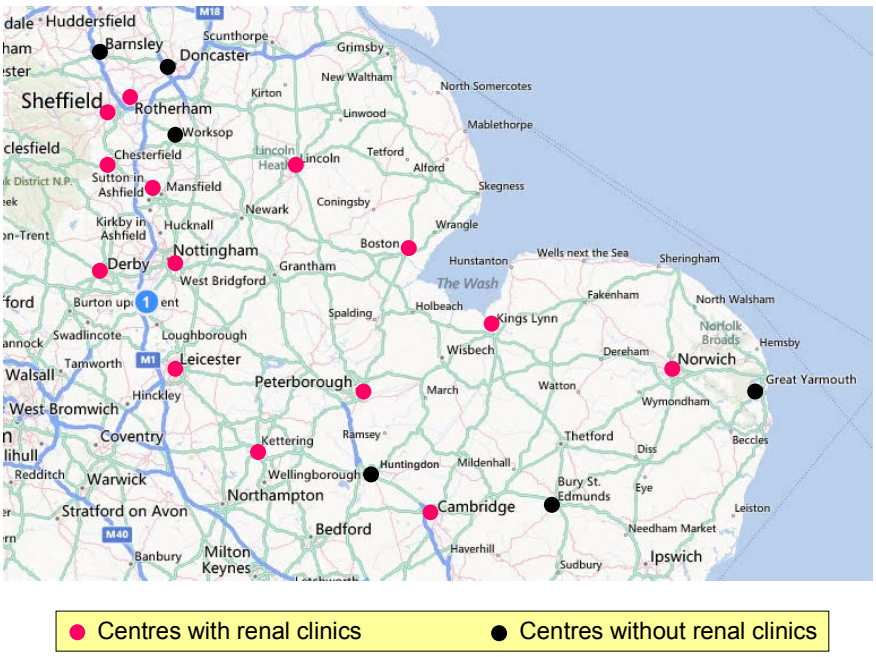
Within the East Midlands, East of England and South Yorkshire, there has been an informal networking of children's renal services that has developed over the last 27 years. The Children's Renal and Urology Unit, now based within Nottingham Children's Hospital, was established in 1985 with the appointment of Professor Alan Watson. A network of outreach clinics was established, initially in the East Midlands, starting with Leicester Royal Infirmary and then expanding into South Yorkshire in the 1990s and finally into local centres within the East of England. There are currently 13 centres where local shared-care clinics happen between 3 and 12 times per year. These are: Lincoln County Hospital, Pilgrim Hospital in Boston, King's Mill Hospital in Mansfield, Leicester Royal Infirmary, Sheffield Children's Hospital, Rotherham General Hospital, Queen Elizabeth Hospital in King's Lynn, Norfolk and Norwich Hospital, Peterborough District Hospital, Addenbrooke's Hospital in Cambridge, Chesterfield and North Derbyshire Royal Infirmary, Derbyshire Children's Hospital and Kettering General Hospital. A map of the EMEESY region showing the locations of centres with and without shared-care clinics at the start of 2013 is shown in figure 2.1.

Six hospitals within the East Midlands, East of England and South Yorkshire (EMEESY) regions have no shared-care clinics yet. These are: Doncaster Royal Infirmary, Bassetlaw Hospital in Worksop, Barnsley General Hospital, Hinchingbrooke Hospital in Huntingdon, West Suffolk Hospital in Bury St Edmonds and James Paget Hospital in Great Yarmouth. Arrangements for seeing patients with chronic or complex nephrological disease vary but include seeing patients in Nottingham or seeing in a close by paediatric renal shared-care clinic.

In addition to formal shared-care clinics, there are informal links for advice by letter/email/telephone, involving all consultants in Nottingham. Advice about acute

paediatric nephrology is usually handled by the on-call consultants in Nottingham and the on-call paediatric team in the local hospital. There are no agreed care pathways for these arrangements.

Figure 2.1. Paediatric centres with or without shared-care renal clinics throughout the East Midlands, East of England and South Yorkshire at the start of 2013.



A large part of paediatric nephrology clinical work relies on good quality renal tract imaging. Imaging from patients in local hospitals is frequently sent to consultants in Nottingham for review at a weekly nephrourology multi-disciplinary x-ray meeting. As before this is currently done without a formal referral and costing, as has taken place in other parts of the UK.

Following the publication of the Nottingham Children's Renal Unit annual report each year, there has been an informal meeting with local paediatric renal leads for some years. In the last five years, this meeting has become more formalised and has had a bigger attendance. In 2011, a full-day meeting was piloted which combined an educational meeting with a network business meeting held at a venue away from a hospital. This meeting was well-attended and positively received by delegates.

For many years there has been a nephro-urology x-ray meeting held twice yearly. The autumn meeting which was predominantly a case-sharing meeting has petered out in recent years but since 2006, the spring meeting has become a theme-focused educational meeting with invited speakers of national and international standing as well as providing a forum for case-sharing.

Although some of the recommendations from *Improving the standard of care of children with kidney disease through paediatric nephrology networks*[1] are already present within EMEESY, we recognised that there is much to be done to provide

equity of access to children's renal services around this supra-region and further developments that would be necessary to provide a 21st century networked clinical service.

- For example, a universal provision of shared-care clinics throughout EMEESY would be a readily measurable improvement.
- The shared-care clinics have been clinician focussed although we emphasise the importance of a multi-disciplinary approach for chronic kidney disease (CKD) clinics in Nottingham. Building MDT support into shared-care clinics is another area for improvement which is included amongst the RCPCH's recommendations.
- Although a regular education programme for doctors currently exists this would need to be developed to include education for other professionals.
- Communication would be enhanced with a network website replacing the need for regular ad hoc emails.

The secondment proposal

Following dialogue with East Midlands SHA specialist commissioners, a one-off resilience grant was offered for network development. The application which was accepted was to support backfill for three individuals at Nottingham Children's Hospital to be able to be seconded one day per week to carry out a health needs assessment and begin to put into place the basics of a network infrastructure. The individuals who were seconded were: Martin Christian (consultant paediatric nephrologist), Shelley Jepson (Lead nurse) and Judith Hayes (senior secretary for paediatric nephrology). In additional Pearl Pugh (part-time senior paediatric dietitian) was funded for an additional four hours per week. These four individuals formed a network core team modelling the roles of clinical lead, network lead nurse, network administrator and lead dietitian respectively.

The aims of the secondment were:

1. To carry out a health needs assessment and gap analysis of paediatric nephrology services throughout EMEESY.
2. To identify the infrastructure required to set-up and sustain a managed clinical network for paediatric renal services.
3. To document how a managed network would improve the quality of care delivered, and what cost savings might be made.

As well as financing the above secondments, the resilience grant also funded:

- Further consultant time backfill to allow for free one-off shared-care clinics for the six centres with no current renal clinic.
- A network core team visit to Glasgow to meet with key individuals in the Scottish Paediatric Renal and Urology Network (SPRUN), the UK's only managed clinical network for children's renal services.
- A one-off education meeting for nurses and dietitians.

3. Health needs assessment – documenting uncosted network work

Most local shared-care clinics are funded on service level agreements. They are costed to include the clinic time itself, travelling time/costs and a nominal additional third of the clinic time for consultant administration time for checking letters and chasing and actioning results.

The two main areas of uncosted work within the network structure are the time taken with giving clinical advice at any time, but particularly outside of the on-service provision. Related to this are the time/personnel involved in reviewing imaging at the weekly nephrourology MDT x-ray meeting.

Clinical advice

For a four-week period from the end of November until Christmas, a survey was conducted to collect information on the extent and type of network communication for clinical advice. No record of these episodes of communication is made though we recognise that for governance purposes, we should aim to record the nature of any verbal advice given.

For several years now, there has been a senior paediatric renal nurse pager which is held by one of the paediatric renal nursing team during office hours and by the ward staff out of hours. This is the main gateway for communication with parents and there are many calls each day. The clinical advice survey focussed instead on requests primarily from local health professionals, mainly local paediatricians. It proved difficult to collect information from all members of the multi-disciplinary team but we did record episodes of clinical advice made to pharmacists, nurses and dietitians during this same period.

During this four week period, 61 episodes of clinical communication were recorded from one consultant (MTC). The breakdown of these episodes by type of communication, local centre and outcome is shown in tables 3.1 to 3.3 below:

The majority of the time taken was with local centres where clinics were done by the consultant in question or with local centres without a shared-care clinic at the time of the survey. In all the time taken for these episodes of communication amounted to 4 hours and 39 minutes, an average of 0.25 PA per week which is separate to administrative time relating to plans made in a shared-care clinic.

Table 3.1. Breakdown of episodes by local centre

centre	number of episodes	time (min)	Shared-care clinic
West Suffolk*	17	69	Not yet
Boston	8	29	MTC
Cambridge	7	45	MTC
Doncaster	6	12	Not yet
Bassetlaw	6	28	Not yet
Barnsley	4	9	Not yet
Hinchingbrooke	4	13	Not yet
Sheffield	3	11	Other
Rotherham	2	6	MTC
Kettering	2	40	Other
Leicester	1	5	Other
Kings Lynn	1	2	Other
Derby	0	0	Other
Lincoln	0	0	Other
Kings Mill	0	0	Other
Chesterfield	0	0	Other
Peterborough	0	0	Other
James Paget	0	0	Not yet
Norwich	0	0	Other
Total	**58**	**269**	

* Many of these episodes related to discussion about the joint follow-up of one complex transplant patient

Table 3.2. Breakdown of episodes by type of communication

Type of communication	number of episodes	time (min)
Email with reply	20	93
Letter received	18	27
Letter with reply	6	20
Phone call	17	129

Table 3.3. Breakdown of episodes by outcome of the episode

Outcome	number of episodes	time (min)
Advice given	23	145
Information noted	18	20
MDT liaison	15	84
Arranged to see in shared-care clinic	5	20

Nephrourology MDT x-ray meeting

Between 28 November 2012 and 20 March 2013, Judith Hayes attended the nephrourology imaging MDT to make notes on patients, their origin of referral, the imaging discussion and the outcome of discussion. The database housing this information is stored on the Children's Renal and Urology Unit shared area (network/current network evaluation/nephrourology x-ray MDT database).

Judith attended for 14 weeks and in that time 161 patients were discussed, an average of 11.5 patients per week.

The breakdown of referring hospital, in order of frequency, is shown in table 3.4.

Table 3.4. Breakdown of referrals to nephrourology MDT by referring centre

centre	n	average/week
Nottingham	58	4.1
Derby	25	1.8
Lincoln	18	1.3
Boston	12	0.9
Sheffield	9	0.6
Kings Mill	7	0.5
Chesterfield	6	0.4
Leicester	6	0.4
Cambridge	4	0.3
Doncaster	4	0.3
Peterborough	4	0.3
Kings Lynn	3	0.2
Barnsley	1	0.1
Rotherham	1	0.1
Other	1	0.1
Bassetlaw	0	0
Hinchingbrooke	0	0
James Paget	0	0
Kettering	0	0
Norwich	0	0
West Suffolk	0	0

An outcome was recorded for 148 patients (92%). The outcomes may be grouped in the following categories: those requiring further imaging (either a different type of imaging or interval scanning), those requiring surgery, those needing referral for treatment such as intermittent catheterisation or biofeedback, those requiring assessment of bladder emptying/uroflow (carried out by paediatric urology clinical nurse specialists), those needing medical treatment (antibiotics or anti-cholinergics usually) and those with a clinical review needed only. Those requiring further imaging, surgery or some form of treatment may be said to have benefited from the MDT discussion. The breakdown of outcome categories is shown in table 3.4.

Table 3.4. Breakdown of discussion outcome.

MDT outcome	
Further imaging/interval scanning	63
Surgery needed	32
Catheterisation	7
Biofeedback	3
Bladder assessment	2
Medical treatment	3
Clinical review	23
No action/other	28

Of those patients whose discussion outcome was for further or interval imaging, the following imaging which was agreed is itemised in table 3.5.

Table 3.5. Breakdown of further imaging resulting from discussion.

Further imaging or interval imaging	
Ultrasound	28
MCUG	13
DMSA	7
MAG3	5
Bladder pressure studies	5
MRI	1
MRU	1
CT	1
IVP	1
Nephrostogram	1

For those patients on whom a decision was taken to proceed to surgery the procedures in questions are shown in table 3.6.

Table 3.6. Types of surgical procedure agreed following discussion.

Procedures required	
Cystoscopy	7
Pyeloplasty	4
STING	4
Ureteric stenting	3
Supra-pubic catheter	2
Lithotripsy	2
Ureterocele decompression	2
Dorsal rhizotomy	2
Nephrectomy	1
Ureteric reimplantation	1
Transplant (safe to proceed)	1
Renal biopsy	1
Unspecified	2

The database demonstrates this is a clinically effective multi-disciplinary meeting with an appropriate number of positive actions resulting from the discussion. The nature of the outcomes supports attendance at the meeting by radiologists, urologists, nephrologists, urology specialist nurses and a stone specialist. More than half of patients discussed are not local Nottingham patients and in particular, Derby and combined Lincolnshire hospitals contributed around 2 patients each per week.

It is suggested that the meeting should continue to receive administrative support. Attendance could be recorded each week which, along with a record of discussion, will become an important record to verify the effectiveness of a multi-disciplinary meeting. The cost of administrative support will include the hour of the meeting and at least another 30 minutes to type up notes. This would be even longer if a pathway for communicating decisions on individual patients back to referring external consultants is developed.

A regular video-conferencing meeting to review nephro-urology patients seen in a joint nephrourology clinic in Addenbrookes has recently been established (no financial agreement for this). In addition, a nephrourology MDT takes place at Kings Mill Hospital prior to each shared-care renal clinic with a paediatric urologist and paediatric radiologist from Nottingham Children's Hospital in attendance. Developing further video-conference meetings would allow local consultants to participate in the discussion and education. They may well also have cost-improvement benefits for local hospitals through a reduction in repeat local imaging which is often not necessary after MDT discussion. One local centre has referred patients for discussion through nephrology, urology or sometimes a mix of both routes. There is a need for a unified referral system for a nephro-urology opinion predicated upon reviewing imaging. Such a referral may alleviate the time taken in shared-care clinics. There ought to be an appropriate tariff for this referral route to ensure appropriate resourcing is in place.

Dietetic input into shared-care clinics

Nottingham Children's Hospital renal dietitians have supported many local shared-care clinics either through their attendance or by subsequent telephone advice. None of this work has been properly costed and there are no service-level agreements for dietetic provision to any shared-care clinic.

As part of the health needs analysis for the secondment, a retrospective audit was undertaken to assess the need for dietetic input to renal patients attending the renal shared care clinics at eight hospitals within the renal network during 2012. Three clinic lists from each centre were pulled with the corresponding patient letters. Some clinic letters were not available. Using the information documented in the letter a judgement was made as to whether dietetic input was required. Some consultants gave direct mentions to the need for dietetic input; whereas with others a subjective clinical judgement based on the information available was made. Over and above this specific advice, the majority of renal patients would benefit from an initial teaching session regarding sodium restriction. The results of the audit are shown in table 3.7.

It is a given that dietetic counselling is an important part of managing children with chronic kidney disease. The documentation of dietetic need from the clinic letters suggested as much as 67% of those patients attending the shared care clinics would have benefited from dietetic input. The clinics which currently have dietetic input clearly had a greater documentation of dietetic need, whereas those clinics with little or no input made little or no mention of dietetic need.

Table 3.7. Audit of the need for dietetic input for patients attending three renal shared care clinics at 8 hospitals during 2012.

Shared Care Clinic	Clinic letter documented or indicated dietetic input was required		
Boston	36%	18%	12%
Cambridge*	38%	50%	24%
Kettering	30%	18%	0%
Kings Lynn	35%	20%	32%
Leicester*	64%	36%	64%
Peterborough	23%	67%	11%
Rotherham	14%	0%	13%
Sheffield	25%	25%	20%

*Indicates a clinic which has a dietitian available at the time

Summary

There is a large amount of work relating to patients not directly under the care of Nottingham Children's Hospital that is delivered either through clinical advice to local colleagues. The time spent on this workload, estimated in excess of 1 PA per week if data from a single consultant are extrapolated for the departmental workload, need to be considered with future commissioning of the service with Nottingham Children's Hospital at the hub of a large network.

Discussion of imaging at a weekly x-ray MDT meeting is a service which can deliver clinical advice from a broad and expert multi-disciplinary team to a referring local paediatrician, whilst delivering potential cost-savings through saving on unnecessary repeat scans. A formally costed referral pathway for the nephrourology MDT instead of clinic referrals should be developed as a more sustainable means to finance the necessary administrative support for this aspect of the service.

Dietetic support for children attending local shared-care clinics is essential. Post-clinic telephone support is a poor substitute for multi-disciplinary review in clinic. The audit of need for dietetic input justifies a consistent workload for dietitians as part of a paediatric renal shared-care clinic and supports the ideal of a paediatric dietitian available in clinic to see these children there and then.

4. Health needs assessment – establishing new shared-care clinics

Within the resilience grant, funding was agreed for one-off shared-care clinics in the 6 centres without clinics – Barnsley General Hospital, Doncaster Royal Infirmary, Bassetlaw Hospital (Worksop), Hinchingbrooke Hospital (Huntingdon), West Suffolk Hospital (Bury St Edmonds) and James Paget University Hospital (Great Yarmouth).

The offer of one-off clinics was accepted for Barnsley, Hinchingbrooke, West Suffolk and James Paget. With the exception of James Paget, all these clinics took place before the end of March 2013. It was not possible to sort a mutually convenient date for James Paget University Hospital within that time and the clinic took place on 12th April. Doncaster and Bassetlaw Hospitals (a single Trust with acute paediatric services on both sites) declined a one-off clinic but agreed to a meeting to discuss on-going shared-care clinics and this meeting took place just outside the secondment time-frame on 17th April.

At each one-off clinic, time was set aside for clinical discussion and a business meeting was also encouraged to discuss how ongoing clinics might be established. We also asked permission to collect email addresses from parents to send a short internet survey about shared-care clinics.

Barnsley General Hospital

The clinic took place on 22 January 2013. Five patients were seen and five patients were discussed after the clinic. Nottingham Children's Hospital staff who went were Dr Andrew Lunn (consultant paediatric nephrologist), Shelley Jepson (Lead nurse) and Pearl Pugh (senior paediatric renal dietitian). A local paediatrician (Dr Sunil Bhimsaria) sat in during the clinic and contact was made with a local community nurse and local paediatric dietitian. The clinical discussion of patients following the clinic included incidences of patients not needing the proposed repeat scans, thus identifying potential cost-savings. A business meeting took place after the clinic at which it was agreed by clinical and managerial staff from Barnsley General Hospital to commence a 3-monthly shared-care paediatric renal clinic.

West Suffolk Hospital

The clinic took place on 28 February 2013. Ten patients were seen (nine follow-up patients and one new patient to nephrology) and a further 21 patients were discussed afterwards. Nottingham Children's Hospital staff who went were Dr Martin Christian (consultant paediatric nephrologist), Shelley Jepson and Pearl Pugh. A local paediatrician (Dr Raman Lakshman) and local paediatric nurse practitioner (Gemma Dale) sat in during the clinic and contact was also made with a local paediatric dietitian. Clinical discussion at the end of clinic concerned mainly which patients would be suitable to transfer from the Cambridge clinic to their more local West Suffolk Hospital future clinic. Of the other patients discussed, two patients who

could be safely discharged to primary care were identified and one patient with a complex urological problem was identified who required discussion at a multi-disciplinary nephro-urology x-ray meeting. A brief discussion between medical staff and local business manager took place after the clinic and it was agreed to commence a 3-monthly shared-care paediatric renal clinic.

Hinchingbrooke Hospital

The clinic took place on 12 March 2013. Nine follow-up patients were seen (five with care currently at Nottingham, three currently seen in the Cambridge clinic and one with shared-care between Cambridge and Nottingham) and a further six patients were discussed afterwards. Nottingham Children's Hospital staff who went included Dr Meeta Mallik (consultant paediatric nephrologist) as well as Shelley Jepson and Pearl Pugh as before. A local paediatrician (Dr Viktoria Dixon) sat in during the clinic but no contact with local nurses or dietitians could be made. A link nurse has since been identified. The clinical discussion included one patient needing a urology referral, one teenage patient needing referral onto adult renal services at Addenbrooke's and one antenatal follow-up patient whose post-natal imaging will require nephrourology review. Managerial staff at Hinchingbrooke Hospital declined a meeting to discuss future clinics having taken advice from local commissioners that there was no funding for such clinics.

James Paget University Hospital

The clinic took place on 12 April 2013. Six patients were seen and five patients were discussed afterwards. Nottingham Children's Hospital staff who went were Dr Jonathan Evans (consultant paediatric nephrologist), Kim Helm (paediatric transplant nurse specialist) and Pearl Pugh. A local paediatrician (Dr Esi Bentsi-Enchill) sat in during the clinic and contact was also made with a local nurse and paediatric dietitian. Clinical discussion at the end of clinic included discussion of one complex patient receiving regular home intravenous treatment, whose shared-care is essential given the distance from Nottingham. This was a rare, valuable opportunity for face-to-face discussion of such a complex child. After the clinic, the local staff confirmed that they would like to set up a regular shared-care paediatric renal clinic.

Doncaster and Bassetlaw Hospitals

There are currently a large number of patients from these two catchment areas, particularly Doncaster, being seen in renal clinics in Nottingham. Discussions about establishing a local shared-care clinic in Doncaster began in 2007 but have been thwarted through insufficient local managerial support in the past. A meeting to discuss future clinics was held on 17 April at Doncaster Royal Infirmary attended by Dr Martin Christian and Sandra Minich (Assistant General Manager for Family Health Directorate at Nottingham University Hospitals) from Nottingham, Dr Vivek Desai (Clinical Lead for Paediatrics for both sites and Consultant Paediatrician at Doncaster) and Dr Lai Men Wong (Consultant Paediatrician at Bassetlaw). There was acceptance of the need to establish shared-care renal clinics at both sites. Subject to

agreement of financing arrangements, it was agreed to establish a 3-monthly full-day clinic at Doncaster and a 3-monthly half-day clinic at Bassetlaw. The Bassetlaw clinics are to be done by the same nephrologist as Doncaster with the Bassetlaw clinics spaced in between the Doncaster ones to allow some flexibility in seeing urgent patients in less than 3 months.

Summary

For five out of six centres, there has been agreement to start new shared-care renal clinics. Since these clinics were held, some agreement has been reached on financing details and dates for clinics in West Suffolk Hospital and Doncaster Royal Infirmary have already been agreed for the rest of the year.

We have previously recognised that discussion of patients at the time of shared-care clinics provides a good opportunity for dialogue and education and wished to incorporate this aspect to a shared-care clinic from the outset. The clinical discussion included examples of patients who could be safely discharged to primary care and patients requiring fewer investigations than was planned by the local team (potential cost savings); it also identified examples of patients requiring further discussion at MDT x-ray meetings or patients needing referral to other services (identifying unmet need). These examples would be likely to be replicated with on-going clinics and represent another example of *value-added* through face-to-face liaison.

Complex patients with rare renal disease managed in centres very far from Nottingham have to receive shared-care through sheer practicality as a default *see in Nottingham* is simply not practical for the family. Local teams cannot be expected to have any experience in managing such conditions and the opportunity to face-to-face dialogue on a regular basis is highly valuable.

5. Lessons from other networks

At the start of the secondment we sought the experience of other clinical networks to ascertain how they functioned, evidence for improved outcomes and the personnel they required. Three networks provided particularly useful information – The East Midlands Children's and Young Peoples Cancer Network (CYPCS), the paediatric diabetes network for Yorkshire and South Humber and the Scottish Paediatric Renal and Urology Network (SPRUN). The first of these networks is based at Nottingham Children's Hospital and dialogue between comparative network post-holders took place on different occasions. The input from the diabetes networks was in the form of phone conversations between Dr Christian and a paediatric diabetes network co-ordinator (Ruth Gordon). SPRUN is currently the only UK paediatric renal network which has any formal structure. Though costly in terms of travel and personnel, a secondment team visit to Glasgow to meet with key members of the network was agreed within the resilience grant budget.

East Midlands Children's and Young People's Cancer Services Network (CYPCS)

CYPCS was established following an SHA review of paediatric oncology services for the East Midlands. As duplicate services in Nottingham and Leicester were rationalised, a managed clinical network involving all other paediatric centres in the East Midlands was established. Top-down governmental funding ring-fenced for cancer services was used to pump-prime the infrastructure and establish key posts including a medical lead (2 PAs – currently divided between Nottingham and Leicester), a network lead nurse (band 8a) and a full-time network co-ordinator.

One of the key initial tasks of the network was the writing of a network operations policy.

The role of the lead nurse within the network is mainly one of overseeing governance and ensuring that CYPCS peer review standards are met. She is also responsible for the development of evidence-based nursing practice throughout the network, dividing her time between the centres and ensuring close collaboration with the MDT. The lead nurse role requires a high level of autonomy and clinical leadership.

The network administrator (Co-ordinating Centre Manager) has a role which has evolved since the original job description was written three years ago. Her main focus currently is the organisation of the MDTs which take place 3-4 times a week. For this she is responsible for adding children to the list, ensuring their imaging is available and having any background information available. She then co-ordinates communication of the discussion outcome for each patient to their GP. She also provides administrative support to the monthly service team meeting and the quarterly commissioning meeting. She also has an important role in peer review.

Paediatric diabetes networks

The development of paediatric diabetes networks has improved professional relationships and service outcomes[2]. To improve outcomes and sustain networks, the paediatric diabetes community have developed a best practice tariff (BPT). BPT works through a sum of money is available to an individual Trust annually to care for a child with diabetes. To achieve that tariff, the Trust has to demonstrate certain outcomes (clinical outcomes such as a certain number of appointments per year, a standard of acceptable HbA_{1c}s per year, input from psychologist/dietitian etc; and non-clinical outcomes like staff signed up to network-delivered training). Funding for the network is then top-sliced from BPT for each Trust. The Trust is dependent upon network membership to earn the tariff and the network then has an incentive to ensure each Trust achieves its tariff.

Scottish Paediatric Renal and Urology Network

Judith Hayes, Pearl Pugh and Martin Christian visited the Royal Hospital for Sick Children in Glasgow on 10 December 2012. Dr David Hughes (consultant paediatric nephrologist, and until recently the network lead clinician) and Linda Watson (network co-ordinator) gave us their time for the whole day. For part of the day we were also joined by Marianne Hayward (Network Manager), Esther Neil (Paediatric Renal Dietitian) and Ursula Monaghan (Paediatric Renal Advanced Nurse Practitioner). For part of the afternoon we video-conferenced with Dr Craig Oxley, Consultant Paediatrician at Aberdeen Children's Hospital who is the current network lead.

The Scottish Paediatric Renal and Urology Network (SPRUN) was set up 2007 with initial funding (circa £300,000) from Scottish Health Department to meet the geographically disparate needs of a Scottish population. There is now a shared-care clinic in every paediatric centre in Scotland. For some of the particularly remote areas such as Orkney and Shetland, use is made of video-conferencing to share care with local health providers.

Outside of Glasgow as the central hub, the Scottish centres are of differing size, and in much the same was as the EMEESY network, they include DGH-sized hospitals as well as children's hospitals (Edinburgh, Dundee and Aberdeen). The amount of designated medical, nursing and dietetic time reflects the size of the centre. For example in the children's hospitals there is around a 0.5 WTE consultant and a full-time nurse plus a significant proportion of a dietitian. In the smaller centres this might reduce to 0.2 WTE consultant time and equivalents for nursing and dietetic time.

Shared-care clinics (SPRUN prefers to use this term over "outreach clinics" as this better describes a partnership model of working between local and tertiary services) are attended by the local paediatrician, local nurse and dietitian as well as the visiting nephrologist. The local paediatrician takes responsibility for booking patients on and screening any new referrals. A truly shared-care system operates in most clinics wherein the local link paediatrician sees all nephrology patients for that

centre and will arrange to take patients back into their own clinics with a clear management plan, referring back to the shared-care clinic only if necessary or part of an agreed plan for joint periodic review.

A re-audit recently carried out by SPRUN has shown that patients are being repatriated to be seen in their local centres rather than in Glasgow. The same audit also highlighted that new shared-care clinics are detecting unmet need – patients seen by local paediatricians who have complex renal disease and should have some specialist nephrology input to their care.

The network steering group initially met 3-monthly but now that the network is established, meetings take place every 4 months. There is a wide representation on the group which includes:

- Medical representative from each health board
- Urologist
- Multi-professionals including nurses, psychology, pharmacy, dietetics
- Patient/parent involvement
- Interest groups such as education, continence, transplantation

The steering group membership also includes a network manager and chair who are responsible for several networks. Terms of reference for the steering group gives it a remit to develop strategic direction, develop strategic alliances, ensure it meets its objectives, support the network team and account for its performance against nationally-set service level agreements. A 6-monthly report is written for the Scottish National Services Division to whom the network steering group are accountable.

For the whole of the West of Scotland (which comprises the majority of the population of Scotland), there is a joint IT system which shares laboratory results and documents (Strathclyde Electronic Renal Patient Record – SERPR). All patients around Scotland are encouraged to sign up for Renal Patient View (RPV). The physician-accessed version is then used to access results. Sign-up for RPV has been set as a clinical service outcome for the network. PACS is networked for the whole of Scotland and images from any hospital can be viewed from Glasgow.

SPRUN make much use of video-conferencing (VC):

- Many shared-care clinics are followed-up with a VC meeting so that results and plans from the clinic can be discussed
- Many network management meetings are carried out by VC as the network lead clinician and network administrator are based in different cities
- Individuals can desktop conference into a monthly educational meeting held in Glasgow or around the country
- The use of video-conferencing is also vital for clinical purposes to access remote parts of the country such as the Islands.

Video-conferencing x-ray meetings are held regularly with other centres. The model developed is that local clinicians document the discussion and agreed plan, which is

shared with the Glasgow team before communicating wider as a safety net to ensure they have correctly understood the nuances of the treatment plan.

The website is the hub of communication. This is hosted via the Managed Clinical Networks domain of NHS Scotland but links to the Managed Knowledge Network of NHS Scotland for all the educational aspects to the website. Guidelines, network steering group minutes and other network documents are found on the publications section of the website. There are also sections for families, both clinical information and about support groups.

There is a full-time network coordinator for SPRUN (band 5). The main aspects of the role include coordinating the videoconferences and other meetings, producing documents such as the annual report, updating the website and coordinating timing of clinics. Around half the time is spent on updating the website. Additional roles undertaken as network co-ordinator include taking feedback from parents and providing a degree of administrative support for locally-run parent support groups. Audits can utilise a national Clinical Audit System for Scotland. Data are quite crude but this has enabled audit to take place outside of the West of Scotland where the IT systems are not yet networked.

Utilising this data source regular audit is carried out to demonstrate the value and impact of SPRUN across Scotland based on four key clinical service indicators:

1. Access to a paediatric renal MDT in a local setting
2. Registration with RPV
3. Distribution of Renal Medicine Information Handbook (a basic patient-held record that is customised to include information on drugs taken by the patient in question)
4. Transition pathway to adult care

Summary

Most lessons were taken from SPRUN because of the greater relevance to a regional paediatric renal network in England. The geography of the EMEESY network is also similar to that in Scotland. Much of the East of England is low-density population and the region is not served well with dual carriageways or motorways. Travelling times to Nottingham from the furthest centre (Great Yarmouth) are in excess of 3 hours which is similar to the journey time between Glasgow and Inverness.

The local hospital profile is similar for the two networks with a range of local hospitals that include integrated children's hospitals with a range of other paediatric subspecialty care (Sheffield, Leicester and Cambridge). To further develop bespoke nephrology services for these children's hospitals along the same lines as SPRUN would require investment in whole-time specialist renal nurses and dedicated dietetic time for nephrology. These are developments that should be planned in conjunction with succession planning for consultant paediatric nephrology support at these sites.

The overall ethos of the network-delivered care in Scotland sets a challenge for locally-delivered care for all children with renal disease, including those on dialysis or with renal transplants. In Scotland, with the support of specialist children's renal nurses, children on peritoneal dialysis with problems such as uncomplicated peritonitis are admitted to other children's hospitals. With the development of nephrology services to these children's hospitals within EMEESY, we too should aspire to that level of shared-care services.

Although there are many similarities with a paediatric renal network (such as a need to include patients in regional registries submitting data to a national registry) one important difference between these two networks is in ownership of patients. Encouraging ownership of shared-care patients by the local team is one area in which we as a paediatric renal network often find challenging. It is especially easy for complex renal patients to be perceived to be the sole responsibility of the tertiary team. In this respect, the philosophical slant of a paediatric renal network is different to a paediatric diabetes network where paediatric diabetes care is largely delivered by local general paediatricians. Moreover, BPT means that local ownership of paediatric renal patients does not have the same onus as does local ownership of diabetes patients where local hospitals are striving to achieve BPT funding with Trusts who don't receive tariff unable to see patients or having to find other ways to finance their diabetes appointments. Application of a BPT would need a different approach to stimulate improved outcomes within a paediatric renal network.

We are persuaded by SPRUN's arguments that the re-skilling of local teams rather than further centralisation of services is more in keeping with Kennedy recommendations. For children seen from centres where local shared-care arrangements are still poorly developed, parents regularly tell us that they would rather be seen in Nottingham rather than their local hospital where "they don't know what they're doing". The appropriate long-term response to this is engaging with shared-care and through clinics and formal educational events, to re-skill local teams to provide gate-keeping service. This is a particularly important aspect for nephrology as there is frequently a "mystique" about children with kidney disease such that they are frequently misunderstood and shunned by junior doctors in training. We expect to find a similar situation with local nurses. As there are no local nurses in place yet, we are at a more rudimentary stage with locally-delivered nursing care and this will be much more dependent on the enthusiasm of local nurses, their managers and the local paediatric link consultant.

SRPUN also offered a more robust approach to shared-care clinics through previewing of the clinic lists by doctor, nurse and dietitian to deliver higher quality, more joined-up care. Similarly a post-clinic review, using VC facilities if available enables MDT input into plans and involves local paediatricians in making decisions based on investigation results. Too often this job is taken on by Nottingham consultants with no involvement of local paediatricians so any opportunities for education are lost.

The face-to-face x-ray meeting that takes place on the same day as the Kings Mill clinic runs along similar lines to the Scottish model with local clinicians taking ownership for bringing cases and documenting discussion/outcome. The fledgling VC x-ray meeting with Cambridge has utilised Nottingham clinicians to document the discussion so far but should move in the direction of local ownership. Cancer services have spear-headed the role of the MDT in decision making. The CYPCS model of administrative support to the MDT provides a helpful template for development of the nephrourology x-ray MDT as a formal decision-making body that can be accessed by local paediatricians and accountable to commissioners.

Peer review of paediatric renal units (and inferred networks) will require an operations policy. Using the template of the CYPCS operations policy we plan to write a network operations policy for EMEESY over the next year which will document the various aspects of the service.

The biggest challenge to the developing EMEESY network will be the implementation of a network infrastructure, including nominated local links for paediatric medicine, nursing and dietetics for each centre without any additional resourcing at present. As local link paediatricians are in place – many grown through goodwill links – the potential exists to put parts of the infrastructure in place utilising these existing local links. There is a need to start by formalising these arrangements and encouraging local paediatricians to quantify nephrology service delivery within their job plans. Nursing support for renal patients should be implied within community nursing for each centre though coverage is variable but it should be possible for most centres to assign a nominated link and develop this through a network support and educational infrastructure.

6. Establishing network infrastructure

Discussions with other networks pointed to several key elements to a network for it to be sustainable. These can be divided into human resource and non-human resource.

Human resources

In terms of personnel, there is a need for defined time within the job plans of a senior nurse, dietitian and clinician to be nursing, dietetic and medical leads respectively. There is also a need for administrative support. The role of the network administrator or co-ordinator would need to involve scheduling clinics, co-ordinating nephro-urology MDTs (securing the availability of imaging and communicating outcomes), organising educational events, the organisation and administrative support to the network steering group and maintenance of the network website. In EMEESY we recognise that the introduction of the new EMED renal IT system for Nottingham offers the possibility to use this network-wide to create a regional registry that would both upload easily to the UK Renal Registry with mandated returns but also allow a single-point to access clinical information about paediatric renal patients from around the network. The role of data manager for the paediatric renal IT system would fit within the remit of a network administrator to justify the need for a whole-time post.

Local leads

One important remit for a senior nurse and dietitian was to identify local nursing and dietetic contacts in each local centre. Whilst we have tried to identify dietetic contacts in the past with some success, there have never been any previous attempts to partner with local nursing. *Improving the standard of care of children with kidney disease through paediatric nephrology networks*[1] recommended link nurses and in Scotland there are link nurses in each local centre with clearly defined roles in sharing nursing care of children with kidney disease. Within our region we had already been well-aware of the need for local nurses to be able to deliver aspects of care closer to home.

Two recent examples serve to illustrate this need. One child on peritoneal dialysis receiving weekly sub-cutaneous erythropoietin needed a local nurse to be able to administer it as her parents were unable to do this. Identifying a local community nurse was a lengthy process and for some time she needed to travel an hour to Nottingham each week. Another child with a tunnelled central venous line for haemodialysis that was not being used for dialysis regularly at that time needed a nurse to access and flush the line each week. As a local nurse either in the community or a local hospital could not be identified, for several weeks the child needed to travel over an hour to Nottingham each week.

Prior to the start of the secondment, there were no local nursing leads identified. By the end of the secondment we had identified local paediatric nurses interested in

taking on a local renal lead for liaison in 14 centres. They are from various backgrounds:

- 5 community nurses
- 4 out-patient nurses
- 2 ward nurses
- 2 advanced nurse practitioners
- 1 continence advisor

Dietetic links have now been made with all 19 shared care centres. Contact was made with dietetic managers, to discuss and share the network vision, with a view to identify a 'link dietitian' who can either attend all or some renal shared care clinic, or be available for liaison regarding interim follow up.

Nottingham-based infrastructure developments

Since the beginning of the network secondment, greater use of the departmental intranet shared area has been encouraged. Within the network folder, we have created a library of sub-folders so that key documents might be stored centrally an accessible to all. There is a sub-folder containing key strategic documents including relevant government or RCPCH documents on networks. Minutes of local and regional meetings are stored there. A local directory of paediatric renal services has been developed and all Nottingham Children's Hospital renal team staff can now access contacts for community nurses, pharmacy, transition services etc. for all local paediatric centres.

The shared area is a secure area which has controlled access supervised by one individual (Shelley Jepson). We have recently begun to put clinic letters from all local shared-care clinics onto the shared area. Until the advent and full functionality of the renal IT system, EMED, this will be a valuable resource when patients known to the unit but not all consultants telephone in with problems out of hours.

Website

A website for EMEESY has been established within the Nottingham University Hospitals website. Stylistic and governance restraints of NUH mean that this has limitations and with time it would need to develop independently to have the full functionality that would be required of a network website.

It can be accessed externally through the address of the original Children's Renal Unit Nottingham: www.childrenskidneynottingham.nhs.uk

Currently it contains information on:

- Services in Nottingham
- Basic parent/patient information with a link to where more disease-specific information can be found
- Information on educational events for professionals
- Guidelines

- Information on the Kinder charity, supporting children and families affected by kidney disease throughout the region

There are plans to develop:

- The services section to include contacts for link paediatricians for all local centres and details of the local shared-care renal clinics;
- The education section to include copies of previous talks given at educational events;
- A section which will include minutes and other documents from all the network steering group meetings, making these publicly available.

The website (and Facebook page, which is discussed in the next section) will be publicised to patients and parents initially through business cards given out at all clinics over the next few months.

We intend to update the website on a monthly basis (this would be the responsibility of the network administrator) and alert stakeholders to significant updates at least quarterly. The Facebook site will be used to alert parents/patients to new relevant information on the website. Email distribution lists to local links for paediatricians, nurses and dietitians will be used to alert to updated professional information.

Network steering group

Taking the lead from SPRUN and CYPCS, and the template from SPRUN we have formed a provisional network steering group which has now met on two occasions. The group comprises Dr Martin Christian (chair), Shelley Jepson (lead nurse), Pearl Pugh (lead dietitian), Judith Hayes (network administrator) and three local paediatricians representing each part of the supra-region: Dr Simon Rhodes (consultant paediatrician at Kings Mill Hospital, representing the East Midlands); Dr Mona Aslam (consultant paediatrician at Peterborough City Hospital, representing the East of England); and Dr Gail Moss (consultant paediatrician at Sheffield Children's Hospital, representing South Yorkshire).

To reflect the composition of the SPRUN network steering group we recognise we need a chair who would be independent and have therefore asked a specialist commissioner if they would consider taking on this role. We also need to include other key stakeholders including: at least one parent representative, representative of the psycho-social team and possibly a paediatric pharmacist. In reality these roles would be chosen from the Nottingham team and for this reason we have decided to await an independent chair before constituting the steering group formally. If EMEESY is to reflect SPRUN in being a nephrourology network (and there are good reasons why this development would benefit patients which are discussed below) a paediatric urologist and urology specialist nurse should be invited to join the network steering group.

In the first two meetings the steering group has drafted its own terms of reference, job descriptions for local link paediatricians and link nurses, and guidelines for local

shared-care clinics. These are about to be uploaded onto the website for a period of consultation.

With the recent publication of the RCPCH's paper *Bringing networks to life*[3], the next meeting of the steering group will be a formulation of a work-plan for its first year based on the principles for effective network functioning outlined in this document.

Education infrastructure

The RCPCH report *Improving the standard of care of children with kidney disease through paediatric nephrology networks*[1] recommended that all members of the multi-disciplinary teams providing care for children in the network are appropriately trained to do so and have access to continuing professional development. We recognised that the twice yearly meetings which had become a regular feature of the network calendar have begun to provide a good educational opportunity for local paediatricians but to meet the report recommendation, we needed to extend that educational infrastructure to include other members of the multi-disciplinary team as has been done in Scotland. Funding for a nurses' and dietitians' training event was agreed as part of the resilience grant and it was proposed to piggy back these training events onto the regular spring nephrouroradiology symposium. As well as simplifying the organisation into one large conference rather than three smaller events, this provided the opportunity for plenary sessions relevant to more than one professional group and over break-times and with travel also provided opportunities for informal *networking*.

Resilience grant support for this conference enabled nurses and dietitians to attend for free. The conference was held at the East Midlands Conference Centre on the University of Nottingham campus where there are facilities for three separate conference rooms. The programme for the conference is shown in table 6.1.

70 delegates attended the conference, representing 17 out of 20 centres (including Nottingham). The breakdown from individual disciplines is shown in table 6.2

Table 6.1. Programme for multi-disciplinary education day on 22 March 2013 (breaks removed)

Time	Doctors	Nurses	Dietitians
0930	Medical overview of daytime incontinence *Speaker: Alun Williams, Consultant Paediatric Urologist, Nottingham Children's Hospital*	Welcome and introduction to the paediatric renal network *Speaker: Shelley Jepson, Lead Nurse, Children's Renal & Urology Unit, Nottingham Children's Hospital*	
0945		Fundamental paediatric nephrology *Speaker: Diane Blyton, Nurse Educator, Children's Renal & Urology Unit, Nottingham Children's Hospital*	
1000	Physiology of the LUT in childhood – the opportunity of new therapies *Speaker: Chris Fry, Professor of Physiology, University of Surrey*		
1015		Chronic kidney disease *Speaker: Andy Lunn, Consultant Paediatric Nephrologist, Nottingham Children's Hospital*	
1030-1100	Q&A		
1115	Bladder assessment *Speaker: Chris Rhodes, Paediatric Urology Nurse Specialist, Nottingham Children's Hospital*		Dietetic management of: Nephrotic syndrome CKD stages 1-3 *Speakers: Pearl Pugh & Emma Kelly. Paediatric Renal Dietitian, Nottingham Children's Hospital*
1135	Urodynamics *Speaker: Kath Halliday, Consultant Paediatric Radiologist, Nottingham Children's Hospital*		
1155	Biofeedback *Speaker: Jo Searle, Paediatric Urology Nurse Specialist, Sheffield Children's Hospital*		
1215	Q&A session		
1230 - 1315	Surgical perspectives *Speaker: Mr Manoj Shenoy, Consultant Paediatric Urologist, Nottingham Children's Hospital*		Dietetic information exchange
1415	Case presentations and discussion	Nephrotic syndrome *Speaker: Martin Christian, Consultant Paediatric Nephrologist, Nottingham Children's Hospital*	
1500 -1600		Network case presentations *Speaker: Kate Baker, Paediatric Renal Nurse Specialist, Nottingham Children's Hospital*	
1615	Network talk and discussion *Speaker: Dr Martin Christian, Consultant Paediatric Nephrologist, Nottingham Children's Hospital*		

Table 6.2. Breakdown of conference attendance by discipline.

Paediatric surgical/urological consultant	10
Paediatric surgical trainee	3
Senior paediatrician	21
Paediatric (medical) trainee	5
Nurse	13
Dietitian	13
Radiologist	4

Nurses who attended represented six centres (though delegates from three further centres were unable to attend because of weather conditions); dietitians who attended represented 11 centres with a further one centre not unable to attend because of the weather.

Feedback on the effectiveness of the educational aspect of the conference was taken and is shown in table 6.3

Table 6.3. Evaluation of nephrouroradiology symposium by discipline attending

	Urologist	Paediatrician	Trainee doctor	Nurse	Dietitian	Not recorded	Overall
number of replies	2	16	5	3	4	4	**34**
relevance to educational needs	3.5	3.8	4.0	3.3	3.8	3.8	**3.8**
overall education quality	3.5	3.7	4.0	3.3	3.8	3.8	**3.7**
effectiveness for CPD	3.5	3.6	4.0	3.3	3.8	3.3	**3.6**
Average	3.5	3.7	4.0	3.3	3.8	3.6	**3.7**

The meeting was evaluation according to the following scheme with scores of 1-4 for each criterion:

Relevance of the meeting to educational needs:

1 No part relevant
2 Fairly relevant
3 Mostly of relevance
4 Highly relevant

Overall quality of the education offered by this meeting:

1 Poor
2 Satisfactory
3 Good
4 Excellent

Effectiveness of the meeting for CPD purposes:

1 Ineffective (learnt nothing relevant to my practice)
2 Partly effective (learnt little relevant to my practice)
3 Definitely effective (will plan to modify my practice in a minor way or present practice reinforced)
4 Very effective (will plan to modify my practice in a major way or clearer understanding of basic principles achieved)

In addition, delegates were specifically surveyed about their views on networks. These answers are shown in tables 6.4 to 6.6.

Table 6.4. Views on paediatric clinical networks surveyed at the multi-disciplinary educational meeting.

Concerning your views on networks before this meeting:			
a. Did you have a clear idea how networks work in paediatrics?			
Yes	19	No	6
b. Did you think there should be a formal paediatric renal network?			
Yes	21	No	0
Considering what you have heard about a more structured paediatric renal and urology network today, which best describes your view?			
I am confident these changes will improve patient care	17		
I am in broad agreement but envisage various obstacles	8		
I am neutral to the idea of more formalised networking	0		
I am cynical that this is a government-led idea that will not impact significantly on patient-care	0		
I think greater structuring of the network will result in poorer patient care	0		
Has your view on networks changed as a result of today?			
No	10		
Yes – more positive towards networks	16		
Yes – more negative towards networks	0		

Table 6.5. Responses to the question: which aspects of the network do you think are most positive?

Clearer patient care pathways and case closer to home
improvement in patients local services
Managed by NHS senior management
Reducing need for patients to travel. Educating and empowering local teams
Increase skills of local paediatricians and consequently increase confidence patients and parents have in their local service
Development and sharing of guidelines. Shared care clinics
That patients will not have to travel huge distances for minor treatment or information
Keeping patients local and being able to work jointly with Nottingham
Locally delivered care with appropriate support
Educational opportunities/training for local teams. Less control but more support for local paediatricians. MDT (ie nurse/dietitian link) for peripheral hospitals
Providing equity of services locally (local shared care). Developing high quality service (value for money). Supporting and educating local services. Developing a website as a main communicating tool.
More shared care working. More local follow-up. Improving education for other professionals
For patients - less travel, less missed school, more confidence in local teams (with more educational opportunities for local teams and training)
Better local care provision. Development of guidelines for use at DGH level.
Unified approach, education, multidisciplinary approach
Shared care and MDT links
Video-link meeting. Post clinic meeting to discuss results and management. Good care for patients and parents (long travel)
Shared care both medical and nursing. That you have a year to develop it!
Collaborative education/work with dietitians

Table 6.6. Responses to the question: where do you see the main obstacles to a more structured network:

Cost
Lack of communication between local consultant and local nurses and dietitians
Resources/funding available
Managed by NHS senior management. Resources of allied specialities
Money
Resources and changes in consultant ownership at our DGH
Lack of staff locally to meet the service needs or if money made available, it will not be shared over the staff who will be expected to provide local services, eg nurses, dietitians
?Locally with my manager
Finance
Financial. Adequately trained professionals (doctor, nurse, dietitian). Families need confidence in local teams.
The problem is commissioning the services for networking
?Funding
Funding
To get district hospitals/commissioners to agree to shared-care clinics
Funding
Time restraints/constraints, resources, already huge caseload
Resources locally - we don't currently provide a renal service (dietetic)

Summary

A five month secondment has enabled a number of basic aspects of infrastructure to be put into place including greater access to network resources for the principal treatment centre, a website, a network steering group and the start of a multi-disciplinary educational programme.

A network website will become the key communication tool for the network, communicating with professionals and patient/parents/public alike but to remain effective will require regular updating. The network strategic vision will be set by the steering group which will also be a key part of the accountability/governance structure of the network as is already in place with other clinical networks.

The first multi-disciplinary conference was a great success. The day of the conference was at the start of the inclement late winter weather and several people who planned to attend were prevented from doing so because of weather conditions. In spite of this, the conference was well-attended and feedback on the educational aspect of the day was overwhelmingly positive. Feedback on network issues revealed positive views towards networks at the start of the day with a majority reporting a clear idea on how networks work. However, 62% of those who responded reported a more positive view on networks by the end of the day. There were common themes in positive aspects to networks including care close to home, empowering/partnering with local services and multi-disciplinary working. Financing of the networks was the most frequently cited obstacle but some also expressed caution about change management in local hospitals.

Human resource aspects to the network infrastructure are crucial to delivering a quality network service. The key secondments initially funded by an SHA resilience grant have been continued for a further 12 months, supported by internal Nottingham University Hospitals charitable funds. Developing business cases for these key network posts will be critical to the sustainability of the network. Without dedicated administrative support, medical and nursing time it is unclear how a website would be maintained or a network steering group continue to meet and function.

7. Public-patient involvement

A variety of approaches were used to gain the views and experiences of patients and carers.

Focus group

A focus group was held in January 2013 in Nottingham Children's Hospital. The parents of four children attended. Dr Martin Christian gave an introduction to the EMEESY network. Shelley Jepson (Lead Nurse) and Dr. Simon Rhodes (Kings Mill Consultant Paediatrician) jointly facilitated the group. The discussion was recorded and transcribed by Judith Hayes. Expenses and refreshments were funded by the resilience grant.

The focus of the discussion was to explore parents' feelings about attending shared care clinics.

The themes that emerged were:

- Parents have confidence in professionals in Nottingham and had trust in individuals
- Parents were reluctant to be seen in shared care clinics due to lack of nephrology training locally
- There is a need for local peer support for families and young people
- There is concern about variation in lab results

It should be noted that the individuals who attended the focus group were all parents of children on dialysis or recently transplanted, with high levels of dependency at that time. None had previous experience of a shared care clinic. Plans are being made to hold focus groups in the East and North of the network to capture the views of a wider patient/parent group.

Patient stories

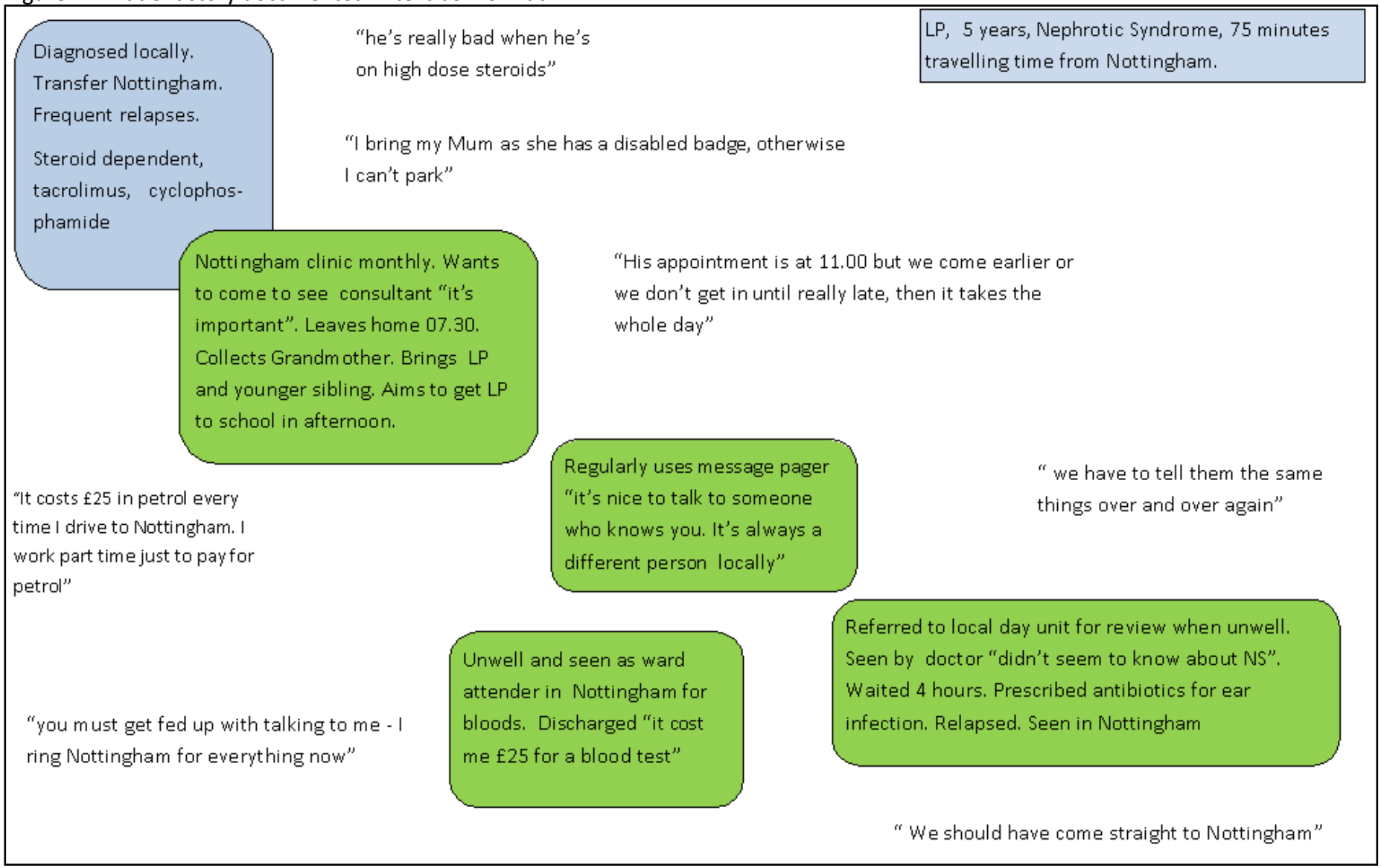
Two patient stories were initially taken and documented in text box format. One of these is shown in figure 7.1.

Themes identified:

- The cost in terms of time and travel to Nottingham clinics
- The impact on the whole family in travelling to Nottingham
- Lack of trust in professionals not trained in nephrology

In January 2013 the team were successful in gaining a Research in Practice grant from the University of Nottingham to support a nurse to undertake further qualitative research. Monique Burgin has begun this work, focussing initially on patient stories with a view to facilitating further focus groups as above.

Figure 7.1 Patient story documented in text box format.



Survey

A survey was created using the surveymonkey tool. A 10-part questionnaire asking questions on time taken to travel to Nottingham, which members of the MDT they accessed at Nottingham appointments and interest in social networking support groups was sent to families via email using addresses collected from individual families seen in shared care clinics. 30 surveys were sent. Seven responses were received. Although the response rate is disappointing several points of interest have been highlighted:

- Patients are generally satisfied with their shared care clinic experience
- The cost in terms of travel, parking fees, child care and lost work is high (range £50 to £350)
- Families want to see a consultant nephrologist at every outpatient appointment.
- Families would welcome regular updates via social networking or support groups

The survey will be available on the network website and the network Facebook page from May 2013 to encourage a wider response.

Social network

Social networking is recognised as a tool to enhance communication and is increasingly used to augment public health communication[4]. Previous attempts by the nephrology team to organise family support groups have not been well attended, often due to the large travelling distances involved for families to meet. A request to the Trust for a network Facebook page was made in November 2012. This was agreed in April 2013. This corporate site is managed by four members of the nephrology team and is now in the public domain (www.facebook.com/emeesynuh).

Visit by health minister

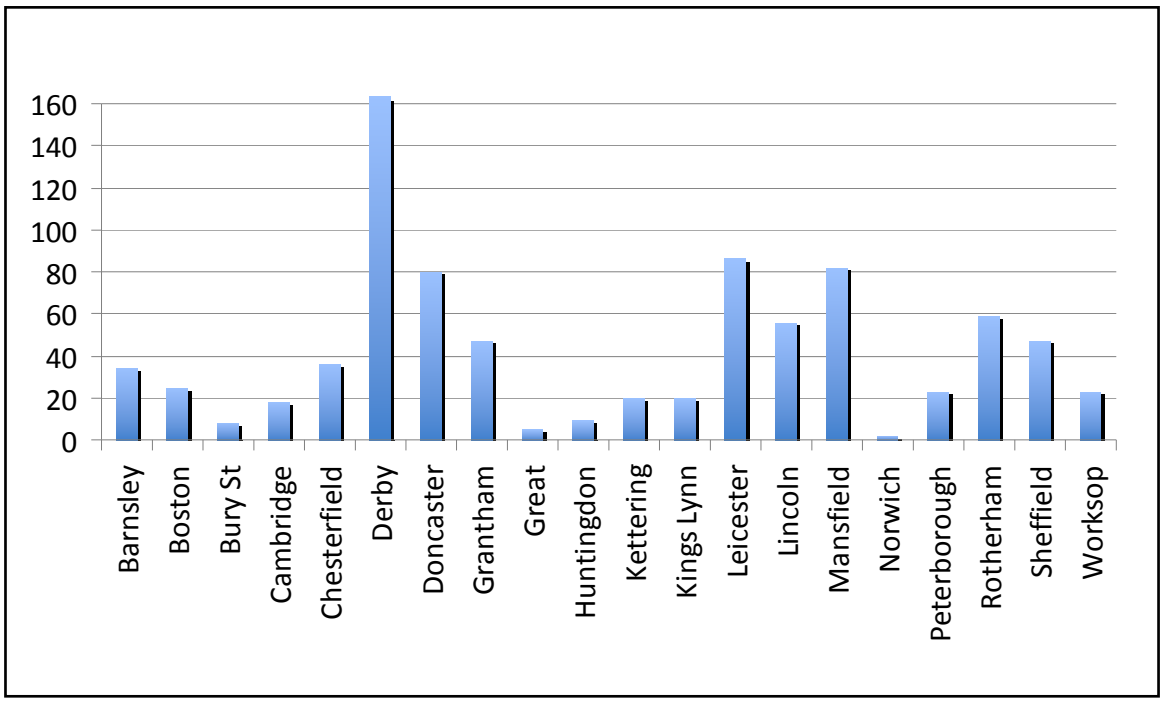
On 15 March, Anna Soubry, a Nottingham MP and junior health minister visited the renal unit at Nottingham Children's Hospital at the invitation of Martin Christian who is one of her constituents. We were keen to take the opportunity to share our plans for network development with a junior health minister. She has since written positively of her visit in her constituency blog. We plan to invite her back in a year's time to review progress.

8. Equity of access to services

Children with kidney disease without a local shared-care clinic have been disadvantaged in terms of their access to local services. This is illustrated well in the patient story of a boy with nephrotic syndrome in section 7. The inequity is more encompassing than simply missing the option for his clinic appointments to be in the local hospital. This has a knock-on effect on de-skilling the local team so that his parents have been dependent upon centralised services in Nottingham for appointments, advice in between clinic visits, unpredictable needs for clinical review in between clinic visits and even interim blood tests. Costs of having to travel to Nottingham are more wide-ranging that simply the cost of transport. It frequently means loss of a day's work for a parent, an additional carer is often required if there are difficulties parking and a whole day's schooling is frequently missed for the child.

As part of the health needs assessment, Nottingham patient data was interrogated to determine the location of non-local patients seen in Nottingham. This piece of work was undertaken by Monica Persson Manrique, a medical student at the University of Nottingham as part of her 4-week Special Study Module in Paediatric Nephrology. She found that of 1730 children seen in Nottingham renal clinics over a 12 month period (December 2011 to November 2012), 49% were from outside the immediate Nottingham catchment area. The results are shown graphically in figure 8.1.

Figure 8.1. 1730 patients seen in renal clinics at Nottingham Children's Hospital between December 2011 and November 2012 categorised by local paediatric centre



Arguably most disadvantaged numerically have been patients from the Doncaster area. 80 patients from the Doncaster area were seen in Nottingham paediatric renal clinics in the 12-month audit period. Unlike patients from Huntingdon, Bury St Edmonds or Great Yarmouth, there has not been another local paediatric renal shared-care clinic able see that capacity of patients and so they have needed to travel well over an hour to Nottingham for clinics.

Establishment of new shared-care clinics means improved equity of access to services for children from these areas. For all children with kidney disease whose local hospital is not Nottingham Children's Hospital, improving equity of access to services is an on-going project which includes:

- Improved access to the multi-disciplinary team locally
- Improved partnership working that will re-skill local teams to build confidence in clinically-assessing children with kidney disease when this is required
- Improved communication of clinical information through better IT infrastructure, such as the communication of blood test results
- Consistency in transport and escort policies when children do have to travel to Nottingham such as for hospital haemodialysis or early post-transplant appointments

Analysis of network patients seen in Nottingham provides a useful outcome measure to review annually. With the development of more and better local shared-care one would anticipate the percentage of non-Nottingham patients seen in Nottingham clinics should reduce each year over the next few years. The setting of an annual reduction might be a useful network target.

9. Quality of care issues

Easily measurable examples of now a more developed paediatric renal network will improve quality of care were evidenced during discussion time following new shared-care clinics. Through the identification of children requiring referral onto specialist services and children whose imaging warranted discussion at a nephrourology x-ray meeting, unmet need has been documented.

Evidence base for the effectiveness of children's renal care

Reports such as *Improving the standard of care of children with kidney disease through paediatric nephrology networks*[1] make a case for development of networks based on fragmentation of service and large distances that many families need to travel to access care. The need for shared-care paediatric renal clinics has been made before[5]. Amongst the benefits listed is the facilitation of rapid accessing of specialist advice, and hence timely referral, that is a product of the working relationships between local link paediatricians and the visiting nephrologist. Pathways that provide specialist care close to home are supported in an earlier government/RCPCH document[6] and also by the Children's Renal NSF[7].

Bringing networks to life[3] provides an evidence base for the benefits of a network against 20 principles for effective network functioning, though much of the evidence is patient-experience based and there would appear to be little in terms of supporting improved clinical outcomes. For patients with CKD there is an emerging evidence base that supports better clinical outcomes through access to a multi-disciplinary team both in adults[8,9] and more recently in children[10].

Survey of current shared-care clinics

As local shared-care clinics have developed, the organisational arrangements have been different with each local hospital. As part of the health needs assessment of the secondment, a survey of the 13 current shared-care clinics was undertaken.

In 10 clinics, there is a joint clinic with a local paediatrician sitting in through the whole or most of the clinic. In one centre a local paediatrician sits in occasionally and in two centres there is no local paediatrician sitting in clinic. In one of these two centres, the consultant runs a parallel clinic.

New patients are booked into the shared-care clinics through discussion with the visiting nephrologist in 12 centres though there are a variety of ways in which the agreement to see in clinic is actioned. Overbooking on the clinic list however, is wholly controlled by the visiting nephrologist in only five centres, partially controlled in a further four centres and not controlled by the visiting nephrologist in four centres. The clinic list is automatically sent to the visiting nephrologist ahead of clinic from four centres but all other centres will send the list when requested.

Clinic letters are dictated by the visiting nephrologist in 11 centres and by the local paediatrician in two centres. All letters are then typed by secretarial staff at the local hospital. Time taken for typing of letters is shown in table 9.1.

Table 9.1. Time taken for shared-care clinic letters to be typed and sent for checking

Typing time	Number of centres
Within 1 week	6
Within 2 weeks	4
Within 1 month	2
Within 2 months	1

Letters that are dictated by local paediatricians are also checked by them. Letters that are dictated by visiting nephrologist are checked by them in 10 out of 11 centres with one local paediatrician checking on behalf of the visiting nephrologist. The usual mechanism for sending letters to and from the visiting nephrologist is via nhs.net.

There is a wide range of processes in place for chasing and actioning results from the clinic. In six clinics results are forwarded to the visiting consultant and in four of these centres the local paediatrician is involved in chasing those results. In five centres results are sent when requested. One centre sends faxes results individually as the paper copies are received and in one centre the results are sent individually from different local consultants according to who looks after the child in question. In one centre the local paediatrician (who has had considerable paediatric nephrology training) actions abnormal results without liaison. In seven centres, the visiting nephrologist and the local consultant liaise over how abnormal results are actioned. For five centres, any actioning of abnormal results takes place directly from the visiting nephrologist, either by amending the clinic letter or through separate direct communication from the visiting nephrologist.

In 11 centres there are robust arrangements if an interim local review of the child is needed. For the other two centres, arrangements are more ad hoc and children may need to come to Nottingham if there is inadequate clinic space before the next shared-care clinic.

For teenage patients needing to transition to adult services, there is a named local adult nephrologist for 10 centres but a tested transition pathway in only five centres.

Summary

Demonstration of on-going improvement in quality of care will be required to justify the continued resourcing of networks. In a specialty of mainly chronic disease, many outcome measures will require long-term follow-up to demonstrate improvement. There is now evidence to demonstrate better long-term outcomes of CKD with multi-disciplinary care. A commitment to delivering care as close to home as possible must therefore consider how care from professionals other than doctors can be shared with local centres.

Short-term outcome measures to use as paediatric renal cQUINs will be challenging. SPRUN have chosen clinical *service* outcomes (registration with Renal Patient View, access to MDT locally etc.) rather than clinical outcomes as these are easier to audit. Starting at a more elementary level, we might agree baseline service outcome measures such as each centre having a nominated paediatric renal lead, a nursing lead for renal and a dietitian with dedicated time for renal patients within their job plan.

The results of the shared-care clinic survey demonstrate a wide range in practice and should form the basis for guidelines and standards. Clear guidelines on issues such as screening referrals, booking onto clinics, involvement of local paediatricians in the clinic, chasing and actioning results should form the basis of local agreements. Standards should be set for time to sending out clinic letters and the transition pathways. This work can then lead into benchmarking individual local centres. Presented as a dashboard compared to agreed targets and the network averages, it can be used as tool to stimulate improvement in individual centres.

10. Potential cost savings

Paediatric nephrology is a high-cost, low-volume speciality. However, throughout the secondment project cost improvements have been noted, alongside potential for quality improvement. As with aspects of quality of care, some are more easily measurable than others.

Clinical discussion following clinics provides a good opportunity to demonstrate cost savings. Following these discussions, there were examples of patients able to be safely discharged to primary care saving on unnecessary out-patient appointments. There were also examples of patients not needing the repeat imaging that had been requested. The nephrourology x-ray MDT is also likely to reduce costs of care by replacing some of the shared-care appointments and through a more conservative recommendation of imaging follow-up.

We recognise repeatedly that children with acute kidney injury or glomerular disease such as nephrotic syndrome have more regular blood tests taken when cared for in local centres. Closer partnership with local hospitals and a commitment to multi-disciplinary education should lead to a greater confidence in local centres to restrict blood sampling according to clinical need.

Education and support for local teams, particularly local nurses, should give them greater confidence to manage the straightforward aspects of conditions like nephrotic syndrome by telephone consultation, saving on the need for some hospital attendances.

On a more global scale, increasing repatriation of patients to local shared-care clinics means less money spent on travel costs, much of which is reimbursed where parents are in receipt of benefits, albeit this coming from a different government department. There is less impact on the economy through fewer working days lost. The financial impact of less family disruption is difficult to quantify but few would doubt that this too is real.

11. Future recommendations

The next 12 months

Through the use of internal charitable funds, a successful application was made to continue part-time secondments along similar lines until March 2014. This "breathing space" should allow time to build on the infrastructure foundations that have been put down during the 5-month resilience grant-supported secondment until the case is made for long-term secure resourcing.

The main aims for the next 12 months are:

- Consolidate new shared-care clinics in 5 new centres
- Establish a shared-care clinic for Hinchingbrooke Hospital
- Consolidate nursing and dietetic links for each centre through occasional support visits to shared-care clinics by Nottingham Children's Hospital MDT staff
- Agree job descriptions for link paediatricians, nurses and dietitians
- Agree guidelines for shared-care clinics
- Develop benchmarking and dashboards for local shared-care centres
- Build on a first successful multi-disciplinary educational meeting to develop regular MDT educational events
- Constitute a formal network steering group
- Agree terms of reference, a strategic vision and an initial work-plan for the network steering group
- Develop the website as a main communication tool with a regular emailing briefing to local linked professionals, alerting them to new information uploaded
- Develop the network Facebook site to engage patients and parents with network issues and encourage local support networks
- Engage with urology colleagues to incorporate paediatric urology services within the network
- Develop clinical and clinical service outcomes that can be measured to test network effectiveness
- Develop business cases for on-going resourcing of network infrastructure and personnel
- Share experience of developing network services to help influence the national direction of commissioning of paediatric renal services

Beyond the next year

To ensure sustainability of the network, investment in core personnel and infrastructure will be required. There must be early discussion with specialist commissioners regionally and parallel discussion with Strategic Clinical Networks and Health and Wellbeing Boards on resourcing of paediatric renal networked services.

The establishment of SPRUN six years ago required large investment which clearly will be unavailable for the foreseeable future of the NHS in 2013. The workload of local link paediatricians, link nurses and link dietitians for most centres should not be considerable. However, over the next 12 months we plan to qualitatively (and quantitatively if possible) estimate the likely increased workload to nurses and dietitians taking on a renal lead role so that this can form part of future negotiations towards commissioning.

We have demonstrated that thus far, a level of networked care has been achieved built largely upon long-standing, good working relationships. Paediatric renal care is heavily dependent on multi-disciplinary teams and frequently cited as a model for multi-disciplinary working. Beyond system-specific skills, paediatric renal teams have much to offer in collaborative, supportive working to help continue to develop these same links with local multi-disciplinary teams.

Of note, two of the centres that have so far been unable to identify nurses to take on a lead renal role have been integrated children's hospitals. It is possible that this is not co-incidental but rather relates to a more sober estimation of the workload that would be required of such a post in such a setting. It is likely that a lead renal nurse role within an integrated children's hospital would consume a considerable amount of time of a single nurse's job and these posts may require additional investment. However, if developed in parallel with long-term planning of overall nephrology services to the integrated children's hospitals within EMEESY, there are benefits of being able to offer more specialised children's renal services in these centres in the future.

Central investment in network leadership will be required. We have estimated that on-going administration of the network would require a network administrator. Discussions with other networks and our own assessment of the workload for a network administrator have led us to conclude that this would need to be a full-time post. Paediatric renal networks usually cover a larger geographical area and number of local centres than do many other paediatric networks. The results-driven nature of renal care emphasises the need for robust IT systems for transferring clinical data and these need to be maintained, thus aligning the role of data manager with network administrator.

Clinical networks cannot function without medical and nursing leadership. A clinical network the size of EMEESY should attract 2 PAs of consultant time for medical leadership and a full-time lead nurse to oversee nursing competencies in all centres and support governance arrangements for the network. Increased dietetic liaison would also require additional dietetic hours. The overall cost for these additional core personnel should be shared equitably across the network. Cost savings identified or predicted in this document would do much to offset the costs. The details of how this might be done, be that through a BPT approach or the expectation of a contribution from each CCG or Trust should be the subject for early discussion with specialist commissioners.

Lessons learned and experience gained through this secondment has wider implications than for this part of England. It is hoped that through sharing experience, the national discussion on the future of commissioning paediatric renal services in networks might be assisted.

12. References

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