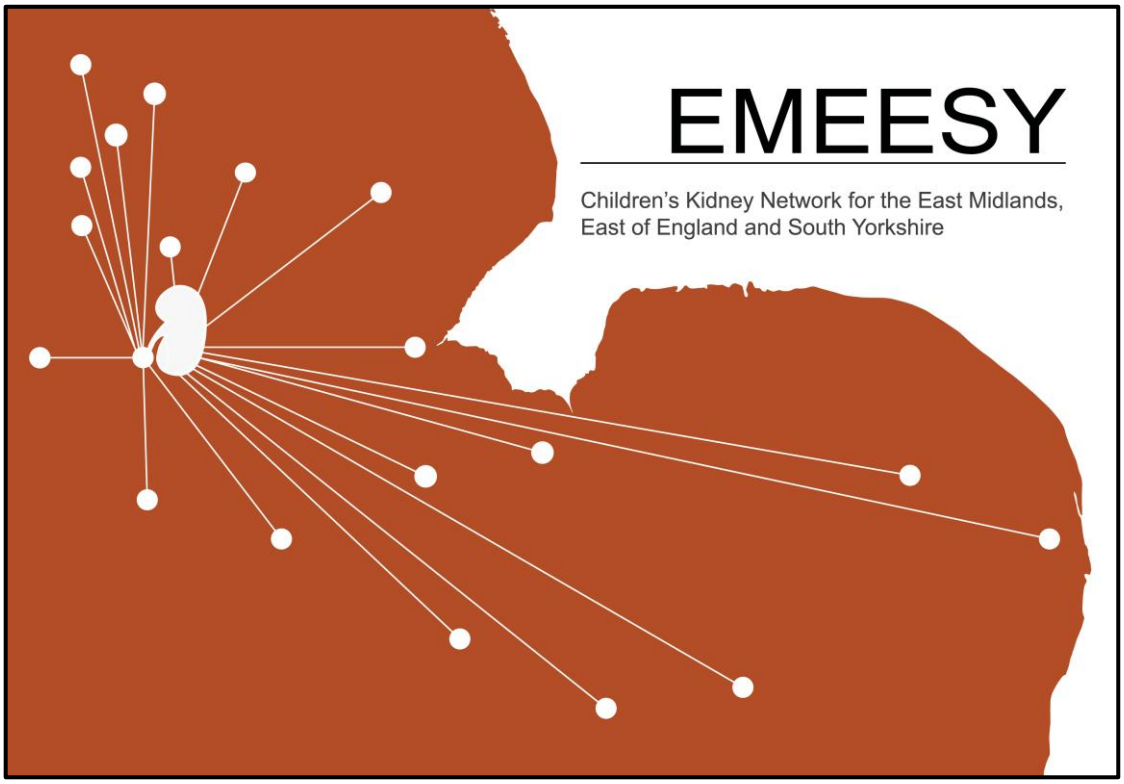
Nottingham Children's Hospital

Nottingham University Hospitals NHS
NHS Trust

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



Annual Report 2014-15

www.emeesykidney.nhs.uk

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

Annual Report 2014-15

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1. INTRODUCTION

This is our second network-focussed annual report and we have continued to develop over this last year.

We have continued to develop locally-delivered services in partnership with local teams so that we cut down on the number of journeys to Nottingham our patients and their families have to make. Since April 2014, new clinics have been established in James Paget (Great Yarmouth), Barnsley and Hinchingbrooke (Huntingdon) so that all paediatric centres throughout EMEESY now have a renal clinic. We have also established that specialist nurses from Nottingham will attend two clinics at each centre per year.

The website is now over a year old and attracts regular hits. We surveyed doctors attending the autumn annual meeting who told us that the most useful pages for them were the Nottingham guidelines, the patient information and the information about education meetings. Statistics for the site tell us that the dietitetic leaflets are the most popular download. The address for the website now goes out on all clinic letters (along with references to the national sites infoKid - children's kidney information - and Medicines for Children). Parents and professionals alike are starting to use the website for sharing important resources.

The Facebook site continues to be active. Social media is used as a tool to communicate information, share renal stories in the national news and allow informal networks of support to develop between families. An unexpected bonus has been an increase in fundraising since the launch of Facebook.

After a long wait, the new renal computer, EMED, was launched in early 2015. Eventually we hope to use this as a full electronic patient record. In the medium term we hope it will generate clinic letters by populating current problem list, current drug list and results. It also offers the possibility to manipulate dialysis prescriptions. With the advent of the UK Renal Data Warehouse next year, we also hope it will eventually be possible to use this sort of renal IT system to access results from other hospitals within EMEESY, making caring for children at a distance much less complex!

2014-15 has seen significant development in transition services around EMEESY with many centres outside of Nottingham starting or developing transition clinics.

Although a network report, much of the multi-disciplinary team activity is focussed on Nottingham although we have worked to develop greater nursing input into shared care clinics this year. As you will read through the report, many of these services do offer support to children and families throughout EMEESY, regularly by telephone but frequently by community visits. The specific activity taking place in centres outside Nottingham can be found in sections 16-20.

This last year has been a particularly challenging one: new developments with network (extra clinics and extra organisation) have increased workload and pressure. To deliver services like this is correct: families feedback their appreciation of being able to be seen locally rather than travel to Nottingham regularly and network-delivered service is in-line with the Paediatric Renal Services National Contract. However, we live in lean financial

times and making a case for a commissioned network is taking longer than we had anticipated. 2014-15 has also been the time when we have lost a considerable amount of our psychosocial support. Nottingham has always championed psychosocial care for children with chronic kidney disease, chiefly through the leadership of Alan Watson, who remains active in publishing into his retirement. It is possible to see his recent publications in section 23 including a review on psychosocial care. It is therefore with great angst that we have seen the recent loss of a social work post (soon to be replaced but as half rather than full-time), dedicated psychology time, nursery nurse play support and a youth worker. We remain committed to these vital support services for our patients and families. Plans are in place to provide interim charitably-funded posts where possible and we remain in discussion with commissioners to include these posts in a securely resourced format for our service specification.

In the last year, we have used charitable funds to decorate the four side-rooms on ward E17, using a window transfer of four different city-scapes: London, New York, Sydney and Dehli/India and other city symbols on the side-room walls. You can see some of this delightful artwork illustrating this year's report.

Martin Christian
Lead Consultant for Paediatric Nephrology
Network Lead for EMEESY Children's Kidney Network
martin.christian@nuh.nhs.uk
June 2015

2. STAFFING

MEDICAL STAFF

CONSULTANT PAEDIATRIC NEPHROLOGISTS

Dr Jonathan Evans (Clinical Director for Family Health; 0.6 WTE clinical)
Dr Farida Hussain
Dr Martin Christian (lead consultant and network lead)
Dr Meeta Mallik
Dr Andrew Lunn
Dr Corinne Langstaff (PT locum until May 2015)

TRAINEES

National grid trainee: Dr Hitesh Prajapati (from August 2013)
Special interest in nephrology (SPIN) trainee: Dr Adamu Sambo (until July 2014)
General paediatric trainee: Dr Sam Deepak (from August 2014)

Adamu Sambo has recently been appointed as a consultant paediatrician with a special interest in nephrology in Gloucester. He takes over there from one of the original SPIN paediatricians, Dr Lyda Jadresic and a nephrology special interest is well-integrated with the post. We wish him all the best for his new appointment.

Hitesh Prajapati will remain in Nottingham to complete his specialty training after August. We welcome back Dr Drew Maxted, who was previously a junior trainee on the ward, as our new national grid trainee from August.

We are also There are 2 junior trainees attached to the ward at any one time for 4-6 months. A number of recent junior trainees have expressed an interest in careers in nephrology.

CONSULTANT PAEDIATRIC UROLOGISTS

Mr Manoj Shenoy (service lead for paediatric surgery)
Mr Alun Williams (transplantation and paediatric urology)
Mrs Nia Fraser

Mr Bharat More, previously a locum consultant in Nottingham, has just been appointed to a new consultant post shared between urology and surgery.

TRAINEES

National grid paediatric trainee: Mr Paul Jackson
Paediatric surgical senior trainee rotates every 6-12 months
Surgical SHO rotates every 3 months

TRANSPLANT SURGEONS

Mr Keith Rigg, Mr Alun Williams, Mr Shantanu Bhattacharjya, Mrs Amanda Knight

Richard Bowen retired as recipient co-ordinator in 2015. His post has been taken over by Kate Taylor. Anne Theakstone and Karen Stopper are the live donor co-ordinators.

SUPPORTING SERVICES

Radiology: Dr Nigel Broderick, Dr John Somers and Dr Kath Halliday
Pathology: Dr Tom McCulloch and Dr Zsolt Hodi

NURSING STAFF

RENAL TEAM

Senior Paediatric Nephrology Nurse and Network Lead Nurse: Shelley Jepson
Clinical Nurse Specialist (Dialysis): Roy Connell
Clinical Nurse Specialist (Transplant): Kim Helm
Renal Nurse Educator: Diane Blyton
Renal Critical Care Educator: Molly McLaughlin
Renal Nurses: Kate Baker (CKD), Sharon Mould (Dialysis), Monique Burgin (Nephrotic)
Renal Nurse Administrative Assistant: Anisah Hussain

HAEMODIALYSIS TEAM

Junior Charge Nurses: David Cooper and Ian Buchan
Staff Nurses: Nichola Hughes, Angela Thomson and Helen Bolam
Haemodialysis support worker: Danielle Barnes

UROLOGY TEAM

Clinical Nurse Specialist: Christine Rhodes
Urology Nurses: Gill Young, Emma Stockdale and Caroline Ward

WARD E17

Ward Manager: Michelle Kirkland

Current nurse staffing: 1 WTE band 7; 3.8 WTE band 6; 9.6 WTE band 5; 1.2 band 2

- From the band 7 and 6 pool, 0.4 WTE is spent on day cases and 46 hours (4 shifts per month) are spent being the out of hours bed manager.
- From the band 5 pool, 0.2 WTE equal (one shift per week) is allocated to Ambulatory Care Unit and 3 shifts per week are allocated as Band 5 floats.
- Out of the band 2 (health care assistant) allocation the Pre-admission Clinic and Ambulatory Care need to be covered every week.

The role of the ward manager is currently included in establishment figures but there is a plan that it will become supervisory and separate from the ward establishment; there is a

plan is to back fill the spaces with band 5 staff nurses. It is also planned to have 3 staff nurses covering the night shift. With these new staffing arrangements the ratio of nurses to patients will be 3:1 instead of the standard 4:1.

DIETETICS

Pearl Pugh and Emma Kelly.

PSYCHOSOCIAL TEAM

SOCIAL WORK

Suzanne Batte. A vacancy for a second social work post is due to be filled in June 2015.

PSYCHOLOGIST

Dr Kathryn Bradley provides a referral-based support service.

PLAY

Play specialist: Claire Hardy
Nursery nurse: Rachel Nieman (until April 2015)

YOUTH WORK

Renal youth development worker: Dorro Hackett (until November 2014). This post was funded by the BKPA. Donna Hilton manages youth and play services for the children's hospital and the Nottingham Children's Hospital Youth Team and volunteers. Matt Tomlin was Young Adult Worker for Nottingham and Derby until March. His post has recently been reappointed and we are pleased to welcome Ms Terri Ellwood.

ADMINISTRATIVE AND SECRETARIAL STAFF

Team leader and network administrator: Judith Hayes
Other secretaries: Sandie McLauchlan and Vicky Cancemi (both urology). Pauline Lievers (medical) left in 2014 and has been replaced by Jodie Clayden. Support secretaries, including Pam Greenbank have been moved to constitute a typing pool resource for the whole of the children's hospital. Secretaries are supported by a team of filing clerks.
Ward receptionist: Diane Walker. From May 2015, Diane has moved into a new role as administrative assistant to the ward manager. Her receptionist post has been re-appointed.
Haemodialysis administrative assistant: Anisah Hussain (from January 2015).

PHARMACY

Paediatric renal pharmacist: Peter Foxon, supported by See Mun Wong (home delivery services). Andrew Wignell is currently seconded as pharmacy lead for the Children's Hospital.

EDUCATION

Teachers: Gary Mace and Karine Williams
Teaching assistant: Hannah Barbary

MANAGEMENT

General Manager for Family Health: Fiona Lennon
Assistant General Manager (Paediatrics): Vicky Holden
Clinical Lead for Children's Services: Dorothy Bean
Matron: Jamie Crew

SUPPORT SERVICES

We acknowledge the help and support from various services essential to running a paediatric renal unit including the support from the renal unit technical staff for the running of the dialysis machines and support in supplies administration. We are also grateful for the housekeeping and domestic support provided on ward E17.

Families whose children are admitted to ward E17 benefit from the accommodation support team and have access to chaplaincy support from Rev Anne Ladd and a team of multi-faith chaplains from the main hospital chaplaincy.

VOLUNTEERS

Finally we are grateful for the voluntary support received from Pat Sands, Pauline Woods and Denise Hardy supporting clinic and ward day care. We are also grateful for the charitably-funded support from the Giggle Doctors and Opus Music who visit the ward and haemodialysis bay each week.

3. ACTIVITY AT NOTTINGHAM CHILDREN'S HOSPITAL

3A. WARD ACTIVITY

During 2014-15, there were 666 admissions under nephrology and 803 admissions under urology. Day case and ward attender activity was recorded separately this year. Day cases are included in the admissions numbers above but ward attenders (including urology nurse activity) is in addition to admissions activity. Urology admission numbers includes day cases, admitted to the Ambulatory Day Care Unit.

The numbers of day case and ward attender activity is as follows:

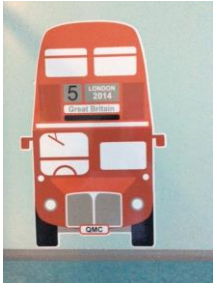
Day case (nephrology)	318
Ward attenders (nephrology)	404
Urology (all non-admitted activity)	80
Urology nurses	584

3B. RENAL BIOPSIES

A total of 77 biopsies were done during the year, 52 native and 26 transplant. There were 78 last year. The number of biopsies remains stable around 75-80 each year.

In 2014-15, the national renal biopsy audit, which was led by Farida Hussain and published in 2010, has been repeated and the manuscript recently submitted for publication.

3C. ACUTE KIDNEY INJURY



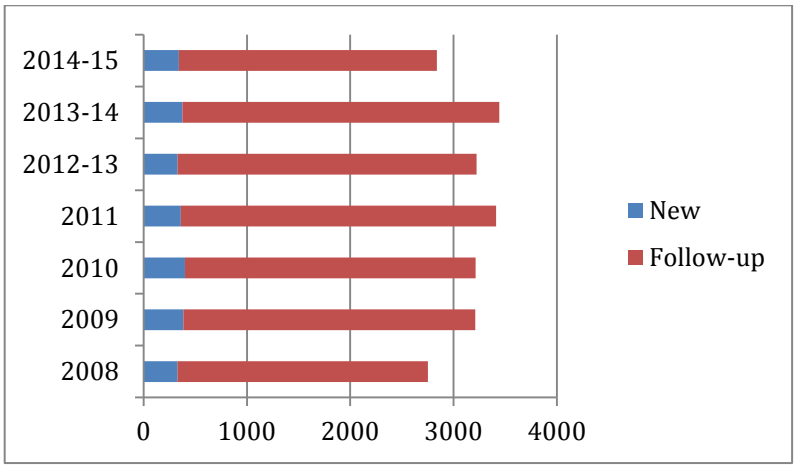
Nine children were admitted to ward E17 with acute kidney injury (10 in 2013-14). Four of those children had haemolytic uraemic syndrome; three out of four of these children required dialysis. The other five children had AKI secondary to urological causes or glomerular disease. One of these needed temporary haemodialysis and one needed plasmapheresis. The other three children were treated with fluid and electrolyte management only.

In addition, other children required renal replacement therapy within a paediatric critical care setting. When this is continuous haemofiltration, the therapy is carried out by critical

care staff but for haemodialysis or plasmapheresis (which take place only in Nottingham), that service is delivered by specialist renal nurses. These numbers are included in section 17 (critical care support).

3D. OUT-PATIENT ACTIVITY

For nephrology clinics in Nottingham during 2014-15, there were 340 new patients seen and 2498 follow-up patients.



Overall there is a reduction in numbers from recent years. There is some year-by-year variation but it is also possible that some activity has transferred from Nottingham clinics to shared care clinics where children are seen closer to home.

The breakdown into different types of clinic is as shown in the table below:

	New	Follow-up	Total
All general clinics	271	893	1164
All CKD clinics	50	1521	1571
Enuresis clinic	19	57	76
Renal-endocrine	0	17	17
Transition clinics	0	10	10

The overall non-attendance (DNA) rate for Nottingham clinics was 18%. For CKD clinics it was 15% and for general nephrology clinics it was 24%. This rate is unacceptably high although it is offset by a chronic over-booking of clinics. Many of the appointments recorded as "DNA" for CKD clinics are likely to be hospital administrative errors due to the frequent flyer and unpredictable nature of CKD clinics. The same cannot be said for general nephrology clinics. After end of year review we have made the following plans to address this DNA recorded rate:

- Ensure that CKD clinics are reviewed for the current and next week at the weekly departmental clinical meeting on Mondays so that hospital administrative errors can be rectified before the clinic day
- Ensure that general nephrology clinic lists are previewed by the consultant at the end of the previous clinic
- Try to convert a DNA clinic into a telephone consultation during or after the clinic to save on unnecessary clinic rebooking

Telephone clinics have been recorded for the last year or longer. During 2014-15, 170 telephone clinic appointments were recorded. This is almost certainly only a fraction of the telephone consultations that take place. For this year, we will be more rigorous in recording telephone clinics in the following scenarios:

- To communicate change of treatment plan after the CKD clinic
- When medical advice is given for returned calls to the renal nurse pager
- For routine consultations for patients on home therapies (peritoneal dialysis or albumin infusions)
- When medical advice is given for returned calls to consultants
- For formally timetabled telephone clinics in lieu of face-to-face continence clinics

4. CHRONIC DIALYSIS

Dialysis therapies are provided at Nottingham Children's Hospital for acute and chronic kidney failure. Peritoneal and haemodialysis are both used for both acute kidney injury (AKI) and chronic kidney disease (CKD). In addition, the haemodialysis unit staff provide apheresis therapies which are used to treat a variety of renal and non-renal diseases in acute and chronic settings. This section deals with dialysis used for chronic diseases; information about dialysis used to treat acute kidney injury may be found in section 3 (Activity at Nottingham Children's Hospital) and section 18 (Critical Care Support).

Roy Connell, Clinical Nurse Specialist for Paediatric Dialysis

HAEMODIALYSIS

CURRENT WORKFORCE:

The haemodialysis unit is staffed by 3.4 WTE dedicated registered nurses (two band 6 nurses (1.4 WTE) and three band 5 nurses (2 WTE) and is managed by a Clinical Nurse Specialist.

Staffing requirements fluctuate between 4.0 and 7.0 WTE. The staffing gap is filled by regular input from all of the specialist renal nurses. This enables staffing numbers to be efficiently managed, and the team to maintain their skills for on call purposes. However, this can impact on others roles if the requirement is ongoing.

The staffing of the unit has been challenging during the past two years due to an increase in younger and more highly dependent children receiving dialysis.

ACTIVITY 2014-15

Overall chronic haemodialysis workload was heavier compared to the previous year. A total of 15 patients received haemodialysis as a chronic treatment over the last year (133 patient months). This compares to 15 in 2013/14, 22 in 2012/13, and 18 in 2011. Ten of the patients attended haemodialysis for the whole 12 months.

However, the number of patient sessions during this period was 1736 compared to 1447 in 2013/14, 1771 in 2012/13, 1684 in 2011 and 2352 in 2010, representing a significant increase in the haemodialysis workload.

The age range of children receiving haemodialysis was between 2 and 19 years.

Six patients were aged less than 5 years in 2014/15 compared to four in 2013/14 and seven in 2012/13, with one requiring dialysis 6 days per week. Children aged less than 5 require more intensive nursing care whilst dialysing and this can add greatly to the workload in the unit.

Patient movement during 2014/15 has seen:

- 2 patients transplanted
- 2 patients converted to PD

WORK-PLAN FOR THE NEXT YEAR:

The launch of the new renal computer was delayed until February 2015 so plans to integrate 'real-time' electronic recording of dialysis sessions will remain on the workplan for 2015-16. Plans to implement a home-haemodialysis service have proved more complex whilst national plans for a home haemodialysis network have taken longer than originally anticipated. Plans are in place to purchase a home haemodialysis machine for training purposes with charitable funds and the introduction of a home-haemodialysis service remains in the workplan.

PERITONEAL DIALYSIS

CURRENT WORKFORCE:

The day to day management of the peritoneal dialysis programme is undertaken by a Band 6 Renal Nurse (1.0 WTE), Sharon Mould (pictured) and overseen by a Clinical Nurse Specialist (1.0 WTE). Alongside the PD programme, the CNS and Renal Nurse have a regular haemodialysis commitment.

The CNS is also responsible for:

- Management of the haemodialysis programme.
- Home therapies (including Albumin infusions)
- Apheresis programme
- Ambulatory blood pressure monitoring

ACTIVITY 2014-15

Thirteen patients received peritoneal dialysis over the last year (104 patient months). This is a similar workload to that seen in the previous three years (15 in 2013/14, 18 in 2012/13 and 19 in 2011) but still significantly down on the numbers seen in recent years prior to this (31 in 2010, 28 in 2009, 27 in 2008).

Five families were trained to undertake peritoneal dialysis at home. These annual numbers are variable: 5 families were trained in 2013/14, 12 in 2012/13, 2 in 2011 and 17 in 2010). The number of families trained compared to the numbers remaining on or transferring off PD is reflective of the ever-changing nature and needs of the PD population.

There were 4 episodes of peritonitis giving an incidence of 1 in 26 patient months (1:18 in 2013/14, 1:18 in 2012/13, 1:14 for 2011 and 1:17 for 2010). The unit's 5-year peritonitis rate is 1 in 19 patient months which meets the recommended Renal Association standard of 1 in 14 patient months. Over half (54%) of the PD patients were aged less than 5 years during 2014/15 and therefore fall in the higher risk category for infections.

Patient movement during 2013/14 has seen:

- 1 patient transfer to adult services
- 2 patients transplanted
- 1 patient converted to haemodialysis.
- 9 patients remained on the PD programme.

WORK-PLAN FOR THE NEXT YEAR

- Update and review of chronic PD guidelines.
- Increase outreach support and update visits.

APHERESIS THERAPIES

Apheresis treatments which include plasmapheresis (or plasma exchange) and lipopheresis are treatments which involve removal of a part of the plasma to treat a diverse range of acute and chronic treatments. Treatments are mainly performed in the haemodialysis unit in addition to the regular patient workload. Therapies are carried out by the staff in the unit or the on-call nurse during out of hours periods.

CURRENT WORKFORCE

There is no dedicated apheresis nurse for the unit so it is important for all of the haemodialysis staff and specialist nurses to maintain their skills in the therapies we offer. The apheresis programme is managed by the Dialysis Clinical Nurse Specialist.

ACTIVITY 2014-15

Overall, the number of patients (acute and chronic) requiring apheresis therapies was two (compared to 8 in 2013/14, 13 in 2012/13 and 13 in 2011) with the number of delivered sessions significantly reduced (39 in 2014-15, 200 in 2013-14 and 195 in 2012-13).

One patient received double filtration plasmapheresis (DFPP) as a chronic treatment during this period with 24 individual sessions being carried. Therapeutic plasma exchange (TPE) was used to treat 1 patient (15 sessions). One chronic apheresis patient transferred to adult services during 2014/15.

Guidelines for apheresis have been written and approved during 2014-15.

WORK-PLAN FOR THE NEXT YEAR

- Audit the therapies performed and complete the 10 year DFPP study.
- Assess the accuracy and application of the newly published apheresis guidelines.

5. TRANSPLANTATION

Nottingham Children's Hospital is one of 10 paediatric transplant units in the UK. Both living donor and deceased donor transplants are carried out. We aim to transplant all children pre-emptively where possible.

Kim Helm, Clinical Nurse Specialist in Paediatric Transplantation
Nottingham Nurse of the Year (Children's and Overall Winner) 2015

WORKFORCE

There is one (0.8 WTE) band 7 clinical nurse specialist, Kim Helm. She is supported by a renal nurse, Kate Baker (0.8 WTE) who is responsible for chronic kidney disease but within this includes work-up for transplantation. All paediatric nephrologists look after children who have been transplanted. The surgical transplant team comprises four consultants, all of whom carry transplants in children. There is a living donor team at Nottingham City Hospital where parents who wish to be considered living donation can be referred.

ACTIVITY 2014-15

The unit performed 6 transplants. At the end of the year there were 8 patients active on the national list with a further 2 suspended. This is an increased number compared to recently (and it has increased further since March 2015). The lower number on the active waiting list from a year before reflects the small number of transplants performed during this year. It is hoped that 2015-16 will bring an increase in transplant activity for the unit.

Source of donor	
Living donor	3
Deceased donor	1
Altruistic donor	2

Despite a small number, we were pleased that the rate of living donor transplants increased to 50% of all children transplanted last year.

Previous treatment	
Pre-emptive	1
Peritoneal dialysis	3
Haemodialysis	2

Most children transplanted last year were already on dialysis. We aim to transplant children pre-emptively where possible but sometimes this is not possible for medical reasons. All transplants last year were first transplants for the children who received them.

Post-transplant, patients are nursed either on the ward, PICU (if <15 kg) or PHDU (if 15-20 kg). However, due to to staffing constraints on ward E17 to provide the 1:1 nursing required for the first 48 hours, all children were nursed on PICU or PHDU.

A total of 95 transplant patients were being followed-up throughout the year. There was patient movement due to transferring to adult services, changing centres or deteriorating graft function requiring a return to dialysis. At the end of the year there were 79 patients under active follow-up. Most patients are followed in Nottingham clinics. There are some children who receive their follow-up in local shared-care clinics; most of these children return to Nottingham for an annual appointment.

Patients transition to adult centres within EMEESY. This year, 5 have transitioned to Nottingham, 4 to Sheffield and 2 to Derby 4 to Leicester and 1 to Norwich. In Nottingham, we try to ensure that young people have at least two visits to the transition clinic before transferring. Kim Helm attended 6 transition clinics. One further patient died post-transplant from an unrelated cause during 2014-15.

Transplant nurses liaise with other professionals throughout the network. Communication has improved since transplant nurses have begun to attend local shared-care clinics with the consultant on a regular basis. Kim Helm attended 19 such clinics including transition clinics this year. This can be combined with updates for the families which can be carried in the clinic, saving on several home visits.

To continue addressing the low living donor transplant numbers in Nottingham compared to other paediatric transplant centres in the UK, a first transplant family information day took place in September 2013 and this was repeated in 2014. The families of all children with CKD stage 4 and 5 were invited. As before, the formal programme included talks from a paediatric nephrologist, a transplant co-ordinator, the transplant clinical nurse specialist and a member of the living donor team. The morning finished with talks from expert patients and parents – two young people who had previously been patients on the unit; one had received an altruistic kidney and the other received a living related donor; the expert parent was in the audience for the previous year's family information day and wished to tell her story of her daughter receiving a deceased donor transplant since. Their stories and other presentations from the family information day have been uploaded onto the Transplantation pages of the EMEESY website. We now hope to make this transplant information day a regular event.

Home visits are an essential part of our standard of care. This year, these included 7 home visits, 5 school visits and 11 Team Around the Child (TAC) or multi professional meetings.

There are regular 3-monthly meetings with the whole transplant team, including the tissue typists from Sheffield. All children on or working towards the transplant list or preparing for living donor transplantation are discussed. This enables good communication about potential problems. The paediatric team felt that a 3-month interval is too long for these discussions and an interim meeting at the QMC campus now takes place every 3 months in between.

Nottingham was the first UK centre to take part in the international multi-centre CRADLE study, trialling an immunosuppressant drug called everolimus which has previously been used safely in

adult transplantation and in a small number of children. By the end of March 2015, 7 children from Nottingham had been recruited and proceeded beyond the randomisation stage of the study, making Nottingham is one of the top recruiting sites for this study of all countries participating. The study is due to complete recruitment during 2015.

WORKPLAN FOR THE NEXT YEAR

We hope to continue to promote live donor transplantation, giving families an opportunity to consider their child's future treatment at a much earlier stage in the patients' journey than before. This is an on-going aim.

We also plan to continue promoting living donor paired/pooled exchange where appropriate and also ABOi donation. At the start of the current financial year we were able to proceed with our first ABOi living donor transplant.

We plan to develop the concept of a transplant annual review to ensure that all patients and their families have a once a year overview of their transplant function and overall health. This was not achieved last year but remains on our workplan for the year ahead.

TRANSPLANT GAMES 2014

Nottingham Children's fielded its biggest team ever with 9 children and young people taking part, bring back a record number of gold, silver and bronze medals.

We are extremely proud of all our athletes! Special mention should go to Declan Bennett who, with a tally of 6 gold and 1 silver medal, won the award for best overall child perfomer and will be representing the UK at the World Transplant Games in Argentina in 2015. Well done Declan!

A huge thanks goes to Kate Frost who so successfully managed the team this year. Kate won a Nottingham University Hospitals Diamond Award in 2014 for her volunteer role as Nottingham Children's Transplant Games Team Manager.

6. CHRONIC KIDNEY DISEASE.

WORKFORCE

There is one (0.85 WTE) chronic kidney disease (CKD) specialist nurse who supports patients and families cared for by all the paediatric nephrologists. She supports patients and families through all stages of CKD and works alongside the nephrologists and transplant nurse to complete the transplant work-up process so they can be activated on the national transplant list. She then cares for patients until the point of either transplant or the start of dialysis.

CKD specialist nurse, Kate Baker

ACTIVITY 2014-15

Home visits are a vital part of the CKD nurse role. A total of 20 home visits were carried out: 8 school visits, 2 MDT meetings and 1 LAC (Looked After Child) meeting.

Part of the work up process for transplantation involves a CKD assessment day co-ordinated by the CKD specialist nurse. This involves the patient and family attending the hospital for a whole day to meet all the members of the multidisciplinary team to discuss dialysis and transplantation in detail. A total of 3 CKD assessment days were carried out this year.

The CKD nurse attends the majority of the 3 monthly transplant meetings over at the City Hospital to discuss the paediatric patients on/awaiting activation on the national transplant list.

Many of the CKD patients are seen in Nottingham and in shared-care clinics at their local hospital as part of our growing EMEESY network. The CKD nurse has attended 8 of these outreach clinics.

TRAINING, RESEARCH AND TEACHING

Another aspect to Kate Baker's role is supporting the RaDaR rare renal disease registry and its associated research studies. Kate currently spends 8 hours per month working on RaDaR.

Kate is on her fourth and final module for her Masters in Health Communication.

WORK PLAN FOR THE NEXT YEAR

- Aim to get all the patients transplant work-ups onto the renal computer EMED so that they are more easily accessed and updated.
- To continue attending shared care clinics especially Sheffield and Leicester as this is where many of our CKD patients are seen.
- To begin to start the vaccination process earlier in the patients' treatment so this doesn't delay their activation on the national transplant list.

7. ANTENATAL SERVICES

Currently, our unit provides an antenatal counselling service in Nottingham, predominantly for patients from Nottinghamshire and Lincolnshire. Women carrying babies who are suspected to have significant renal abnormalities are referred for counselling by the two Nottingham fetomaternal centres (QMC and City Hospital).

Meeta Mallik, Lead for Antenatal Services

ANTENATAL COUNSELLING

Counselling is provided by three consultant paediatric nephrologists. The counselling service is individualised and dependent on the nature of the suspected problem. Expectant mothers are seen either in the paediatric nephrology clinic, or jointly with specialist colleagues at the fetomaternal centre. Patients receive detailed information regarding the potential diagnoses and a postnatal management plan tailored to each case is made with. We liaise regularly with our fetomaternal and neonatal colleagues to ensure that mechanisms are in place to undertake these plans.

From April 2014 – March 2015 we provided antenatal counselling for 18 women.

POSTNATAL MANAGEMENT

We receive between 2-4 referrals each month for babies delivered in Nottingham with an antenatally detected urinary tract abnormality (AUTA). In the last year, 41 post-natal referrals were received. We have a comprehensive guideline in place for the management of such cases and postnatal investigations and management are arranged in line with this document. Advice is also offered for babies delivered across the EMEESY network.

For complex cases, management is discussed at our multidisciplinary nephrouroradiology meetings. Again, imaging for babies born across the network is also imported for review at these meetings.

Nottingham has well established research reputation in this field. The outcome data for several cohorts of babies delivered with AUTAs has been published. Our most recent study compares the incidence and outcome of babies born between 2011-2013 with those born between 2007-2009 and has been accepted for a poster presentation at the 2015 ESPN meeting. We aim to submit this study for publication in 2015.

WORKPLAN FOR 2015-16

Antenatal services, was one of the key topics at the March 2015 Annual Paediatric Nephrouroradiology Symposium. During this meeting, the need for antenatal counselling across the EMEESY network was discussed. Our workplan for 2015-2016 will focus on counselling across the network. We plan to liaise with fetomaternal centres across the region and other teams who already provide counselling to mothers expecting babies with significant renal abnormalities. In line with the national service specification for paediatric

nephrology, our aim is to provide specialist counselling delivered by a paediatric nephrologist when appropriate. We would be particularly keen to offer this service to the parents of babies who are anticipated to have significant long term renal problems. Expanding this service is likely to create a small increase in the numbers of patients seen in shared care clinics. The necessity for timely counselling may mean that not all cases can be seen at a shared care clinic, some patients may need to be seen in Nottingham.

We also plan to write up outcomes latest cohort of patients and submit this for publication as described above.

8. UROLOGY

Urology surgical in-patients are nursed on ward E17. Other children who undergo day-case procedures are admitted through the Ambulatory Care Unit. Numbers for admissions (including day case procedures) are found in section 3a above.

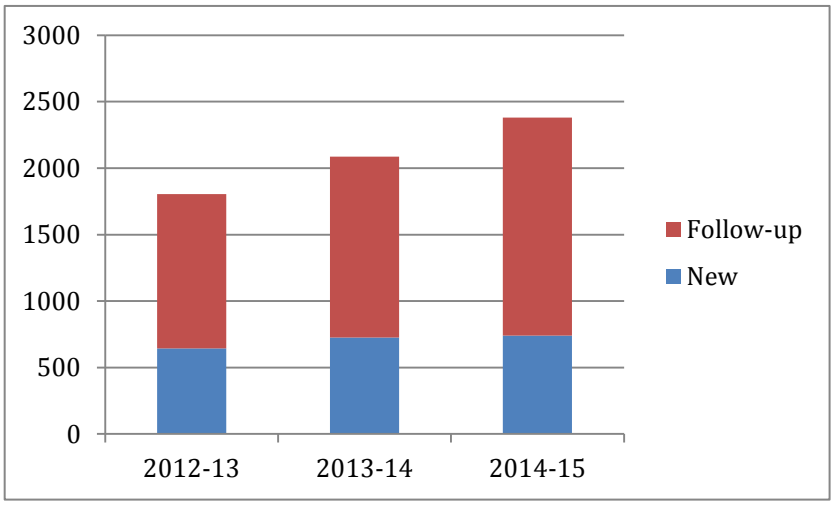
Manoj Shenoy, Lead for Surgical Specialties
Notttingham Children's Hospital

WORKFORCE

The consultant paediatric urologists are Mr Manoj Shenoy, Mr Alun Williams and Mrs Nia Fraser. Mr Williams also undertakes transplantation work for adults and children; his on-call is covering the transplant rota. Mr Bharat More covered Mrs Fraser's clinical work during her maternity leave. He has recently been appointed to a substantive consultant paediatric surgeon/urologist at Nottingham Children's Hospital and we welcome him back.

There is one national grid paediatric urology trainee and one paediatric surgical registrar-level trainee.

2014-15 ACTIVITY



Clinics took place in Nottingham Children's Hospital at the QMC Campus. Numbers of children seen in Nottingham paediatric urology clinics are shown in the figure above. There has been a 14% increase overall in out-patient activity from the previous year (16% increased activity from the previous year).

Non-attendance rates for paediatric urology out-patient clinics were 29% last year, 9% for new appointments and 39% for follow-up appointments.

As well as general urology clinics, there are monthly neuropathic bladder clinics and a regular clinic for children with disorders of sexual differentiation that is run jointly with paediatric endocrinologists.

Mr Williams does regular young persons' urology clinics at the City Hospital Campus. He also does operating sessions and clinics at Derbyshire Children's Hospital and Chesterfield Royal Hospital. Mrs Fraser does clinics at Kings Mill Hospital and Lincoln County Hospital.

9. UROLOGY NURSING

2014 was a year in which changes from the previous year were consolidated and still further new areas of practice developed. The nocturnal enuresis service led by Caroline Ward continues to flourish and produces some excellent results as you will see below; we were asked to take on the nursing care and overall management of children undergoing MRI urography and this has continued in 2014. The pelvic floor biofeedback which we began to offer our patients in January 2013 has developed still further and we have now begun to support the young people in our disorders of sexual development clinic. Finally we are soon to start the new treatment of TENS for overactive bladders we will be only the third children's hospital in England offering this service.

Throughout the year we have endeavoured to maintain a well organised, professional and caring team.

Christine Rhodes, Clinical Nurse Specialist in Paediatric Urology

WORKFORCE

There are four paediatric urology nurses: Christine Rhodes (0.8 WTE), Gill Young (0.53 WTE), Emma Stockdale (0.48 WTE) and Caroline Ward (full-time). In August 2014 we were granted an extra 11 hours taking the service to these hours. The difference this makes will be demonstrated in our overall productivity and the fact that we no longer having a waiting list for bladder assessments.

ACTIVITY 2014

The number of children currently requiring our service is:

- 392 Children with a neuropathic bladder
- 273 Children with daytime enuresis

CHILDREN'S OUTPATIENT DEPARTMENT

Total number of children seen in clinics by the urology nurses in 2014 was 385, a similar figure to that of 2013. This figure does not include the nocturnal enuresis clinic.

We continue to provide care and assessment within the out-patient setting.

There remains no paediatric continence nursing service within Nottingham County PCT or within North Nottinghamshire covering the area of Mansfield and until this is addressed these children continue to be referred into our service for advice and ultra sound screening.

This year the urology nurses have commenced attending the Disorders of Sexual Development (DSD) clinic.

NOCTURNAL ENURESIS SERVICE

Since its commencement in September 2011 when Caroline Ward was appointed to this role, the patient workload has from 5 patients to 74 prevalent patients at year end 2014.

We offer a personalised, dignified, patient-centred approach to nocturnal enuresis giving the Child/Young person the opportunity to tell us their patient story. We obtain vital baseline information using a structured approach and the supportive literature from the National Institute for Health and Clinical Excellence (NICE) for the management of bedwetting in children and young people. This enables Caroline to consider the treatment options available for use in treating nocturnal enuresis with the issue of an enuresis alarm as a first-line treatment option and/or the consideration of medicinal support if required. The decisions that are made are supported by a consultant nephrologist or urologists and additional specialist paediatric urology nurse support.

Telephone consultation support is offered. For families who live at a distance from Nottingham, this reduces the travel and financial pressures that travelling to clinic can incur. All patients are followed up by telephone 2-3 weeks after issue of an enuresis alarm or any medicine commencement/changes. Caroline is the named nurse contact for nocturnal enuresis which allows her to build a rapport with the patient and their family. She is in a position to offer a holistic approach to enuresis; often managing psychosocial or emotional concerns that occur from incontinence issues.

58 new patients were seen in 2014 with 16 long term patients. Of the 16 long term patients, 50% of these patients have been with this service for greater than a year and the other 50% have been with us for over 2 years.

Of the children who have been with us for greater than a year:

- 3 have relapsed after a period of dryness
- 3 are non-compliant but have experience dryness when compliant
- 2 are medicine monitoring/consultant support but are currently dry

Of the children who have been seen for over 2 years

- 3 have relapsed after a period of dryness
- 3 are non-compliant but have experienced dryness when compliant
- 2 medicine monitoring/consultant support

46 in total are dry since the service started. 22 last year (Sept 2013-2014) with 14 dry on the alarm only, 5 with medication/alarm combination. 60 alarms have been issued this year.

DAY CASE ASSESSMENTS

Total number of children requiring day case bladder assessment was 206, an increase of 39%. This examination is popular as we can obtain quite detailed information about how the child's bladder functions on a day to day basis which can be very valuable when deciding what the next method of treatment will be. It gives the urology nurses an opportunity to discuss at length the child's wetting and toileting pattern, there fluid intake and how generally the family cope with this difficult and embarrassing problem.

URODYNAMICS

Total number of children undergoing this investigation was 57, a decrease from last year's 75 children. We lost 18 urodynamic sessions this year as we continue to have some difficulties in finding appropriate medical cover for these sessions. Most of these procedures continue to be done using Entonox to insert urethral catheters, generating a considerable cost saving from the avoidance of supra pubic catheter (SPC) insertion requiring general anaesthetic.

CLEAN INTERMITTENT CATHETERISATION

38 children / parents, were taught clean intermittent catheterisation, plus a further 74 children (an increase of 56%) were brought into hospital for their supra pubic catheter changes. We are pleased to say through the renal teams networking (EMEESY) group that Peterborough and now Kings Lynn are now happy to change supra pubic catheters within their hospital which has reduced the number of families travelling all the way up to Nottingham for this procedure.

COMMUNITY

We have carried out 31 homes and school visits a figure almost identical to last year's numbers. We continue to follow the agreement set that only essential home/school visits should be carried out and when possible we have asked parents/carers and schools to travel in to hospital to see us for teaching, training and other advice.

The service made 2429 phone calls to parents, 208 phone calls to health-care workers and 232 phone calls to schools, a total of 2869 phone calls.

BIO-FEEDBACK

We remain one of a handful of children's hospitals to offer pelvic floor rehabilitation through bio-feedback. The children who would benefit from this form of treatment are those with dysfunctional voiding (DV). This means at the very time the child's sphincter and pelvic floor should be relaxed to enable the child to void completely it is contracting and not allowing a free flow of urine and complete emptying of the bladder. Each child is offered a course of 6 consecutive week's therapy with each session lasting around 1 hour. We commenced our service by seeing 3 children a week but

had to increase these sessions such that we are seeing 6 children a week due to the increase in demand. The service is primarily run by Gill Young and Caroline Ward.

Following discussion with the urology nursing team at Sheffield Children's Hospital in March 2014 we have commenced a biofeedback diagnostic assessment before committing to a treatment course. This helps to prevent treating children who will not benefit from a six week course of pelvic floor bio-feedback.

28 children attended for bio-feedback in 2014. There were 167 sessions, an increase of 56% from 2013.

DISORDERS OF SEXUAL DEVELOPMENT (DSD) CLINIC

The DSD clinic, which was established in 2006, runs approximately every 12 weeks. It is staffed by a urologist, an endocrinologist and a psychologist. This is in line with a national service specification.

In 2013 the urology nursing team was approached to become involved in the DSD Clinic with a long term aim and goal of supporting the teenage girls attending this clinic who require vaginal dilatation. Non-surgical dilation for neo-vaginal creation is the first line treatment of choice for vagina agenesis and is successful in 85% of cases. A urology nurse (Chris Rhodes) has been involved with the clinic since 2014. She liaises with gynaecology nurse specialists in terms of equipment and practice.

TRANSCUTANEOUS NERVE STIMULATION (TENS) FOR THE TREATMENT OF OVERACTIVE BLADDERS

Throughout the year we have been gathering information on TENS treatment of overactive bladders. In Europe this method of management has been available for patients for some time but not so here in the UK. The only other centres in the UK that carry this form of treatment are Liverpool, Evelina Children's Hospital (London) and Aberdeen. We have sought the help and advice from all of these centres. All expressed a very positive attitude to the treatment in fact the Evelina have now developed their own TENS clinic and issued over 160 TENS machines in the last 12 months reporting excellent results.

A protocol for this treatment together with a parents' information sheet have been written. TENS machines have been purchased at a cost of approximately £20. The child comes into hospital for instruction on how to use the machine, then take's home the machine and uses it every night for 2 hours for a period of 12 weeks.

We hope to commence this treatment in 2015 and look forward to reporting outcomes in next year's report.

SECRETARIAL SUPPORT

In August 2014 Vicky Cancemi's PA role was adapted to help support the urology nursing service and as such Vicky now books in all of our appointments, manages our electronic

diaries and is the named person on our letters for confirmation of their appointments or subsequent alterations that may be required. This as lead to a much more efficient service and the re-deployment of these roles from the nurse specialist is another factor relating to the increased number of patients we have seen in 2014.

ACADEMIC ACTIVITY

Christine Rhodes remains the chairperson for the RCN Children's Urology Continence Community and continues to work closely with the RCN. Christine Rhodes and Gill Young have continued to teach on a wide variety of educational courses, study days and conferences.

March 2014. Chris Rhodes presented at EMEESY Nephrouroradiology Symposium on *The role of the urology nurse in managing children with CKD*.

March 2014. Chris Rhodes presented at the Paediatric Nephrology Nurses' Annual Conference on *Managing complex urological problems in children with renal dysfunction*.

May 2014 25th European Society of Paediatric Urology conference (Innsbruck - Austria)

June 2014. Chris Rhodes spoke at the conference on children's continence ran by Coloplast.

June 2014. Chris Rhodes chaired the British Association of Paediatric Urology Nurses meeting (President) in Birmingham.

November 2014. Gill Young spoke at the ERIC 25th anniversary conference in Birmingham on the subject of bio-feedback.

WORKPLAN FOR 2014-15

- To develop the TENS service
- To develop the urology nurse role within the DSD clinic
- To further evaluate the new biofeedback service
- To publish the experience of using Entonox to support urethral catheterisation for urodynamics.

10. PHARMACY

Pharmacy services are provided by Peter Foxon, whose spends around 0.5 WTE working with the children's renal unit and PICU. He advises on prescribing for in-patients and out-patients. He also advises paediatric pharmacists throughout EMEESY on prescribing specialist renal drugs and gives advice about prescribing in renal impairment.

ACTIVITY DURING 2014-15

Children with renal transplants and children with chronic glomerular disease, like nephrotic syndrome may receive medication delivered to their homes through Healthcare at Home. During 2013-14, there were problems with this service through a distribution base move and the collapse of a competitor service leading to a significantly greater workload. We met regularly with staff from Healthcare at Home to help address problems and are pleased that the situation has improved so that we are once again able to offer the service to new patients.

Two children have continued on eculizumab for atypical haemolytic uraemic syndrome, delivered by a paediatric nurse through a long-term port device and supported by BUPA Healthcare.

As part of a cost-improvement project, we aimed to convert all patients (transplant and nephrotic patients) receiving Prograf® to a generic form of tacrolimus (Adoport®) now that the drug is out of patent. The switching process was subjected to a careful risk assessment and earlier on during the year we felt unable to progress because of concerns with home delivery services. Now that the Healthcare at Home problems have been overcome, at the end of the financial year we set in motion a chain of events, aiming to convert patients two weeks before their next clinic appointment to ensure an early tacrolimus level check. Data from large adult transplant centres who have converted patients' form of tacrolimus suggest that only <1% patients will require a dose change.

Pharmacy has a page on the EMEESY website which has been used to update professionals around the region on news about availability or other updates with commonly-used renal drugs. It is also the place where we have stored the high-risk monographs, drug guidelines that have been written in Nottingham for intravenous drugs that may have different clinical implications for patients with reduced kidney function. The list of these drugs is now almost complete and is available for professionals in other EMEESY centres to share.

WORKPLAN FOR 2015-16

- Complete Adoport® switch
- Continue to update EMEESY website regularly
- Explore further aspects of network role

11. DIETETICS

Nutritional support for children with chronic kidney disease is a key aspect to management to support health and growth.

Pearl Pugh, Senior Paediatric Renal Dietitian

WORKFORCE

The dietetic service provided to the paediatric renal unit during 2014-15 was staffed by Emma Kelly (1.0 WTE, band 6) and Pearl Pugh (0.6 WTE, band 7). Pearl reduced hours to undertake a worked secondment to neonatal services between April and June 2104. To compensate for this Ruth Prigg (band 6) provided 0.3 WTE support. Both dietitians are members of the Paediatric Renal Special Interest Group (PRING) and aim to attend at least one of their twice-yearly meetings. Pearl Pugh is a member of the EMEESY network steering group. Pearl is also a member of the Nottingham University Hospital Ethics Committee.

ACTIVITY DURING 2014-15

CONTACTS

	2009	2010	2011	2012	2013-14	2014-15
Total number of renal patients	225	224	187	188	242	239
New patients	87	71	76	70	74	75
Total dietetic activity	1732	1765	1540	1456	1745	1849
Mean number of contacts	7.7	7.9	8.24	7.74	7.2	7.7

The mean number of contacts here refers to the average number of dietetic contacts each renal patient has had in one year. This figure has remained stable over the last 7 years and shows the intensity of dietetic support that may be required for renal patients.

Cover is provided for all in-patients and CKD clinics that take place on a Tuesday and Thursday morning. Only urgent referrals were seen in the Wednesday nephrology clinics. During periods of full staffing a dietitian attended an outreach clinic with the consultant in Leicester this has been identified as a priority for input.

BREAKDOWN OF NUMBER OF PATIENT CONTACTS

	2006	2007	2008	2009	2010	2011	2012	2013-14	2014-15
In-patients	678	661	771	764	768	628	622	690	613
Out patients	411	333	447	366	376	488	561	656	667
Dialysis unit							64	107	169
Home/school visits	3	1	2	1	1	0	1	0	3
Telephone	470	330	394	423	430	424	187	292	122
Total	1562	1325	1614	1554	1575	1540	1435	1745	1574

There is a large discrepancy between the totalled number of patient contacts on this table where it is broken down into individual categories compared to the total number of contacts above. Further analysis of the data shows that these contacts include the following:

- telephone conversations with health care professional
- writing social service reports
- dietary analysis
- calculating feed plans
- setting up home enteral feeding contracts
- writing to GP re supplements
- developing resources

Not recorded here, is a significant amount of time spent supporting shared care dietitians.

TYPES OF TREATMENT CONTACTS

	2007	2008	2009	2010	2011	2012	2013-14	2014-15
Oral calorie supplements	285	390	415	435	456	205	213	614
Gastrostomy feeding	357	375	460	569	387	221	437	433
NG/NJ tube feeding	175	225	246	184	319	171	265	259
PN	7	38	7	29	4	10	38	8

A more detailed breakdown of the composition of consultatations is shown below. Each consultation may comprise of more than one element.

	2013/14	2014/15
Dietary assessment - computerised	35	21
Dietary assessment - other	13	42
Healthy eating advice	176	136
Simple or single dietary recommendation e.g. low Na, low fat	6	25
Complex or disease specific dietary advice e.g. diabetes, renal	877	873
Controlled nutrient/portion	3	
Oral supplements	386	540
Nasogastric tube-feeding	327	257
Gastrostomy tube-feeding	479	433
Central parenteral nutrition	39	8
Peripheral parenteral nutrition	3	
Energy dense diet	128	174
Weaning advice	34	31
Nutrient enriched infant formula	95	74
	2601	**2664**

TRAINING, RESEARCH AND TEACHING

ABSTRACT/ PUBLICATIONS

Renal Nursing 4th Edition; ed Nicola Thomas. Wiley Blackwell 2014. Acknowledgement in chapter 13; Renal Nutrition pp 339-381.

RESEARCH

EMEESY Network Service development (PP)

CONFERENCE PRESENTATIONS/TEACHING

Network meeting with Leicester, Sheffield, Leicester and Cambridge. Presented on the vision of the Network Paediatric Renal Dietetic service (PP, April 2014)

International Congress on Renal Nutrition and Metabolism. Wurzberg, Germany. Presented on 'What I Tell my Families About Renal Diets for Children with CKD' (PP, May 2014)

Nurse teaching on the Renal education Day (EK, June 2014)

Sheffield critical care nurses (EK, June)

EMEESY Network Annual Education Day. The Olde Barn Hotel, Lincs. Reskilling paediatric dietitians to provide a service to renal patients (PP/EK, Oct 2014)

Paediatric Renal Interest Group and International Conference, Mottram Hall, Cheshire. Presenting a case study on growth and CKD. (EK/PP, Nov 2014)

Involved in dietetic student training (EK ongoing)

COURSES ATTENDED

Clinical Audit Awareness in Nottingham University Hospitals (PP, June 2014)

Masters in Research Methods mentorship programme, Nottingham University (PP, March, April 2015)

INNOVATIONS/WORKING GROUPS/COURSES

Organised work experience sessions for dietetic student (EK)

Updated diet sheet (PP/EK)

PLANS/ TARGETS FOR 2015-16

- To complete annual dietetic assessments involving analysis of 3 day food diary on all dialysis patients.
- To complete an annual dietary assessment report for all dialysis patients

- Continued involvement in teaching of new staff and educating existing members of staff with regard to the renal diet
- Continue to improve menu choices for patients on E17
- Continue to develop and review dietetic resources
- Continue to work on a strategy to improve phosphate compliance in children and young people

12. SOCIAL WORK

Social work support to children with chronic kidney disease and their families is provided currently by a half-time social worker. The post was been part-funded by the British Kidney Patient Association until 2014 but has now been incorporated within the establishment of support posts. The second post is currently vacant but we hope to recruit to it in the very near future.

Suzanne Batte, Paediatric Renal Social Worker

ROLE OF THE SPECIALIST PAEDIATRIC RENAL SOCIAL WORKER

Chronic kidney disease is a life-long condition which has complex psychosocial implications for the child and other family members which requires long term support. Suzanne has continued to aim to provide a high standard of psychosocial care to children and their families through traditional social casework and counselling skills. This service is provided on the renal ward, outpatient clinic and dialysis unit. The support offered includes being available during ward admissions to discuss emotional, practical and financial implications. Home visits are also undertaken to follow up needs in the community.

Suzanne has continued to visit families with specialist renal nurses at critical times during the treatment process including emotional trauma at the time of diagnosis, prior to transplant listing and at the commencement of dialysis. Particular practical issues that families face include storage and space when starting peritoneal dialysis at home or coping with long journeys and treatment three times a week for those on hospital haemodialysis. Sometimes a parent will have been forced to give up work too and so they will require help to look at their finances. The BKPA are a great source of support for lower income families and Suzanne continues to submit regular applications.

The broad range of families' backgrounds requires individual responses. Suzanne is skilled at assessing the needs of children from a wide range of religious and cultural backgrounds. She also works with parents who have learning difficulties and mental health issues. Social workers work with children who have involvement from Social Care due to safeguarding issues. The impact of a specialist paediatric renal social worker is to ensure that local authority social workers, teachers and other professionals understand the impact of chronic kidney disease on families where there may already be substantial concerns. Being an advocate for families whilst monitoring concerns is a difficult task to balance, but having an experienced paediatric renal social worker who understand the thresholds for considering when children may be at risk of significant harm is essential in the team.

Advocacy work is an expectation of the renal social work role. Suzanne has continued to represent the needs of children and their families with other agencies including housing departments, employers, the Benefits Agency, schools, nurseries and further education establishments. She has sometimes been required to attend appeals tribunals in relation to Disability Living Allowance.

2014-15 ACTIVITY

At the current time, the social work provision is much reduced. However, effective planning and organisation has ensured that the service continues, with priority given to children subject to child protection plans, those receiving dialysis and children awaiting transplantation. Suzanne is currently based more in the hospital during this period so that ward patients and clinic patients continue to receive support. Weekly attendance at the chronic kidney disease out-patient clinics ensures that Suzanne can see families and be available to offer advice and support. For families attending infrequently, this provides an opportunity to assess how they are coping. It is clear that a comprehensive psychosocial service requires two social workers to ensure that families receive support throughout the whole treatment process.

Suzanne has made 25 home visits in the last year. She has attended 9 Child in Need/Child Protection conferences/Core Group meetings, 13 Team around the Child (TAC) meetings and made 6 school visits. This is less than half of the number of community visits made in the previous year with 1.5 WTE posts and illustrates the resourcing needs of a busy children's kidney network.

Suzanne receives regular supervision from an experienced social work team manager. This ensures that she can obtain advice about on-going work with families and discuss care plans. The supervision also focuses on training and developmental needs as this is a requirement for registration to practice as a social worker.

Suzanne is a member of the BASW Special Interest Group which promotes the work of renal social workers nationally. This ensures that she keeps informed about developments that impact on her daily work as indeed the group is a great source of information and advice.

Presentation at the annual EWOPA conference has not been possible this year due to pressures on meeting a service requirement.

CHALLENGES FOR THE YEAR AHEAD

We hope to appoint a replacement full-time social worker later in the near future. It is almost inevitable that this individual will have limited experience working with children who have chronic kidney disease so a considerable amount of skilling for the new appointee will be required.

13. PLAY

CURRENT WORK FORCE:

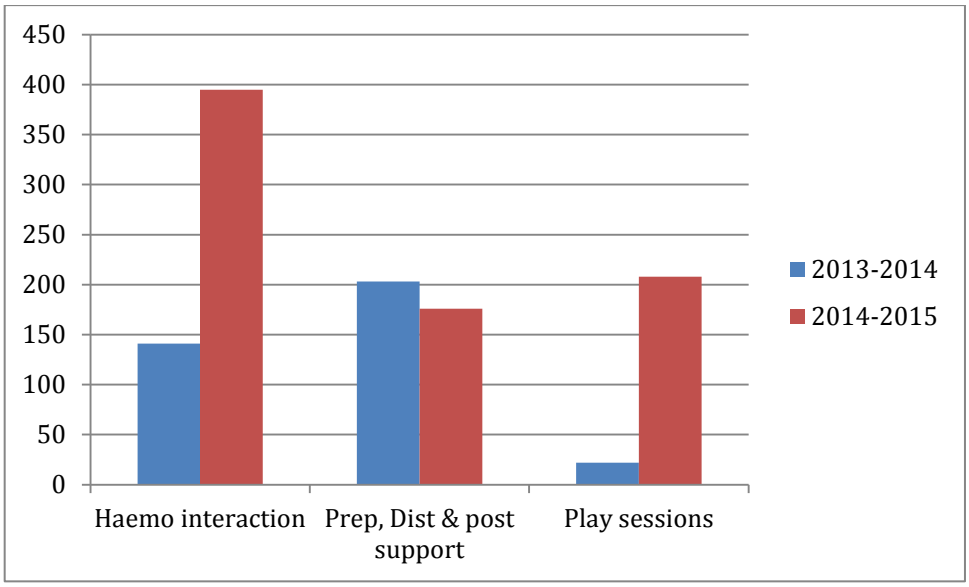
One full time health play specialist (Claire Hardy) and one part time (25 hour) nursery nurse in post since October 2013 increased to 30 hours per week from October 2014 until March 2015. Unfortunately it was not possible to continue the post with that source of charitable funding. A subsequent successful application has been made to the BKPA and we hope to appoint to a full-time post for one year in the near future.

ACTIVITY DURING 2014-15

This table below shows the episodes of patient interactions:

Month	Urology	Tx Prep	Haemo patient interaction	Prep, distraction, post support	Sibling Support	Biopsy Support	Support other areas	Play session	Sensory play	Renal Clinic	Home/school visits	General play	Emotional Support	Family Support	Totals
APR			24	28	21	2	7	16	4	13		44	19	23	**201**
MAY	2		46	39	8	2		23		23	2	52	35	31	**263**
JUN	1	1	39	32	2	5	1	27	3	9		72	49	38	**279**
JULY			85	26	8	4	1	20		2		106	43	63	**358**
AUG			67	7	12			25	2			90	12	15	**230**
SEPT			56	32	3	5		39		1	1	57	52	26	**272**
OCT		1	53	31	9	9	1	30	4	2	1	102	33	36	**312**
NOV		1	49	17	0	3	2	25				82	20	16	**215**
DEC	2		33	15	9	3		7				43	19	25	**156**
JAN		2	55	32	12	9	4	27	9			87	23	69	**329**
FEB		3	33	20	10	7	3	27	2	3		40	25	33	**206**
MAR			49	22	4	7	1	28	1			50	34	17	**213**
TOTAL	**5**	**8**	**589**	**301**	**98**	**56**	**20**	**294**	**25**	**53**	**4**	**825**	**364**	**392**	**3034**

As you can see from the figure below the number of haemodialysis patient interactions has more than doubled with 2 play staff on the unit



During 2013-14, many more sessions of support for procedures took place compared to play sessions. This was due to the fact that for much of that time there was only one hospital play specialist whose time was prioritised for procedure preparation.

This changed considerably in 2014-2015 when the number of sessions of procedure support was almost the same as the number of play sessions delivered. Having two members of the play team allowed for play sessions to continue whilst patients were being support in treatment rooms and other departments for distraction, preparation and post procedural support.

SIGNIFICANT ACHIEVEMENTS:

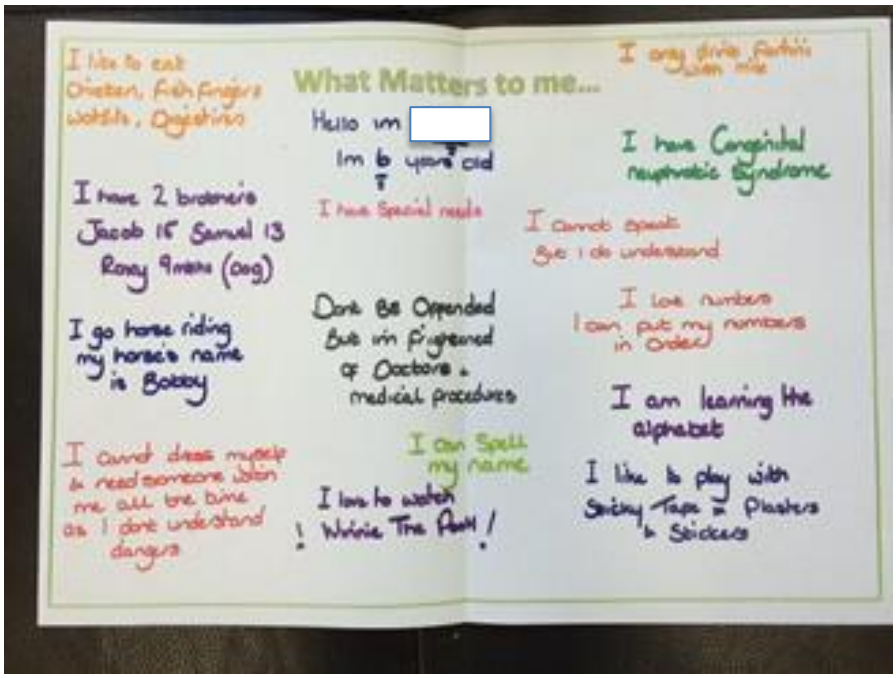
- More general play and play sessions carried out on the ward and in haemodialysis due to nursery nurse appointment
- Teaching sessions in Japan and continued link with supporting the development of the hospital play specialist role in Japan
- Moves to developing more preparation tools and looking at how to make them more accessible i.e. on devices.

PUBLICATIONS AND PRESENTATIONS:

- Student open days
- Teaching sessions in Japan as part of the Japanese HPS development programme.
- Senior Nurses meeting on my visit to Japan
- Presentation to Wollaton Rotary club about NCH
- Senior nurses meeting on the *What Matters to Me* project

EXAMPLES OF *WHAT MATTERS TO ME* PROJECT

What Matters to Me was trialled on E17 after the Children's Hospital Hub saw a presentation at a conference in France in 2014. It has worked well particularly with the patient who have communication and development difficulties, and is now being trialled on E39 and PCCU with the hope that it will roll out to all childrens wards.



PLAN FOR 2014-2015:

- To appoint another nursery nurse into post on E17
- To structure the way we work to ensure that all areas are covered (haemodialysis bay, ward, clinic)
- To continue to do carry out home and school visits
- To link with other renal play specialists nationally, including visiting other areas to see how services are run.
- To develop tools and resources for transplant and dialysis preparation that can be accessed by other centres
- To present at international conferences on the role of hospital play

14. YOUTH WORK

The BKPA-sponsored Renal Youth Development Worker post came to an end in November 2014 and we said goodbye to Dorro Hackett, wishing her well with her paediatric nursing studies.

ACTIVITY DURING 2014-15

In the absence of a dedicated Youth Worker for Renal Services, young people can still receive support and participate in projects and activities through NUH Youth Service.

The Youth Work Team is based on E Floor, East Block in the 'Youth Room' and consists of:

- Donna Hilton (Youth Service Manager)
- Mark Howard (Senior Youth Worker)
- Lucy Rychwalska-Brown (Young People's emotional Health Worker)

We also have sessional staff to help run the Youth Club and other projects, along with a team of dedicated volunteers, including young adult renal patients.

The Youth Service offers a variety of activities and resources for young people, aged 11 – 25 years) accessing hospital services; these include:

ONE-TO-ONE SUPPORT AND COUNSELLING

During difficult times, young people can offload informally and receive advice and support from one of the Youth Workers. There is also the opportunity to meet with Lucy, who is a trained counsellor and relates specifically to young people and can offer more in-depth support if needed.

YOUTH ROOM DROP-IN SESSIONS

For young people staying in hospital, there is an opportunity to visit the Youth Room daily and take part in a wide variety of activities with other young people and the youth work team. From Mario Kart to art and craft activities to a cup of tea and a chat, there is something for everyone.

YOUTH CLUB

For in-patients, and those living locally, Youth Club runs every Wednesday evening from 7-9pm at the Monty Hind Centre on Leen Gate (just behind the QMC). Young people come along and meet other young people, taking part in a wide variety of activities such as pool, table tennis, arts and crafts, cooking, drama, music, sports, games consoles and other projects.

MONDAY NIGHT ACTIVITY GROUPS

For in-patients, and those living locally, Monday sessions run from 6:30-8:30pm in our Youth Room within the hospital. They consist of the following:

- 1st Monday of the month: Youth Achievement Awards – gain a nationally recognised accreditation for any activities and projects you are doing with the Youth Service
- 2nd Monday of the month – 'Beyond the Brick' – a Lego© based social group to have fun and express yourself!
- 3rd Monday of the Month: 'Let's Cook!' – improve your cooking and baking skills, try new recipes and meet other young people.
- 4th Monday of the month: 'Chat & Snap!' – a photography group to learn new camera skills and take part in exciting media projects.

YOUNG PEOPLE 4 CHANGE

If any young people 11- 19 years want to have their voices heard and represent young people's views in hospital, then our Youth Forum is the ideal group. Meeting on the last Tuesday of every month in the Youth Room, young people can meet together to share ideas, comment on hospital policies and leaflets and engage in some exciting youth-led projects.

INNOVATIONS

Our Young Adult Group 'Prospect' is for young adults 16-25 years who might need support around transition, independence, life skills, CV building and/or want to meet other young adults. The group meets every Friday morning in the Youth Room from 10am – 1pm. Trips and social outings are also organised for the group.

In February 2015 the Nottingham Children's Hospital Grand Round focussed on youth work. The session included interviews with four young people who access or have accessed youth services at the Children's Hospital. Three young people (including Sophie and Avais, whose stories feature on the Young People's pages of the EMEESY website) have completed training and returned to be volunteers with the youth service. Ascribing quantitative outcomes to youth work can be difficult but seeing the self-assurance of all these young people, their acceptance of their own chronic illness and desire to reach out to help other young people left no-one in the audience in any doubt of the benefits of youth work.

WORKPLAN FOR THE YEAR

We have not managed to secure sustainable funding for a renal youth worker over this year and this remains amongst our top priorities. We are seeking other avenues of charitable-

support in the short-term in the hope of embedding this post within the funding structure for the whole EMEESY children's kidney network.

CONTACT

For further information, see the youth service website: www.nuhyouthservice.org.uk

Telephone: 0115 970 9421

Email: nuhyouthservice@nuh.nhs.uk

Find us on social media:

Facebook **NUH YouthService**

Twitter **@NUHYS**

Ward E17 youth room

15. PSYCHOLOGY

Currently, due to an overall shortage of psychologists for Nottingham Children's Hospital, psychology support for the children's renal service is provided on a referral-only basis. This falls well-short of the recommendations in the BAPN Multi-Professional Working document of 2003 which would recommend at least 2 WTE for a service covering a population of 6 million. This referral service is provided by Dr Kathryn (Kat) Bradley.

Some psychological support continues to be provided by other members of the psychosocial team but further reductions in numbers of staff comprising the psychosocial team make this increasing difficult. In this last year, we have lost a youth worker, a full-time social worker and a nursery nurse.

ACTIVITY DURING 2014-15

The number of referrals month by month since Kat are shown below:

Date	Number of referrals	Average wait (to nearest day)
June 2014	5	97
July 2014	1	79
August 2014	1	54
September 2014	7	37
October 2014	4	60
November 2014	1	70
December 2014	1	41
January 2015	0	-
February 2015	2	53
March 2015	1	63
Total	**23**	**55**

The average wait to be seen is nearly 8 weeks and this indicates the need for greater resourcing even with the small numbers of referrals shown here.

Reasons for referral are shown in the table below:

Main reason for referral	Number of patients
Behaviour	6
Mood (depression, anger, anxiety)	4
Continence	3
Coping with illness/treatment	3
Adherence	2
Procedural anxiety	2
Trauma	2
Fatigue	1
Pain	1
Selective eating	1
Sleep	1

The type of psychological input required by these children or young people is shown below:

Type of Input	Total number of sessions
Telephone follow up longer than 5 minutes	60
Face to face outpatient appointment	18
Consultation with team	18
Child not brought to appointment	6
Inpatient contact	5*
Face to face in renal clinic	3
Initial referral more appropriate for other agency	3
Home/school visits (an exception due to large region and limited time)	1

*(2 urgent/immediate, 3 planned)

WORKPLAN FOR 2014-15

Additional dedicated psychology sessions is included in the business case for specialist commissioners. We hope to supplement a 0.5 WTE post if successful with an additional 0.2 WTE hours for research development to allow us to continue the strong tradition we have had for pscychosocial research in the field of childhood chronic kidney disease. We would apply for charitable funds to support this research element on a fixed term basis (2 to 3 years maximum) with the intention that this is pump-priming for the incumbent to generate further research proposals and write further grant applications.

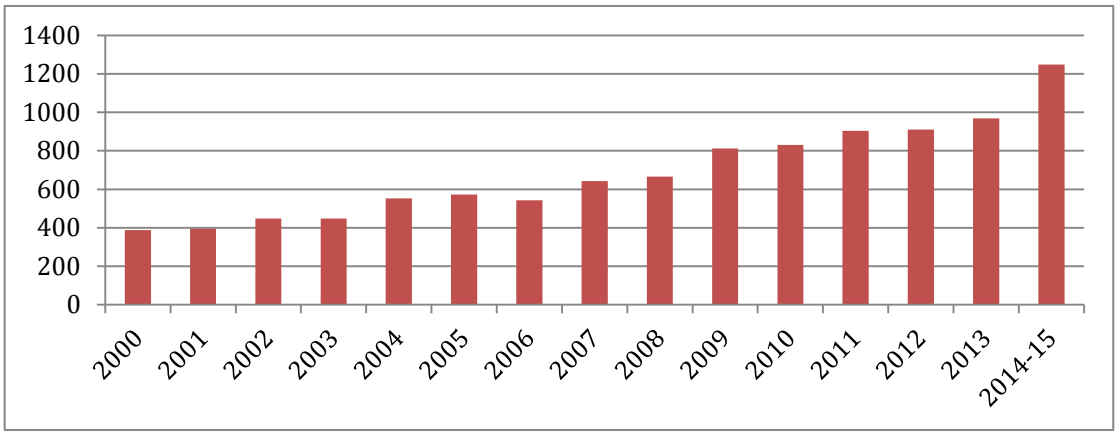
16. ACTIVITY IN LOCAL CENTRES

Numbers of children seen in local shared-care clinics has continued to grow. New on-going clinics have been established during 2014-15 in Barnsley District General Hospital and James Paget University Hospital (Great Yarmouth). Finally, in September the first ongoing clinic took place in Hinchingbrooke Hospital (Huntingdon) meaning that all 19 local paediatric centres within EMEESY outside of Nottingham have a regular paediatric renal shared care clinic.

During 2014-15, we have aimed to take a nurse to two clinics at each centre per year. Dietetic support for shared-care clinics has been more problematic with the current dietetic workforce but it remains an aspiration to increase the hours of Nottingham-based dietetic time to be able to provide the same level of support as for nursing.

Most local paediatric centres have a medical lead for renal patients. Where there is a local nephrology-interest paediatrician ("SPIN") in post, arranging interim reviews or chasing up results of investigations done in local hospitals is much easier and improved quality of care for the patient results. When shared-care clinics are carried out by the local SPIN paediatrician and visiting paediatric nephrologist together, care plans can be made and frequently the future care can be shared between locally-run and these joint clinics.

ACTIVITY DURING 2014-15



Growth in overall shared-care clinic numbers since 2000 is shown in the above graph. Numbers seen during 2014-15 were even greater than the predicted numbers from last year and represent an increase of 29%. This represents 31% of all our out-patient activity compared to 22% from the previous year. With new clinics just establishing in the three centres above, with several centres requiring additional clinics and with additional activity developing in Sheffield and Nottingham it is anticipated that 2015-16 will see still further growth in patient numbers seen in local shared-care clinics.

WORKPLAN FOR 2015-16

Plans for revising all service-level agreements are on-going but have proved more challenging than was forecast. It remains our aim to bundle all the activity as specialist commissioning and to secure an appropriate tariff for these clinics to ensure sustainable funding for the network.

17. CRITICAL CARE SUPPORT

CURRENT WORKFORCE

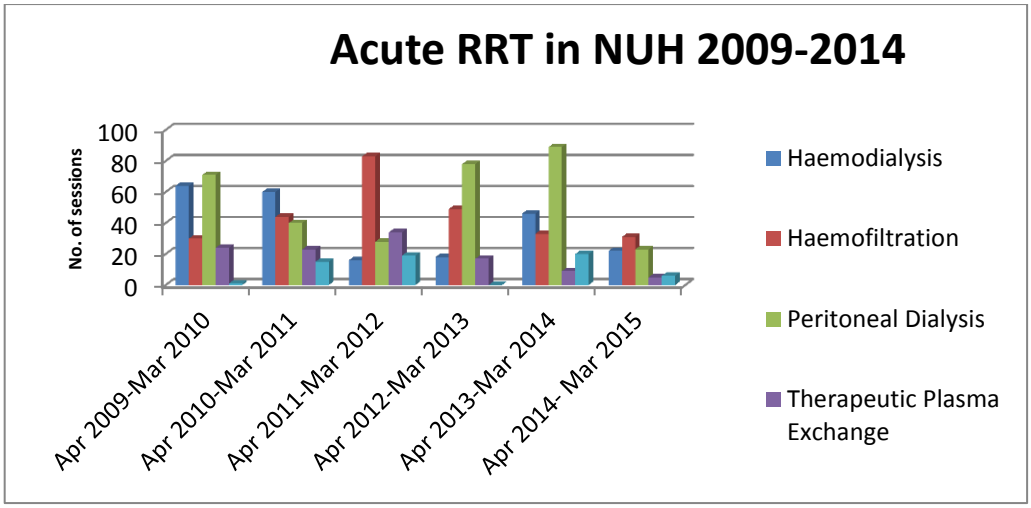
The Renal Critical Care Educator (0.8 WTE) provides specialist nursing support and education for staff caring for children within the regional PICUs covered by the EMEESY network. This includes Nottingham, Sheffield and Leicester (Glenfield and Leicester Royal Infirmary). Some support is also provided to Addenbrookes, but this is more as an in reach rather than outreach service.

Molly McLaughlin, Renal Critical Care Educator

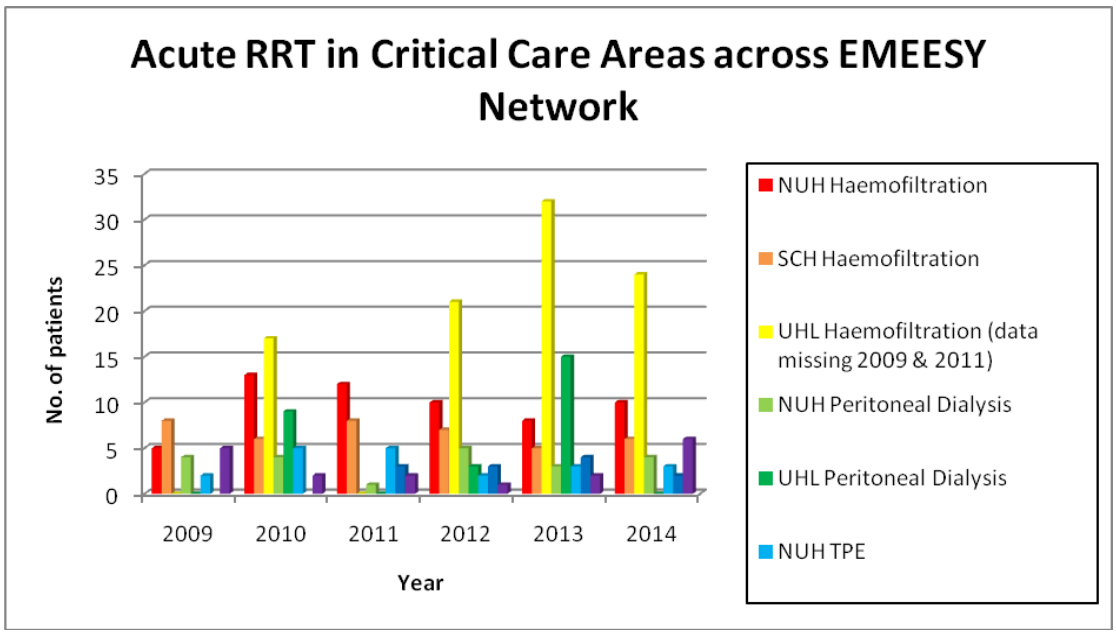
Renal critical care education focuses mainly around Continuous Renal Replacement Therapies (CRRT). There are increasing numbers of children with acute kidney injury (AKI). requiring CRRT within PICU's, however the frequency and predictability of these treatments remains very varied. This means competence and confidence of PICU staff in delivering such specialised treatments can vary greatly. The renal critical care education support therefore aims to increase exposure to such treatments and improve their knowledge and practical skills through simulation, ad hoc bedside teaching, formal classroom teaching or study days and supervised practice when a patient is undergoing treatment.

ACTIVITY DURING 2014-15

The Childrens Renal and Urology Unit provides all modalities of acute renal replacement therapy (RRT) on an intermittent or continuous basis and works closely with PICU, PHDU and NICU to deliver these treatments. From April 2014 to March 2015, 24 patients received acute dialysis therapies within Nottingham University Hospitals (NUH) (9 had haemodialysis, 12 haemofiltration, 4 peritoneal dialysis, 2 plasma exchange and 2 double plasmafiltration). These were either delivered on E17, PICU, PHDU or NICU. Below breaks down the number of sessions delivered (in NUH only) in comparison with previous years (as haemofiltration is a continuous therapy 1 session is equal to 1 day of treatment).



Below highlights the RRT activity across this network, specifically within the critical care areas (PICU, PHDU, NICU). The year covers the calendar year, not financial year. All the data refer to number of patients, not number of sessions.



SIGNIFICANT ACHIEVEMENTS/INNOVATIONS

2014 has been a varied year across the network. Leicester Royal Infirmary (LRI) continues to develop its continuous veno-venous haemofiltration (CVVH) service, treating the first 5 patients in 2014. There has been a significant turnover of staff trained to deliver this treatment, which has made the ability to maintain a core team of staff quite challenging. More time and resources have been required at this site to sustain a safe and effective service.

January 2014 saw the start of a new follow up pathway for all children who have received RRT for AKI within the regional PICUs. Now all children who fall within the EMEESY

catchment area will be followed up lifelong following AKI within PICU. To date 19 patients have been referred for follow up care. There continues to be problems in ensuring the initial referral is made, this is all being developed to ensure a more streamline process in the future.

The Regional CVVH Simulation Days expanded further last year with the first day being run here at NUH. The number of trusts invited to these days has also expanded to four, as nursing staff from Addenbrookes PICU are now able to attend the days. The four trusts now covered are Cambridge University NHS Foundation Trust, Nottingham University Hospitals NHS Trust, Sheffield Childrens NHS Foundation Trust and University Hospitals of Leicester, which incorporates all the PICU areas within EMEESY network. These days encourage working collaboratively to provide standardised care for children with AKI requiring CVVH across EMEESY.

PUBLICATIONS/INVITED LECTURES

June 2014 – Taught on AKI and RRT for Paediatric Critical Care Module at Anglia Ruskin University

October 2014 – Taught on AKI and RRT for Paediatric Critical Care Module at Sheffield Hallam University

November 2014 - Taught on Managing fluids in infants and children, AKI and RRT for Paediatric Critical Care Module at University of Nottingham

February 2015 – Taught on AKI and RRT for Paediatric Critical Care Module at De Montfort University

Member of PICS Renal Sub Group

WORKPLAN FOR THE YEAR

- To continue to develop and consolidate the CVVH service at LRI.
- To do further research into citrate anticoagulation for NUH. During the pCRRT conference this summer, the plan is to meet with colleagues from Europe, who are utilising the citrate programme with the same equipment as NUH. This will hopefully provide more information to enable us to progress further with this option.
- To develop the Regional CVVH Simulation Days further to provide a more inter-professional approach.
  To improve the referral system for patients post AKI within PICU.

18. NETWORK MANAGEMENT

The main thrust of network management during 2014-15 was focussed upon securing an appropriately costed out-patient clinic tariff with all service-level agreements in favour of activity belonging to Nottingham in order that this provides long-term and sustainable resourcing for the network. A business case was written with additional posts and part-posts that included all those which were previously charitably-funded but have now been lost (described above) as well as sufficient administrative support, medical, nursing and dietetic leadership to maintain the network infrastructure. The proposal was submitted under the coding and counting framework but was not successful. We remain in discussion with specialist commissioners who are advising how we should re-submit this proposal for the next financial year.

The network steering group (NSG) comprises: Jon Gulliver (specialist commissioner), Martin Christian (network lead/chair), Shelley Jepson (network lead nurse), Judith Hayes (administrator), Pearl Pugh (network lead dietitian), Simon Rhodes (East Midlands SPIN), Gail Moss (South Yorkshire SPIN), Mona Aslam (South Yorkshire SPIN), Andy Robb (urologist), Alun Williams (urologist), Andrew Wignell (pharmacist). A vacancy exists for a local nurse. Psychosocial team and parent/patient input into the group is co-ordinated by Shelley Jepson. The NSG met before education meetings in November 2014 and March 2015 with an interim meeting held in Peterborough in June 2014.

During 2014-15, there have been opportunities to develop work with Sheffield and Leicester Children's Hospitals. As part of a package working towards succession planning for nephrology services in Sheffield, Nottingham Children's Hospital have been offered some sessional work to contribute towards a business case for a new consultant. Leicester Children's Hospital have similarly offered some additional hours towards extending the monthly shared-care clinic to a full-day clinic. During this year, Dr Peter Houtman, consultant SPIN paediatrician at Leicester has announced his retirement and we are in negotiation with Leicester to develop a business case for a first truly-network consultant paediatric nephrologist who will deliver services in Leicester and Nottingham and help develop more specialist services in Leicester.

The website was launched at the end of the last financial year. We have seen increasing numbers of hits each month and have had much positive feedback about it from professionals patients/carers alike. The most popular pages for professionals accessing the website are the Nottingham guidelines, the dietetic downloadable resources and the information on education meetings. Developing a culture of internet communication is slow but we now have the network website (www.emeesykidney.nhs.uk) on all Nottingham and shared-care clinic correspondence and we use every opportunity to signpost patients/parents to resources on the website or linked to it. An editorial team for the network (comprising Judith Hayes, Martin Christian, Shelley Jepson, Pearl Pugh, Anisah Hussain and Tim Ryan from Volute) meet every 3-4 months to troubleshoot any problems and discuss developments. We have applied for a development budget from the Kinder Appeal to allow us to continue to develop this important resource.

WORKPLAN FOR 2014-15

Over the next year, our main aim again will be to secure sustainable resourcing for the posts required to fulfil the service specification for children's renal services and to support the network required to deliver the care.

We continue to aim for a SPIN paediatrician in each local centre and involved with the shared-care clinic. We continue to try to develop links with local nurses and dietitians. Rolling out service level agreements for all new shared-care clinics and developing existing ones.

We hope to appoint a new consultant paediatric nephrologist this year to help deliver shared-care clinics in this many locations. We also hope to be able to appoint a locum consultant paediatric nephrologist to maintain nephrology services at Leicester Children's Hospital. We will also continue to work closely with Leicester and Sheffield to develop services there.

National peer review of children's renal services has recommenced and we anticipate that a pilot will take place during the current financial year. We expect EMEESY to be involved in that.

Education meetings have continued to attract a high turnout of local paediatricians. It has been encouraging to have a small but faithful core of local nurses attending and we plan to continue to develop the multi-professional nature of the education delivered at these training days.

19. TRANSITION

Transition is an important area of focus for our unit. The CQC report on transition *From the pond into the sea* published in June 2014, highlights the importance of good transition planning. We continue to provide strong support for transition by identifying a key worker for all young people with CKD who are approaching transition and we hold specific transition clinics in the major renal centres across our region.

Meeta Mallik, Lead for Transition

Other transition-focussed activities include home visits to aid in preparation for transition and joint home visits with colleagues from adult centres to prepare for transfer. We hold drop-in coffee sessions together with colleagues in adult units to give young people the opportunity to meet these teams in an informal setting.

Our youth work team offers a comprehensive service to support the transition process. The service offers drop-in session for patients and a regular youth club. Patients are also invited to attend an annual transition residential. Home visits together with our specialist nurses are offered in selected cases where the need for increased input is identified.

In the past, we held a successful transition workshop for young people and their families. In 2014, we did invite patients to another workshop but unfortunately this was cancelled due to low numbers. It may be that young people already feel adequately supported by the home visits and transition clinic process currently in place.

Young people are encouraged to come in to the first part of consultations on their own joined later by their parents from the age of 14 years (younger for some patients). Copies of clinic letters are sent directly to young people from the age of 16 years. We currently have a single page transition planning reminder in place as a tool for transition. We are now planning to change to the nationally accredited *Ready-Steady-Go* tool for transition planning. Plans are in place for this tool to be accessible via digital health records in the future.

TRANSITION CLINICS 2014-2015

The table below shows the location and numbers for each transition clinic.

We have a well-established link with Sheffield Kidney Institute and last year we held two transition clinics – one in Nottingham and one in Sheffield with the team form the adult unit. MDT meetings were held at the beginning of these clinics. Members of the adult MDT were involved in transition planning with joint home visits arranged for selected cases.

In the past, joint clinics with the Leicester team were held in Nottingham. This year, we relocated these clinics to Leicester General Hospital. We held two clinics 6 months apart. Three to five patients attended these. In the future we plan to incorporate a tour of the hospital with the clinic. As we have capacity, we will also offer this clinic once a year to patients with CKD 3-5 and renal transplant patients currently seen at the Leicester shared care clinic.

Centre	Date	Number of patients seen
Nottingham	April 2014	9
	October 2014	3
	November 2014	8
	March 2015	2*
Sheffield	September 2014	9
	March 2015	2
Leicester Royal Infirmary	October 2014	9
	April 2015	
Leicester General	April 2014	Data unavailable
	October 2014	Data unavailable
Lincoln	March 2015	5
Derby	2 clinics in 2014-15	4 per clinic
Cambridge	September 2014	4
	March 2015	3
Cambridge transplant	September 2014	2

*Reduced deliberately as colleague in sick leave

We also held twice yearly transition clinics with the Leicester team at Leicester Royal Infirmary for patients transitioning via the shared care clinics held there.

The other two major nephrology centres in our region are Derby and Cambridge, last year we held 2 dedicated transition clinics at each centre.

We have now developed links with our adult nephrology colleagues in Norwich, Doncaster, Kettering, Boston and Lincoln. We have arranged for patients to be seen jointly at these centres on an ad hoc basis. In the Norwich clinic, approximately 12 patients were seen informally with the link adult nephrologist during the year; in Doncaster, approximately 5 joint consultations took place during the year.

WORKPLAN FOR 2015-2016

We have a well-established transition process, but documentation of the pathway needs to be improved. We need to ratify our draft transition guideline and pathway.

In addition to liaising with adult nephrology colleagues, we need to involve GPs in the transition process, particularly for those patients who will be transferring to primary care for follow-up; this will be reflected in our pathway.

Implementing *Ready-Steady-Go* has been delayed slightly by administration issues. We aim to have this paperwork in use this year.

Health passports are currently not widely used in our unit. We plan to liaise with our youth work colleagues and involve young people in assessing the different passports available. We aim to incorporate health passports in future transition planning.

We aim to improve the Leicester transition clinics by offering more patients the opportunity to be seen at Leicester General Hospital next year. We plan to liaise with our adult colleagues there to improve this experience by offering a tour of the unit.

20. EDUCATION AND TRAINING

Nursing Renal Education is supported by a part-time Paediatric Renal Nurse Educator at 0.76 WTE, over three days per week. Cover for the Haemodialysis unit is included in these hours; the need fluctuates dependent upon staffing and number of acute patients. The educator also supports the on call renal nursing service.

Diane Blyton, Nurse Educator

Multi-professional education for local staff within the EMEESY network is provided with two education days which are now embedded within the calendar. The autumn meeting is a themed meeting with a medical focus; the spring meeting is a nephrouroradiology meeting and of interest to paediatric surgical and radiology staff as well. The autumn meeting also includes the network annual general meeting. Both meetings are held at roving venues within the geography of EMEESY, aiming to be as accessible as possible for those travelling from the extremes of the area covered. During 2014-15, both meetings were held in conference centres with residential facilities and were sponsored by pharmaceutical/nutrition companies in order to subsidise the registration cost, particularly for non-medics who have much less access to study leave funds within their hospital.

NURSING EDUCATION DELIVERED

All newly qualified nurses (6) commencing on ward E17 on their first rotation had a two-week supernumerary orientation period. This included a dedicated education day. This was not provided for every nurse rotating to the ward. These nurses will receive input on the study days discussed below. Additional support provided as identified to staff on E17. Four renal teaching days, and four urology/surgical days were delivered in June and September providing additional teaching and updates to the ward based nursing staff.

Three members of staff were trained to set up and manage peritoneal dialysis (PD).

Five central venous access study days were provided, as planned for nursing staff across the Children's Hospital. An additional session was provided for new staff starting on Paediatric Critical Care because of exceptional need. Ongoing support of assessment of practice is also provided.

The Paediatric Renal Nursing Team and Haemodialysis Unit continue to be a spoke nursing student placement, linked to ward E17 as a hub base. In addition the educator teaches renal content within the pre-registration curriculum.

MULTI-PROFESSIONAL EDUCATION DELIVERED

The 2014 autumn meeting was held at The Olde Barn Hotel in Marston, near Grantham. The main theme was acute kidney injury but also included a session on network development with professionals from the Scottish Paediatric Renal and Urology Network joining to share their own network development. A total of 41 individuals attended: 28 doctors, 6 nurses, 4 dietitians, 2 administrative staff and 1 pharmacist.

The 2015 spring meeting was held at Eastwood Hall, near Nottingham and was titled *Nephrourology at the fringes*, focussing on antenatal and transitional care. A total of 38 individuals attended, including 27 doctors, 9 nurses, 1 dietitian and 1 social worker.

With speakers' permission, talks from both meetings are uploaded to the education section of the EMEESY website after the education days to be a resource available again as needed.

SIGNIFICANT ACHIEVEMENTS OF THE YEAR

The Children's Nephrology: Care and Management module ran for the first time this year. Three ward based nurses and two specialist/dialysis nurses undertook the module, which is distance learning in delivery.

TEACHING/CONFERENCES

Teaching was provided to nurses on the two EMEESY education days in 2014-15.

The educator attended the RCN education conference and the Nephrology Nurses Conference.

WORKPLAN 2014-15

- Renal and urology study days planned for July 2015, to continue teaching away from the ward. The aim is to provide teaching for staff away from the ward environment on an annual basis.
- Simulation training planned for 2015, initially to focus on managing patients on PD.
- Complete work commenced to enable dopamine administration post-transplant on E17.
- Develop e-learning options for ongoing education of nurses within the renal service and EMEESY Network. Links have been made with the Learning@nuh team.
- Continue to provide updates and training for extended roles for staff on E17 and the specialist nursing team.
- Multi-professional education days planned for October (renal genetics – a joint meeting with geneticists from the four genetics centres within EMEESY) and March 2016 (theme and venue to be confirmed).
- October meeting to contain whole day's separate dietetic programme

21. CLINICAL GOVERNANCE AND AUDIT

Clinical governance is a systematic approach to maintaining and improving the quality of patient care. An important part of this approach is to identify incidents which have or may have caused harm and to take measure to prevent future incidents. We therefore routinely collect information on incidents through the hospitals reporting system. In the financial year 2014-2015 we reported 93 incidents of which 73 did not cause harm, 18 were considered a low level of harm and 2 were considered a moderate degree of harm. The category of incidents followed a similar pattern to the trust. Categories with 5 or more incidents are shown in the table below:

Category	Degree of Harm			
	None	Low	Moderate	Total
Medication	22	1	0	23
Equipment / medical devices (clinical)	9	0	0	9
Aggression, violence and harassment	4	4	0	8
Blood transfusion	4	3	0	7
Environmental / infrastructure	6	0	0	6
Delay /failure to treatment or procedure	5	0	0	5
Safeguarding vulnerable people	1	2	2	5

Learning outcomes were reviewed for each incident with areas for improvement most often noted in clinical practice and staff communication. More than one learning outcome can be derived from each incident. The learning outcomes of the categories with five or more incidents are summarised in following table:

	Clinical practice	Communication with patient	Communication with staff	Delivery of care	Equipment use	Hospital environment	Organisational culture	Patient supervision	Staff education / Knowledge / Training	Staffing levels	No learning	Total
Medication	13	2	7	0	0	0	0	0	1	0	1	24
Equipment / Medical Devices (Clinical)	2	0	0	2	8	0	0	1	0	0	0	13
Aggression, Violence and Harassment	0	2	5	1	0	0	0	3	0	0	0	11
Blood Transfusion	4	0	4	0	0	0	0	0	0	0	0	8
Environmental / Infrastructure	0	0	4	0	0	1	0	0	0	2	0	7
Delay / failure to treatment or procedure	0	1	4	0	0	0	1	1	1	0	0	8
Safeguarding Vulnerable People	3	0	1	1	0	0	0	0	1	0	0	6
Total	22	5	25	4	8	1	1	5	3	2	1	77

Audit is embedded as part of the clinical governance structures within Nottingham. It is being developed across our network as part of the evolving clinical governance of the network.

National audit data are submitted to the UK Renal Registry on all patients requiring dialysis or transplant. These have been reported and our results are comparable to other paediatric renal units in the UK. The reports may be viewed on the UK Renal Registry's website (www.renalreg.com).

Our outcome data regarding transplantation are also reported nationally as part of the NHSBT Kidney Advisory Group data. These data present outcomes at one and five years for patient and graft survival. Although within the expected statistical variation our five year graft survival data were below the national average in 2014. The latest data show that these are improving but we are still reviewing our practice to consider how we can make further improvements.

General audit of practice as part of the Nottingham Children's Hospital audit work plan including consent, medical records, infection control and prescribing are ongoing. Ward E17 was commended for a consistently high achievement in many areas.

Local audit is facilitated through regular audit and governance meetings. The focus of the audits includes growth and nutrition, anaemia, peritonitis rates, CVL infection rates and renal biopsy complications. An audit workplan is in place to ensure they are reviewed regularly.

22. PATIENT EXPERIENCE AND FEEDBACK

The EMEESY philosophy is to involve patients, parents and carers in the development, day-to-day delivery and evaluation of our service. A number of formal and informal communication methods have been used to ensure that patients and their families have access to information and opportunities to contribute to service delivery. The use of social media has enhanced our ability to share information using minimal time and resources.

Shelley Jepson, Senior Paediatric Renal Nurse and PPI Lead

COMMUNICATION

Patients and families have a named nurse and a named consultant. 24 hour advice from the nursing staff is available via pager which is made available to families throughout the network. An average of 30 calls per week are managed. Patients are able to contact their consultant via secretarial staff and an appointment for call back can be arranged.

The unit continues to link families of newly diagnosed patients with others to promote information sharing and peer support.

INFORMATION

The network website www.emeesykidney.nhs.uk continues to develop. New software has been purchased which has enabled us to display information booklets. Regular audits demonstrate that the website has a growing number of hits each quarter. The EMEESY Facebook page has over 200 followers. Parents and carers regularly post news, comments and questions via this site. Facebook has also been successfully used to disseminate information, advertise events and support fundraising. No posts or comments have had to be removed.

The EMEESY twitter account is used less frequently by families, however it has been used to share news with professional colleagues.

INFORMATION EVENTS

Transplant information day to raise awareness of issues around transplantation. 12 families attended.

Transition workshop: This event was organised but cancelled due to low numbers attending. The workshop has been re-scheduled.

10 families attended the British Transplant Games accompanied by volunteer staff members.

PATIENT AND CARER INVOLVEMENT

Three parents volunteered to represent parents and carers on the EMEESY steering group. One parent dropped out due to a change of personal circumstances. One parent was unable to contribute due to her child's condition at the time. A third parent was sent minutes following the meeting. This highlights the practical difficulties in involving parents with chronically ill children.

Two parents have commented on the website glossary.

Young people from the EMEESY network are involved in youth work participation events.

WORK PLAN

- Quarterly review and update of EMEESY website including monthly blog
- Identify patient/carer advocate to attend EMEESY steering group
- Information events for transplantation, nephrotic syndrome and transition
- Support families to attend transplant games
- Involve families in EMEESY cycle fundraising events

22. RESEARCH

Research is considered a core part of the clinical care that is delivered in Nottingham and across the Network. At Nottingham and within EMEESY we strive to embed research within our everyday multi-disciplinary practice.

Andy Lunn, Research Lead

WORKFORCE

Currently there is 1 WTE research nurse (Olivia Silkstone) within the Clinical Research Network (CRN) who is employed to facilitate the research work in Nottingham. We are grateful to the tireless effort she and other members of the CRN team have done to help achieve the successful delivery of the research studies we are involved. A second nurse (Helen Gregory) working 0.5 WTE in research as part of a split clinical post within the department was appointed in January 2014. Helen has stepped down from the research aspect of the post in order to work fully in the clinical arena. Following a review of the post, a research administrator (band 4) has been appointed in her place to give more time supporting the breadth of departmental research. Other members of the clinical team in Nottingham are also involved in research according to the requirement of active studies at that time. There is 1 PA of consultant time, supported by the CRN, which is divided between the 5 consultants. This includes one consultant who is a member of the British Association for Paediatric Nephrology / CRN clinical studies group.

RESEARCH ACTIVITY

The research activity is divided between commercial studies and non-commercial studies supported by NIHR funding. All research is conducted ethically approved and performed according to Good Clinical Practice standards and guidelines. Details of current studies and numbers of recruited patients are below:

REGISTRY STUDIES

Study Name	Summary	Contact	Status
aHUS Eculizumab Regsitry	Registry based study of aHUS	Jonathan Evans Olivia Silkstone	Stopped recruitment – target achieved
RaDaR	**Ra**re Renal **D**ise**a**se **R**egistry	Martin Christian Kate Baker	241 patients recruited. Recruitment ongoing.

COMMERCIAL STUDIES

Study Name	Summary	Recruitment actual (target)	Contact
CRADLE	Unblinded RCT of Everolimus, low dose tac and steroid withdrawl vs standard pred, tac and MMF. Consent at transplant, randomise at 4-6 weeks after transplant.	7(5)	Martin Christian Lindsay Crate
CONNECT MCI-196-E14	Unblinded, randomised dosing, safety and efficacy study of Colestilan (phosphate binder) in dialysis patients. Screening, washout then 17 weeks of fixed dose randomised to calcium carbonate (control), low, medium or high dose Colestilan.	Study discontinued by company	Andy Lunn Olivia Silkstone
CONNECT MCI-196-E15	Variable Colestilan dose extension of above study.	Study discontinued by company	Andy Lunn Olivia Silkstone

NON-COMMERCIAL STUDIES

Study Name	Summary	Recruitment actual (target)	Contact
Genetic basis of renal tract abnormalities	Genetic study – one blood test, clinical proforma recording medical history and data collection sheet. Study also recruiting parents of affected children.	33(20)	Andy Lunn Olivia Silkstone
PREDNOS	Blinded placebo controlled RCT of short versus long course of steroids for initial treatment of nephrotic syndrome. Recruitment complete nationally – in follow-up phase.	8 (6)	Andy Lunn Oliva Silkstone
PREDNOS 2	Blinded placebo controlled RCT of 6 days of 15mg/m^2 prednisolone at time of URTI to prevent nephrotic relapses.	6 (6)	Martin Christian Olivia Silkstone
HOTKID	An unblinded randomised trial of standard (50-75th centile) vs aggressive (<40th centile) control of blood pressure in patients with CKD.	6 (5)	Andy Lunn Olivia Silkstone
RaDaR – SSNS	Genetic and steroid response study in patients with nephrotic syndrome. Previously only open to patients with steroid resistant nephrotic syndrome but inclusion criteria now expanded to any child with nephrotic syndrome. Requires one blood test.	34 (15)	Martin Christian Kate Baker
RaDaR - MPGN	Genetic and immune system testing in patients with MPGN. Requires one blood test every 6 – 12 months.	28 (20)	Martin Christian Kate Baker

We have closed some studies and this has allowed us to focus on the studies where we have had more success in recruitment. This success has been demonstrated as we were one of

the largest recruitment centres for the PREDNOS study, are the second largest recruiting center for RaDaR and the largest recruiting centre in the UK for CRADLE.

We continue to look for new research opportunities and seek to work towards being able to offer every patient the opportunity to be involved in research and supporting paediatric nephrology research in hospitals across the EMEESY network.

23. AWARDS, SELECTED PUBLICATIONS AND EXTERNAL ACTIVITY

AWARDS

Kim Helm, Nottingham Nurse of the Year, 2015

PUBLICATIONS

Indications, technique, and outcome of therapeutic apheresis in European pediatric nephrology units.
Paglialonga F, Schmitt CP, Shroff R, Vondrak K, Aufricht C, Watson AR, Ariceta G, Fischbach M, Klaus G, Holtta T, Bakkaloglu SA, Zurowska A, Jankauskiene A, Vande Walle J, Schaefer B, Wright E, Connell R, Edefonti A.
Pediatr Nephrol. 2015 Jan;30(1):103-11.

Distributed expertise: qualitative study of a British network of multidisciplinary teams supporting parents of children with chronic kidney disease.
Swallow V, Smith T, Webb NJ, Wirz L, Qizalbash L, Brennan E, Birch A, Sinha MD, Krischock L, van der Voort J, King D, Lambert H, Milford DV, Crowther L, Saleem M, Lunn A, Williams J.
Child Care Health Dev. 2015 Jan;41(1):67-75.

Montelukast: a novel therapeutic option in eosinophilic peritonitis.
Forbes TA, Lunn AJ.
Pediatr Nephrol. 2014 Jul;29(7):1279-82.

Safety profile of desmopressin tablet for enuresis in a prospective study.
C Van Herzeele…..J Evans …. *et al*.
Adv Ther. Online Publication 12.12.14.

Eculizumab in pediatric patients with atypical hemolytic uremic syndrome.
L Greenbaum….. J Evans… et al.
Kidney International (in press 2015).

Predictive parameters of response to desmopressin in primary nocturnal enuresis.
C Van Herzeele, J Evans et al.
J Ped Urol 2015, doi: 10.1016/j.jpurol.2015.03.007

Short course daily prednisolone therapy during an upper respiratory tract infection in children with relapsing steroid-sensitive nephrotic syndrome (PREDNOS 2): protocol for a randomised controlled trial
Webb NJA, Frew E, Brettell AE, Milford DV, Bockenhauer D, Saleem MA, Christian M, Hall AS, Koziell A, Maxwell H, Hegde S, Finlay ER, Gilbert RD, Booth J, Jones C, McKeever K, Cook W, Ives NJ, on behalf of the PREDNOS 2 study group.
Trials 2014, 15:147 doi:10.1186/1745-6215-15-147

Renal tubular disorders
Broodbank D, Christian MT
Paediatrics and Child Health. 2014; 24(7): 278-88.

Corticosteroid-free kidney transplantation improves growth: 2-year follow-up of the TWIST randomized controlled trial.
Webb NJ, Douglas SE, Rajai A, Roberts SA, Grenda R, Marks SD, Watson AR, Fitzpatrick M, Vondrak K, Maxwell H, Jaray J, Van Damme-Lombaerts R, Milford DV, Godefroid N, Cochat P, Ognjanovic M, Murer L, McCulloch M, Tönshoff B.
Transplantation. 2015 Jun;99(6).

Adherence to transition guidelines in European paediatric nephrology units.
Forbes TA, Watson AR, Zurowska A, Shroff R, Bakkaloglu S, Vondrak K, Fischbach M, Van de Walle J, Ariceta G, Edefonti A, Aufricht C, Jankauskiene A, Holta T, Ekim M, Schmitt CP, Stefanidis C; European Paediatric Dialysis Working Group.
Pediatr Nephrol. 2014 Sep;29(9):1617-24.

Psychosocial support for children and families requiring renal replacement therapy.
Watson AR.
Pediatr Nephrol. 2014 Jul;29(7):1169-74.

Challenges in the management of bilateral single-system ectopic ureters in male infants.
O'Connor E, Peeraully R, Shepherd G, Shenoy M.
Urology. 2014 Jun;83(6):1373-7.

Hyperphosphataemia in chronic kidney disease. Evidence Update December 2014 : A summary of selected new evidence relevant to NICE clinical guideline 157 'Management of hyperphosphataemia in patients with stage 4 or 5 chronic kidney disease' (2013)
Evidence Update 72
Roy Connell part of evidence update advisory group

CONFERENCE PRESENTATIONS

Improving the care of children with renal problems via EMEESY; a paediatric nephrology network
S Jepson, M Christian.
Poster presentation at UK Kidney Week, Glasgow, May 2014.

Childrens nurse recruitment and specialist career pathways
S Jepson and R Connell.
University of Nottingham October 2014

Characteristics of a primary nocturnal enuresis population and predictive value of screening parameters.
C Van Herzeele, J Evans *et al.*
Poster Presentation at ESPN, Porto 2014 (Pediatr Nephrol 29:1785) and at American Urological Association 2014.

Eculizumab inhibits thrombotic microangiopathy and improves renal function in pediatric patients with aHUS.
L Greenbaum…. J Evans….. *et al*.
Presentation at ESPN, Porto 2014.

Renovascular hypertension: a single centre paediatric perspective.
Prajapati H, O'Neill R, Christian M, Mallik M
Presentation at ESPN, Porto 2014 (Pediatr Nephrol 29:1712)

Design and baseline characteristics of CRADLE: A study evaluating the efficacy and safety of everolimus to reduce CNI exposure and to withdraw steroids in pediatric renal transplant recipients.
M Christian, A Bjerre, L Wennberg, R Ettenger, L Pape, B Tonshoff, L Dello Strologo, P Niaudet, D Martzloff, M Vergara, A Balfour, P Lopez
Presentation at ESPN, Porto 2014 (and at World Transplant Congress, 2014)

Psychosocial treatment of CKD: What are we doing right? What could we do better?
J Heath, S Batte, M Christian, A Watson
Presentation at EWOPA, Porto 2014.

EXTERNAL RESPONSIBILITIES

Martin Christian

- BAPN Honorary Secretary
- Paediatric representative on AKI National Programme (education stream)
- Member of National Peer Review pilot steering group for paediatric renal services
- Member of Trial Steering Committee for PREDNOS2 study

Andrew Lunn

- BAPN Communications Officer
- Member of paediatric nephrology clinical studies group
- Member of BAPN Clinical Standards and Guidelines Sub-committee

Meeta Mallik

- Chair NUH Drugs and Therapeutics Committee
- Member of BAPN Clinical Standards and Guidelines Sub-committee

Jonathan Evans

- NUH Clinical Director for Family Health
- Member of CQC inspection team

Hitesh Prajapati

- BAPN Trainee Representative

Manoj Shenoy

- Service Lead for Surgical Specialties, Nottingham Children's Hospital
- BAPU representative on Specialty Advisory Committee for Royal College of Surgeons
- MCQ examiner group for the Inter-Collegiate Board

Alun Williams

- National Institute for Health and Care Excellence Fellow 2013-16
- MRCS examiner

Shelley Jepson

- Member of National Peer Review pilot steering group for paediatric renal services

Roy Connell

- Member of Specialist Interest Group for Paediatric Nephrology Nurses

Christine Rhodes

- Chairperson for the RCN Children's Urology Continence Community

24. PRIORITY WORKPLAN FOR 2015-16

During the next year we will prioritise the following items from our workplans:

1. Re-tender the service with an appropriate out-patient tariff to fund the infrastructure and MDT posts required
2. Sort a robust system to record all telephone consultation work
3. Ensure that all new AKI patients are registered on EMED
4. Procure NxStage machine in preparation for developing a home haemodialysis service
5. Update resources for biopsy and transplant preparation
6. Recruit two new consultants – one substantive post based in Nottingham; one locum post working half-time in Leicester
7. Develop a business case for a substantive consultant post to cover Leicester service
8. Pilot a network-wide audit
9. Pilot patient experience outcome measures in out-patient clinics throughout the network
10. Develop tutorial videos to be embedded in the website