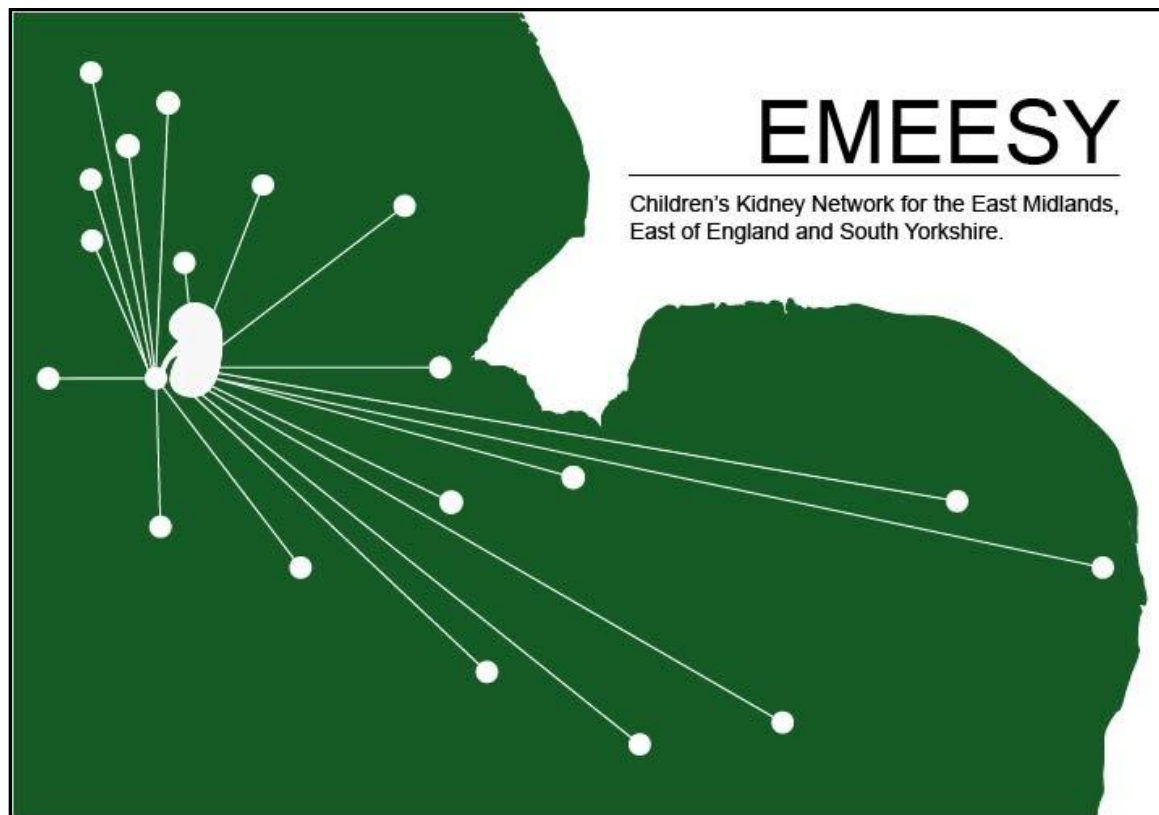
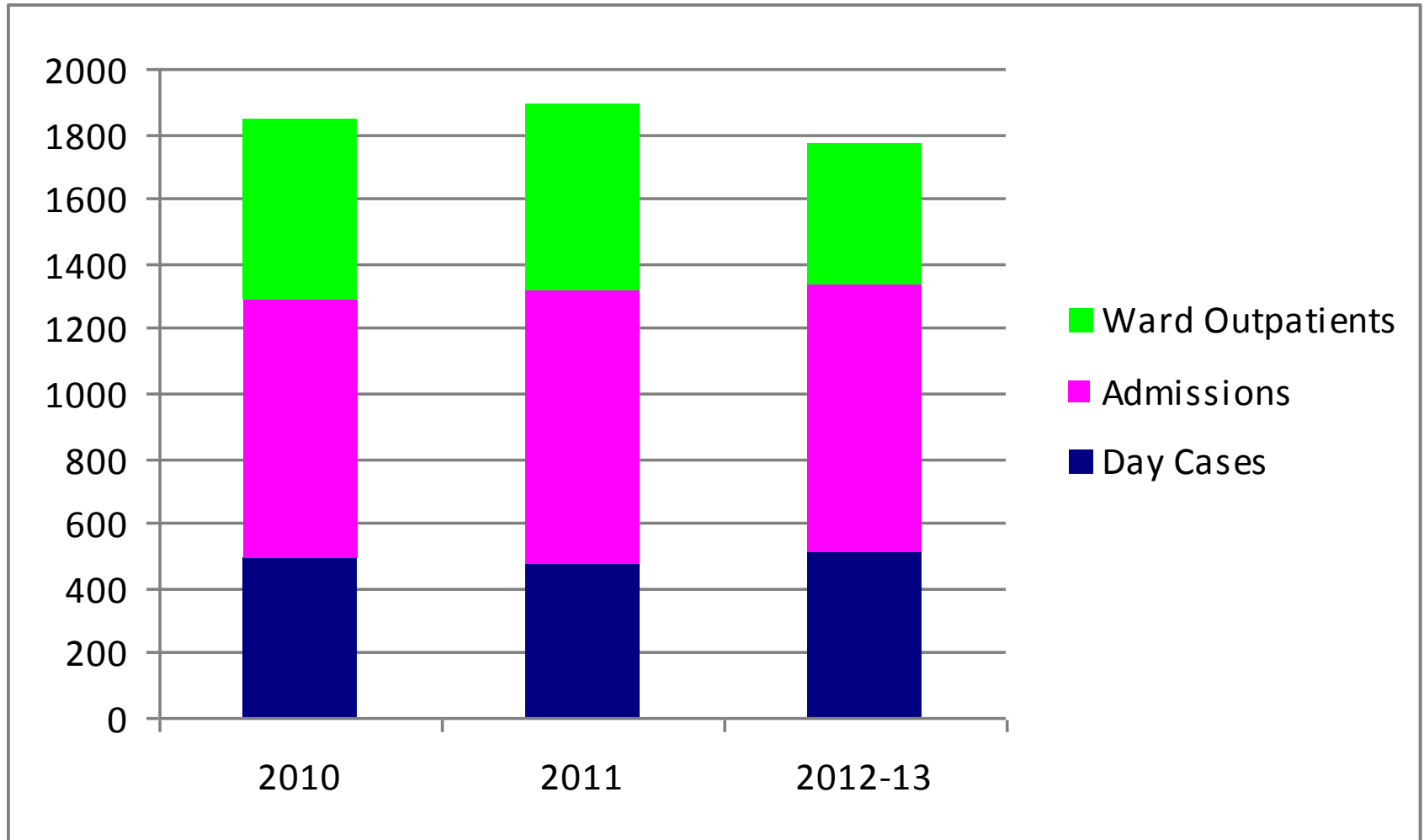


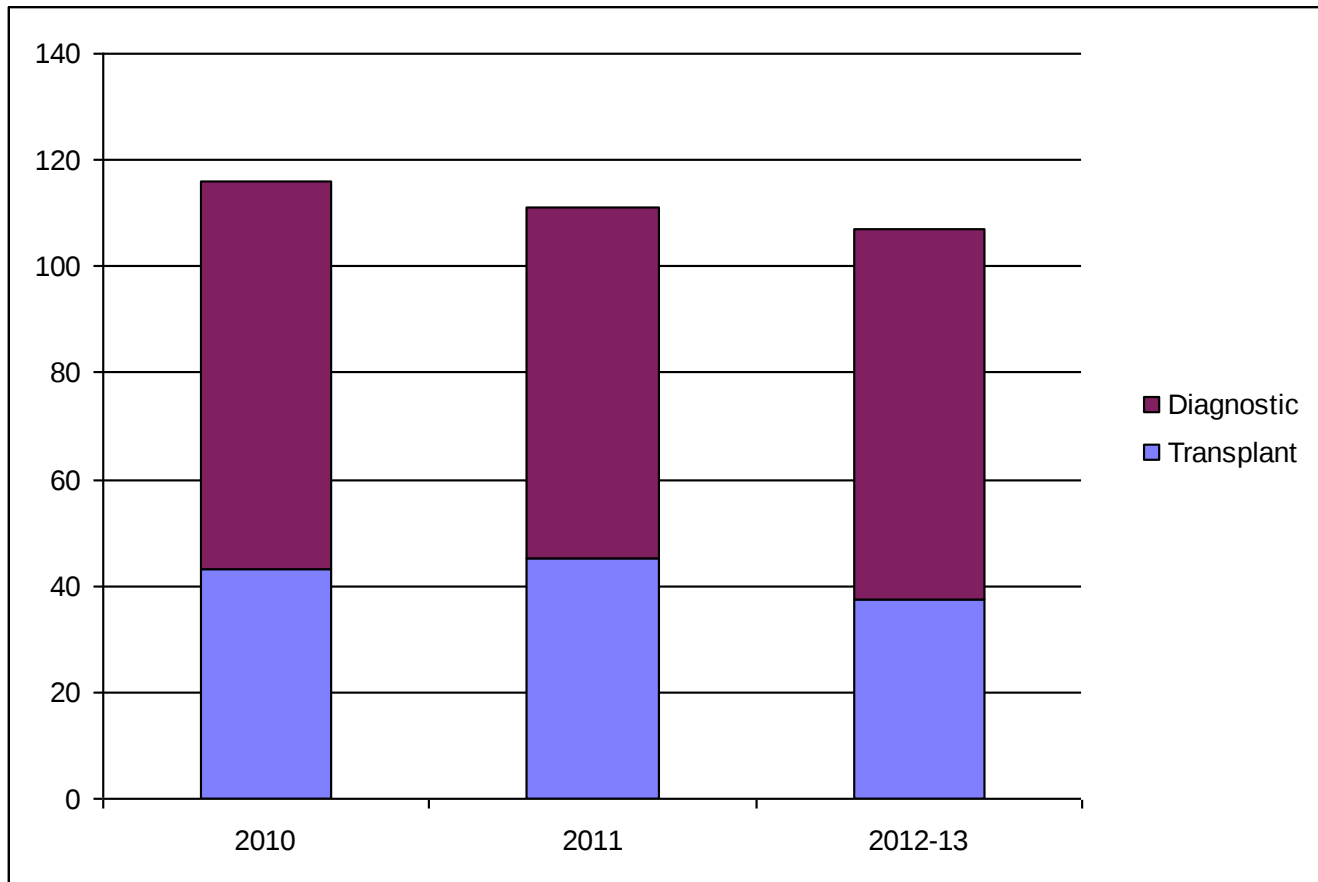


Annual General Meeting 2013

E17 ward activity



Renal biopsies



Nottingham 12 (9)
Cambridge 3 (2)
Kings Lynn 0 (1)
Barnsley 1 (3)
Kettering 2 (2)

Derby 6 (4)
Norwich 7 (6)
Kings Mill 2 (3)
Sheffield 7 (7)
West Suffolk 3 (1)

Leicester 6 (6)
Chesterfield 3 (1)
Peterborough 1 (8)
Hinchingbrooke 0 (0)
James Paget 0 (0)

Boston 0 (0)
Doncaster 3 (5)
Rotherham 1 (4)
Lincoln 3 (3)
Bassetlaw 1 (0)

Transition clinics

- Twice yearly clinics for:
 - Nottingham
 - Sheffield
 - Leicester
- Includes MDT discussion on upcoming patients
- Developing plans for Derby, Addenbrookes

Shared-care clinics

	2008	2009	2010	2011	2012
Pilgrim	73	76	88	85	88
Lincoln	57	63	38	57	N/A
King's Mill	55	62	56	64	48
LRI	121	113	122	108	118
Sheffield	38	42	36	38	37
Kings Lynn	35	45	59	59	60
Norwich	58	81	82	81	79
Addenbrooke's	105	131	113	171	165
Peterborough	41	51	58	59	50
Rotherham	51	63	67	67	71
Chesterfield	32	68	58	48	54
Derby		17	54	40	51
Kettering				26	34
Total	666	812	831	903	855*

Chronic haemodialysis

- 22 patients between January 2012 and March 2013
- Number of patient sessions during 2012 was **1771** compared to 1684 in 2011
- 7 patients <5 years (1 in 2011)
- Considerable sessions for apheresis treatments
- aHUS patients

Chronic peritoneal dialysis

- **18** patients between January 2012 and March 2013 (19 in 2011)
- **12** families trained to do PD at home
- 31 days admission for PD-related problems (100 in 2011)
- **7** episodes of peritonitis in **126** patient months (1 in 18 patient months)

Transplantation

- 9 transplants in 2012 (22 in 2011)
- 1 LRD; 7 DBD; 1 DCD
- Study news
- 2013 developments to improve LRD rates

Background

- Offered “resilience” grant funding from East Midlands SHA specialist commissioner to develop network
- Up to £70k subject to suitable proposal
- £30k awarded for:
 - Staff backfilling for consultant, senior nurse, secretarial and dietetic hours
 - Travel expenses (trip to Glasgow)
 - Funding educational meeting



Aims

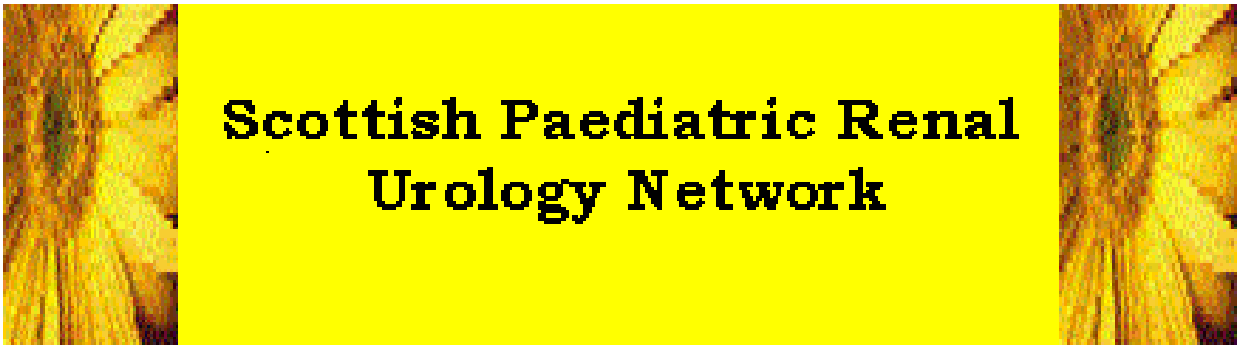
1. To carry out a health needs assessment and gap analysis of paediatric nephrology services throughout EMEESY.
2. To identify the infrastructure required to set-up and sustain a managed clinical network for paediatric renal services.
3. To document how a managed network would improve the quality of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

Health needs assessment – documenting uncostered network work

- Clinical advice given – iro 0.25 PAs per consultant per week
- Nephrourology x-ray meeting
- Dietetic input into shared-care clinics

Establishing new shared-care clinics

- Combined clinics with attempts to foster local nursing/dietetic leads
- Patient/parent feedback taken
- Clinical discussion encouraged (part of package; potential cost-savings)
- Business meeting to discuss future of clinic



Scottish Paediatric Renal Urology Network

- Established with Scottish Health Dept funding in 2007
- Services in all paediatric centres throughout Scotland
- DGHs and integrated children's hospitals
- Network steering group
- IT links
- Effective website and education strategy
- Use of videoconferencing

Establishing infrastructure

- Local leads
 - 13 local nursing leads identified
 - Dietetic leads in all centres
- Business cases for central network lead/administration roles

Website

- www.childrenskidneynottingham.nhs.uk
- Hosted within NUH for now
- Details of services in Nottingham
- Contact details for local centres
- Guidelines
- Minutes of steering group meetings
- Educational resources

EMEESY

Children's Kidney Network

for the East Midlands, East of England and South Yorkshire

NHS
England

Home

What is EMEESY

Individual Centres

Kidney Disease Information

Young Persons Area

Professionals Area

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Useful Links

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Kidney Disease Information

Patient Information

Article Title

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Network steering group

- Medical lead
- Nursing lead
- Dietetic lead
- Administrator
- SPIN representatives from EM, EE, SY
- Planning to meet 3-monthly
- Draft ToR based on SPRUN
- Further constitution
 - Commissioner to chair
 - Urology lead
 - Local nurse rep
 - Pharmacy rep
 - Parent rep
 - Psychosocial rep

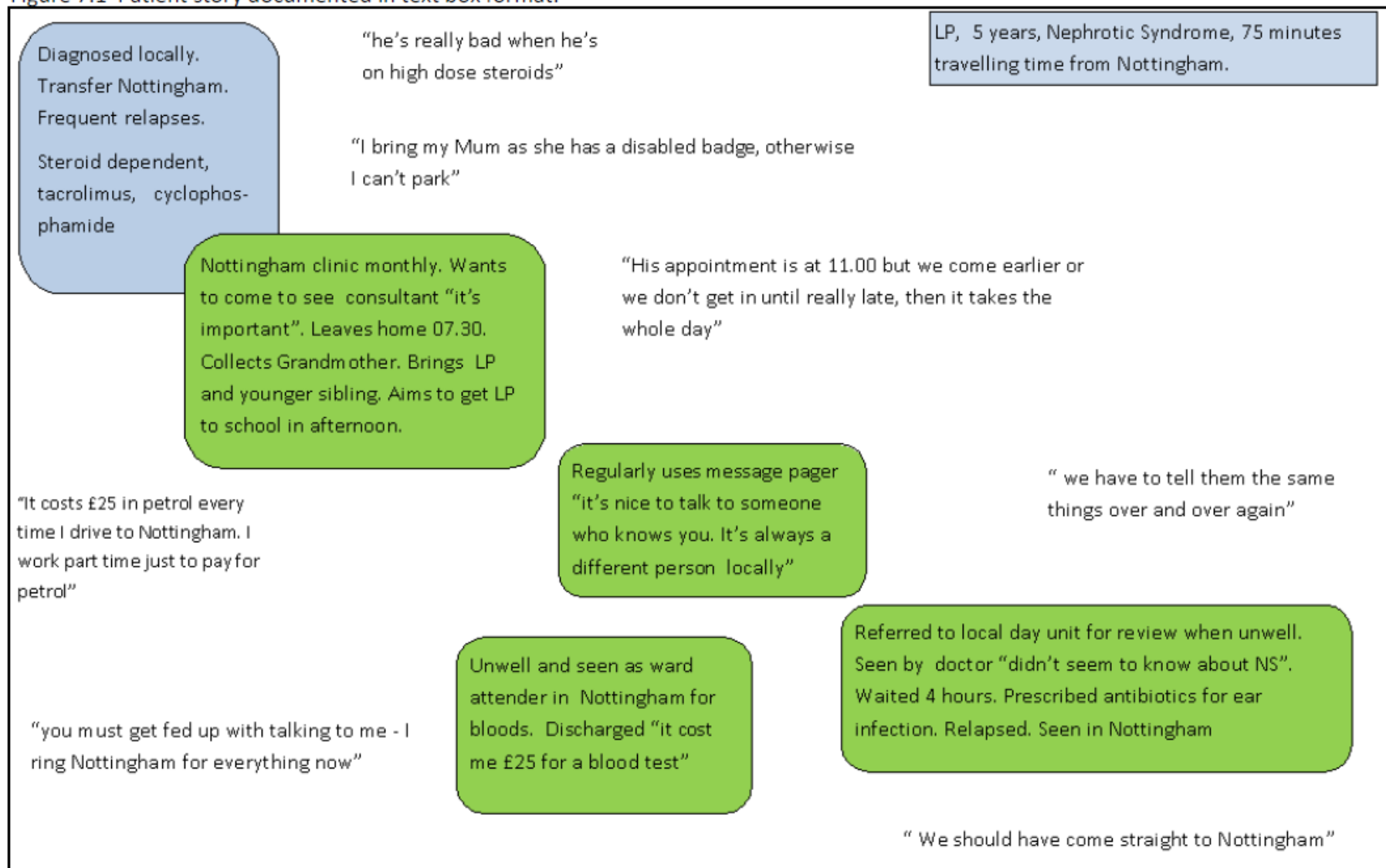
Education infrastructure

- Existing structure:
 - Spring nephrourology symposium
 - Autumn medical education/network meeting
- 22 March 2013:
 - Multi-professional education meeting
 - Separate streams for medics/nurses/dietitians
 - Some plenary sessions
 - Opportunities for informal networking over breaks/journeys

Public-patient involvement

- Patient stories
- Focus group
- Survey
- Facebook
- Visit by health minister

Figure 7.1 Patient story documented in text box format.



Focus group themes

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

Survey

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

facebook

Email or Phone

nottinghamchildrensrenal@gm

Password

Log in

☐ Keep me logged in

Forgotten your password?



EMEESY
is on Facebook.

To connect with EMEESY, sign up for Facebook today.

Sign Up

Log in

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

**EMEESY**

5 likes · 2 talking about this

Like



Health/Medical/Pharmaceuticals

This is the official Facebook page for the Children's renal network for the East Midlands, East of England and South Yorkshire.

About



Photos



Likes

Highlights

**EMEESY**

13 hours ago

We are delighted that the Viking Challenge has chosen the Kinder Appeal as their charity this year. The Viking Challenge is an off road cycling event in the Vale of Belvoir which raises lots of money for good causes.

To volunteer, sponsor us, or just to find out more, see <http://www.vikingchallenge.org.uk/>

Like · Comment

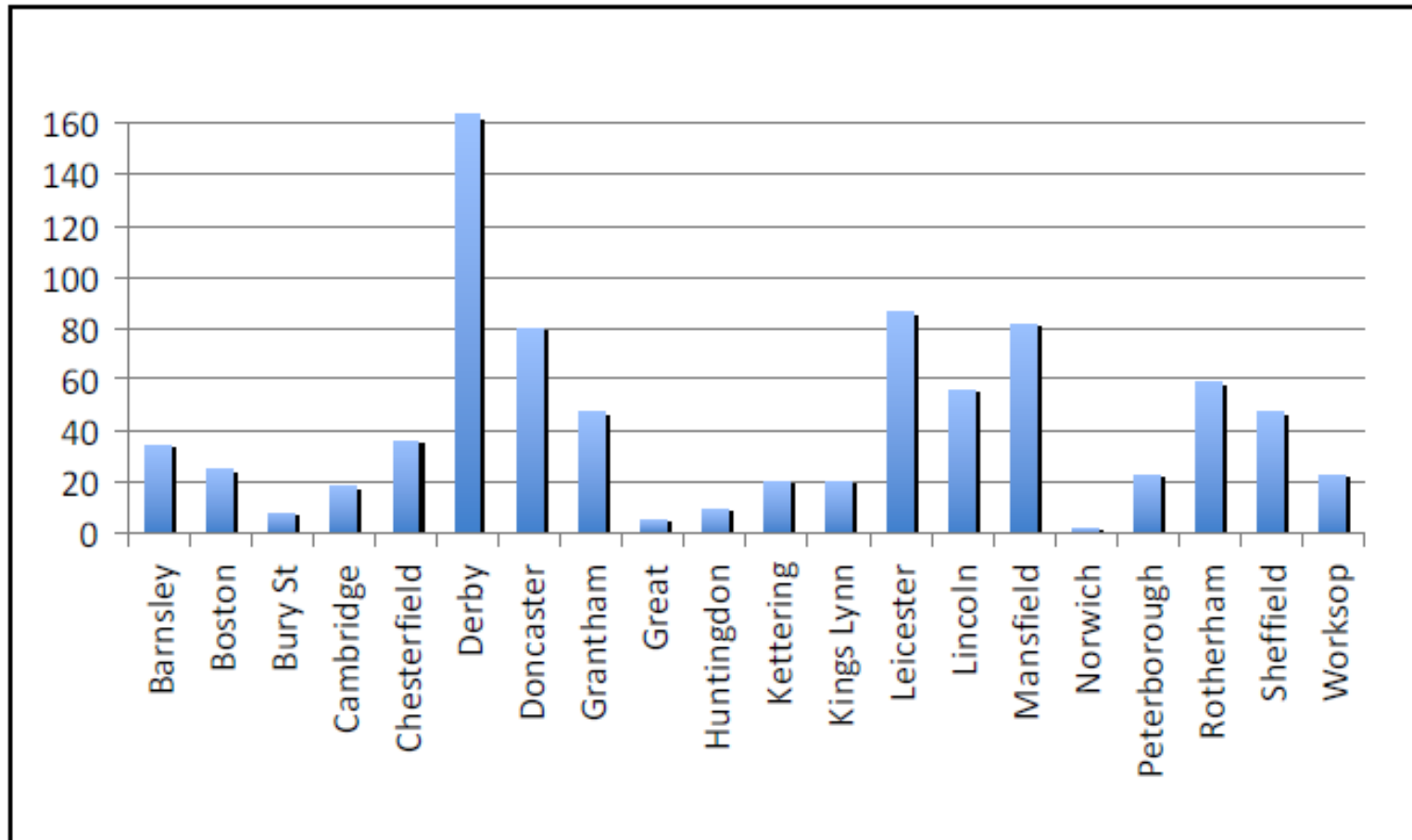
EMEESY shared a link.

Recent Posts by Others on EMEESY

See all

Equity of access to services

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



Quality of care

- Evidence base for MDT care
- Survey of current shared-care clinics
 - Variations in paediatrician involvement

Cost savings

- Earlier safe discharges
- Few radiology investigations requested
- Fewer blood tests
- Skilling local teams to manage by phone – fewer hospital attendances
- Transport costs
- National economic impact

Next 12 months

- Charitable funding to continue secondments
- Consolidate new shared-care clinics
- Benchmarking/dashboards for local centres
- Constitute formal steering group
- Educational infrastructure
- Share experience nationally to contribute to national commissioning debate

SAVE THE DATE!

EMEESY paediatric nephrourology spring symposium

Friday 21st March 2014

Theme: chronic kidney disease

Venue: to be confirmed

Programme to include: evidence for medical/surgical interventions to prevent CKD, developmental nephrourological disorders, case management of complex urology in CKD

Plans for parallel sessions for nurses, dietitians, pharmacists. Please also encourage your paediatric surgical and radiologist colleagues to come!

Watch website and email briefings for more information

www.childrenskidneynottingham.nhs.uk

Autumn meeting 2014

- Friday 10th October?
- Venue?
- Theme suggestion: Acute kidney injury
- Topics to cover:
 - NICE AKI guidance
 - AKI in neonates
 - Follow-up for AKI
 - HUS and progress on eculizumab study

Urinary tract infection in infants, children and young people under...QS36 List of quality stat - Microsoft Internet Explorer p

http://publications.nice.org.uk/urinary-tract-infection-in-infants-children-and-young-people-under-16-qs36/list-of-quality-statements

NICE UTI quality standard

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Quality Standards Issued: July 2013

QS36 Urinary tract infection in infants, children and young people under 16

View the summary and implementation tools Previous Next

Select chapters to print, save or share

List of quality statements

Statement 1. Infants, children and young people presenting with unexplained fever of 38°C or higher have a urine sample tested within 24 hours.

Statement 2. Infants, children and young people with a urinary tract infection have risk factors for urinary tract infection and serious underlying pathology recorded as part of their history and examination.

Statement 3. Infants, children and young people with a urinary tract infection caused by coliform coliform bacteria have results of microbiology laboratory testing differentiated by *Escherichia coli* (*E. coli*) or non-*E. coli* organisms.

Statement 4. Children and young people who have had a urinary tract infection are given information about how to recognise re-infection and to seek medical advice straight away.

Previous Next

- Introduction
- List of quality statements
- Quality statement 1: Presentation with unexplained fever of 38°C or higher
- Quality statement 2: History and examination – recording of risk factors
- Quality statement 3: Laboratory reporting – differentiation of *E. coli* and non-*E. coli*
- Quality statement 4: Information about recognising re-infection
- Using the quality standard
- Diversity, equality and language
- Development sources
- Related NICE quality standards
- Supplementary information: testing strategies
- Quality Standards Advisory Committee and NICE project team
- About this quality standard

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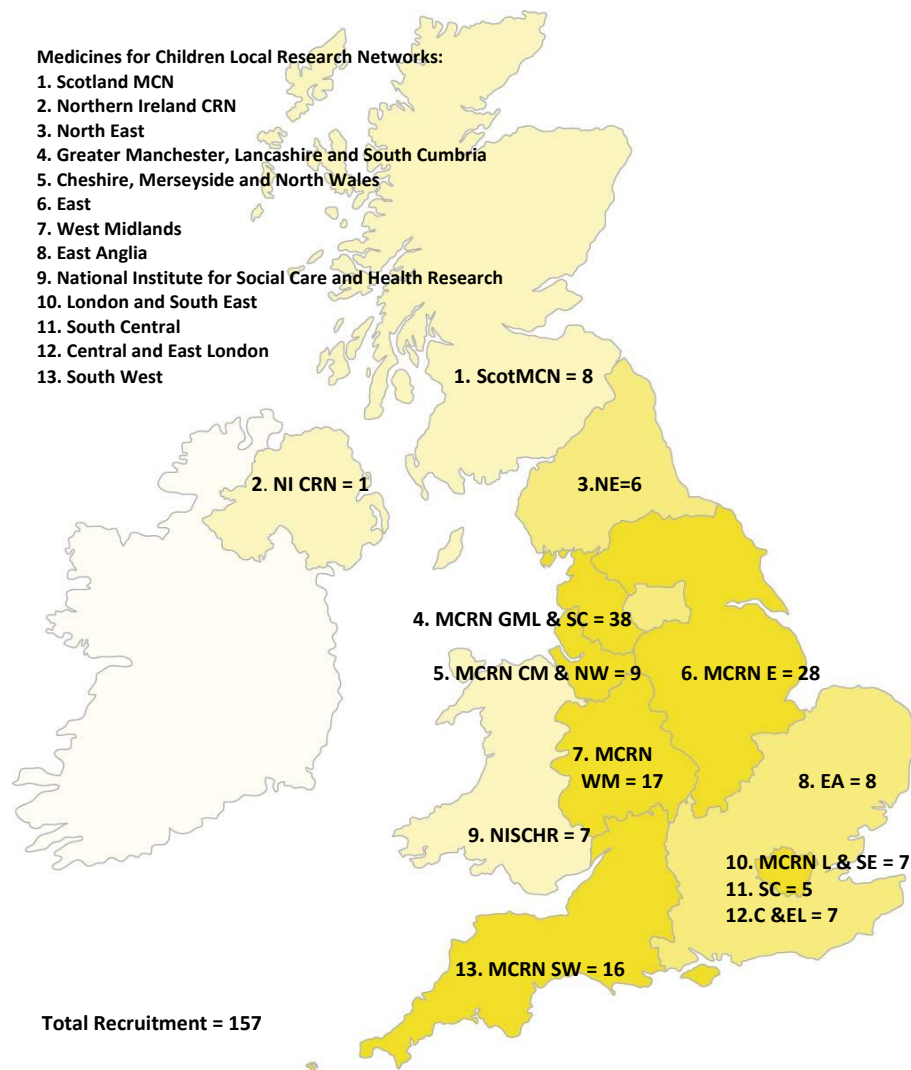
Research update

- PREDNOS
- PREDNOS2
- RaDaR
- AKI follow-up study

PREDNOS Recruitment

Medicines for Children Local Research Networks:

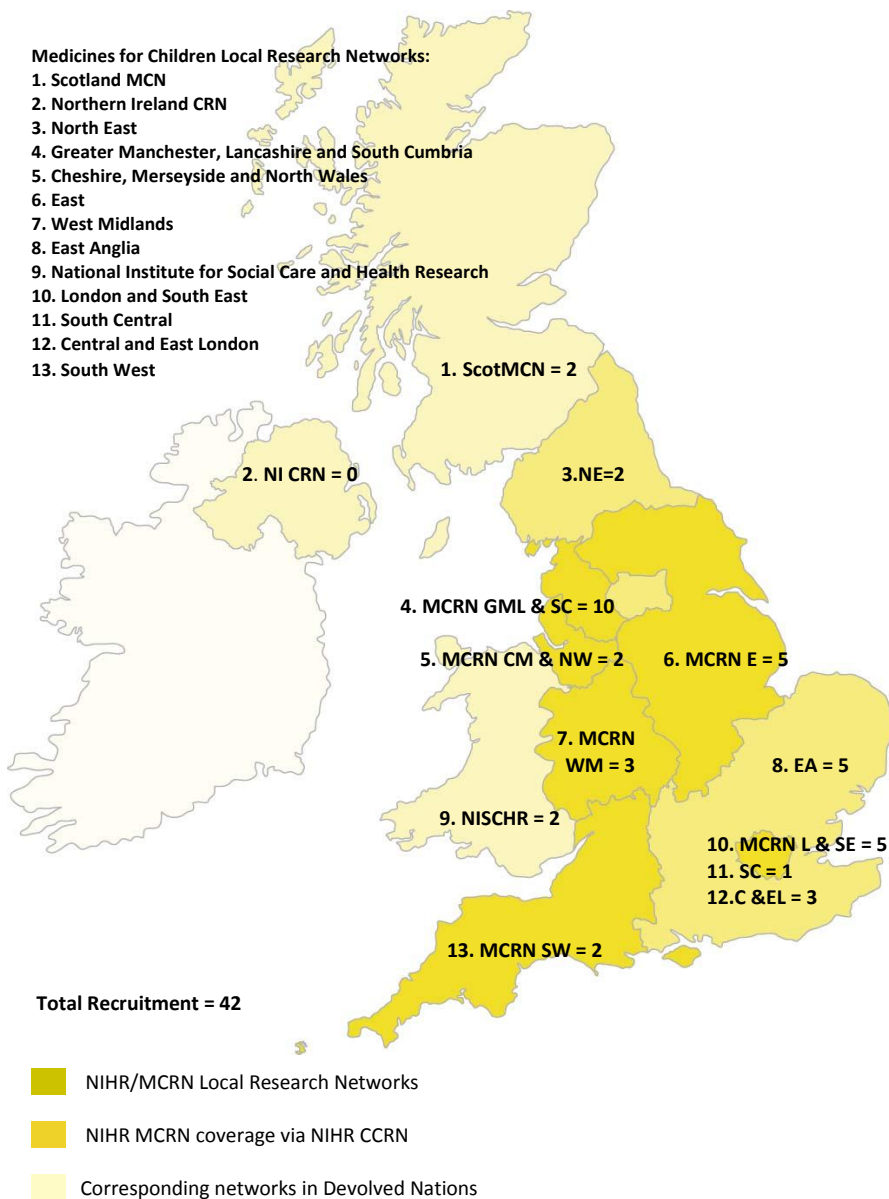
1. Scotland MCN
2. Northern Ireland CRN
3. North East
4. Greater Manchester, Lancashire and South Cumbria
5. Cheshire, Merseyside and North Wales
6. East
7. West Midlands
8. East Anglia
9. National Institute for Social Care and Health Research
10. London and South East
11. South Central
12. Central and East London
13. South West



- NIHR/MCRN Local Research Networks
- NIHR MCRN coverage via NIHR CCRN
- Corresponding networks in Devolved Nations

Recruitment to date 25th September 2013

PREDNOS 2 Recruitment



Recruitment to date 24th September 2013

BAPN update

- SPIN membership
- Winter meeting: 13 December,
Birmingham Children's
- InfoKID

www.infokid.org.uk



infoKID

Information for parents and carers
about children's kidney conditions

Coming in Autumn 2013

infoKID will provide information for parents and carers about kidney conditions in babies, children and young people. Read about conditions, tests, treatments and supporting information - on screen or in downloadable leaflets.

For more information please go to www.rcpch.ac.uk/infokid.

Disease specific guidelines

- Available now or coming soon:
 - Antenatally detected urinary tract abnormalities
 - Nephrotic syndrome
 - Hypertension
 - HSP
 - Hyperkalaemia
 - Acute kidney injury

Any other business?

Remember to complete your
evaluation forms please!