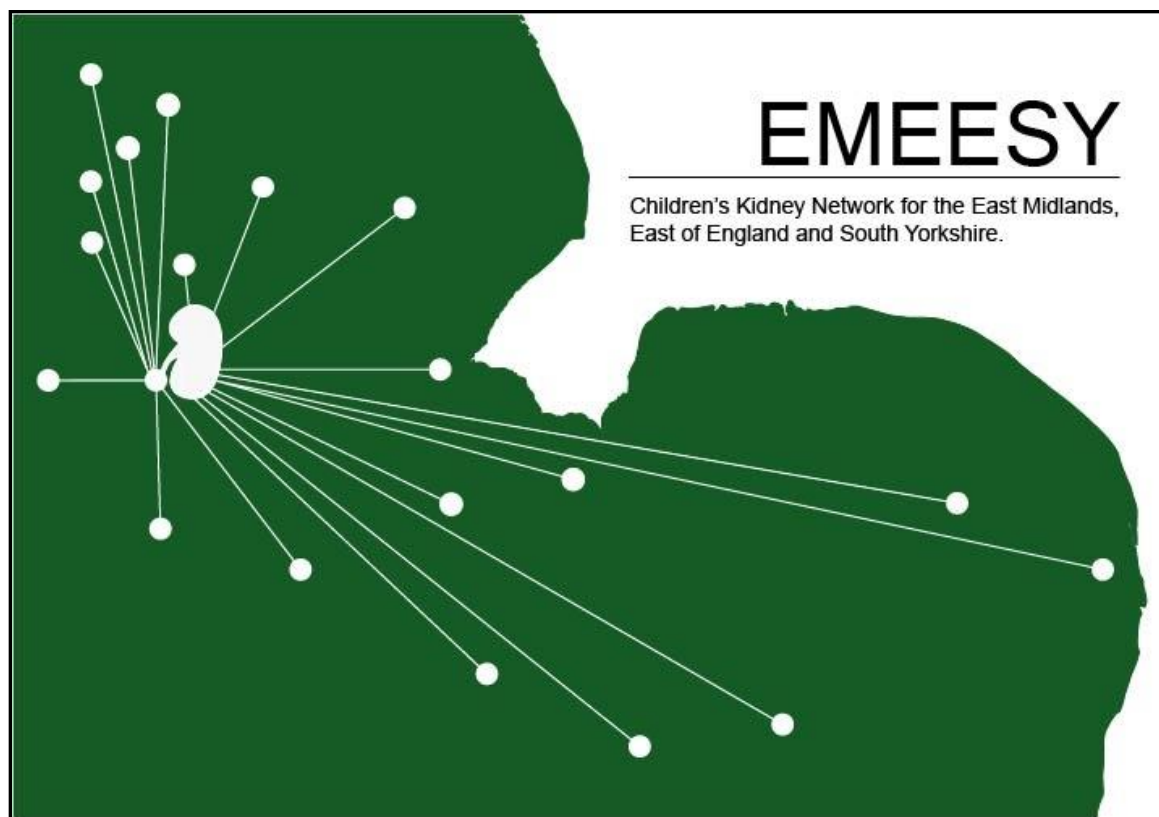
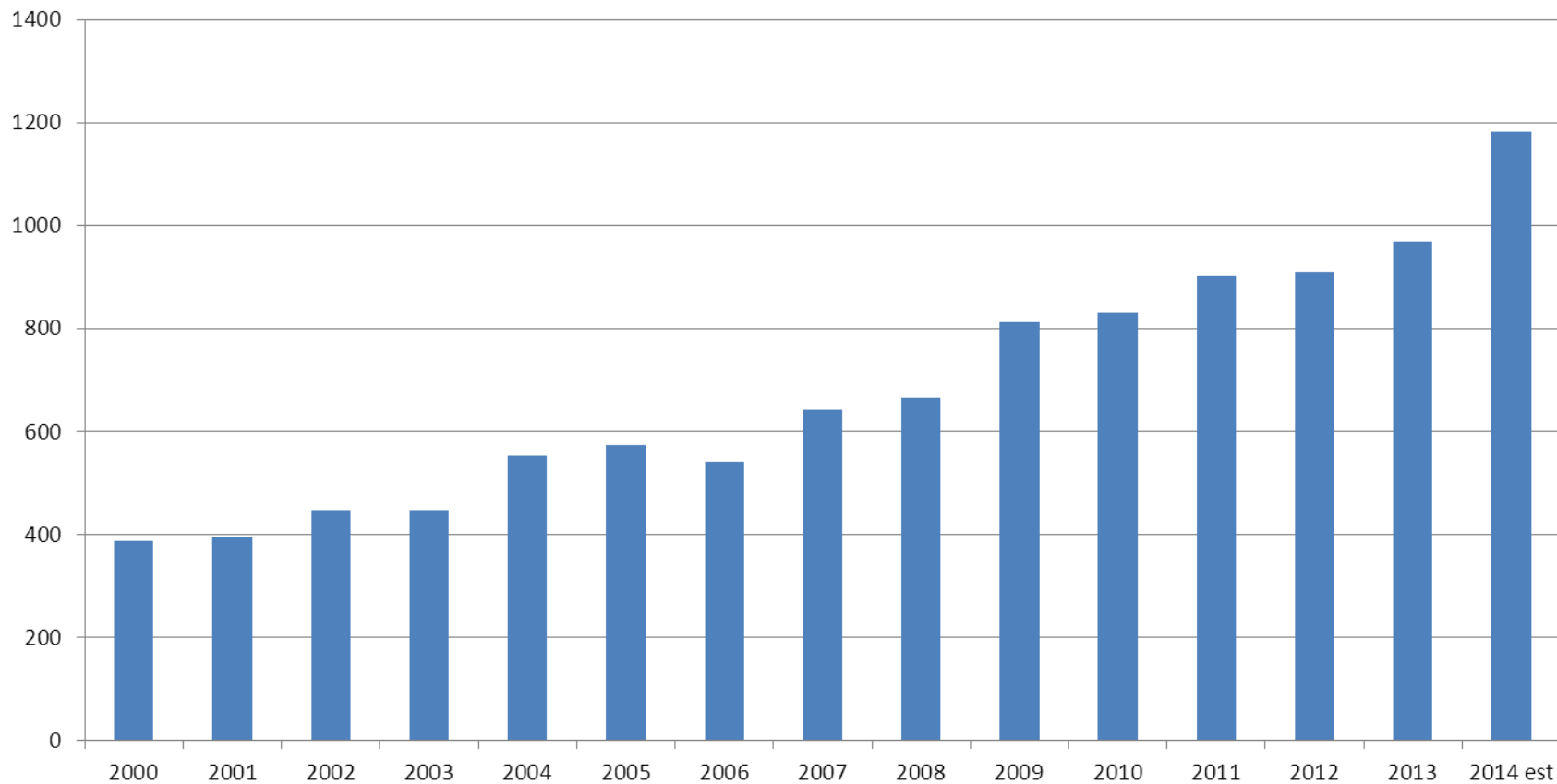




Annual General Meeting 2014

Shared-care clinics



Local renal lead

Centre	Renal lead
Sheffield Children's Hospital	S
Addenbrookes Hospital, Cambridge	L
Kettering General Hospital	L
Peterborough City Hospital	S
Barnsley General Hospital	-
Norfolk & Norwich University Hospital	L
Lincoln County Hospital	L
Derbyshire Children's Hospital	L
James Paget Hospital	L
King's Mill Hospital	S
Leicester Royal Infirmary	S
Rotherham General Hospital	-
Pilgrim Hospital, Boston	S
Doncaster Royal Infirmary	-
West Suffolk Hospital	L
Grantham Hospital	S
Bassetlaw Hospital	-
Queen Elizabeth Hospital, King's Lynn	L
Chesterfield Royal Hospital	L
Hinchingbrooke Hospital	L

IT support

Centre	Local IT access	Remote access
Sheffield Children's Hospital	P	-
Addenbrookes Hospital, Cambridge	-	-
Kettering General Hospital	-	-
Peterborough City Hospital	Y	P
Barnsley General Hospital	Y	P
Norfolk & Norwich University Hospital		
Lincoln County Hospital		
Derbyshire Children's Hospital		
James Paget Hospital		
King's Mill Hospital		
Leicester Royal Infirmary		
Rotherham General Hospital	-	-
Pilgrim Hospital, Boston	Y	-
Doncaster Royal Infirmary	P	-
West Suffolk Hospital	-	-
Grantham Hospital	Y	-
Bassetlaw Hospital	P	-
Queen Elizabeth Hospital, King's Lynn		
Chesterfield Royal Hospital		
Hinchingbrooke Hospital		

Transition clinics

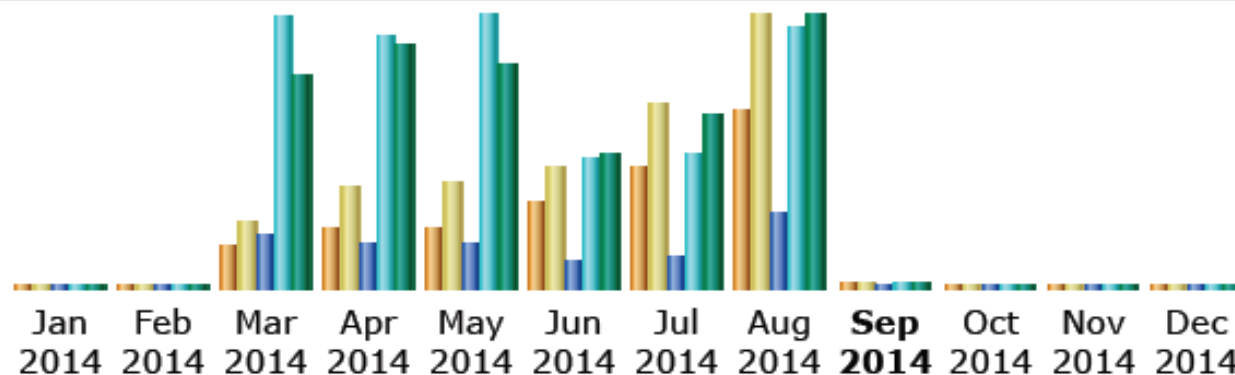
- Twice yearly clinics for:
 - Nottingham
 - Sheffield
 - Leicester
 - Cambridge
- East of England DGHs centralising transition at Addenbrookes
- Includes MDT discussion on upcoming patients
- Informal process in place for
 - Derby
 - Doncaster and Bassetlaw
 - Norfolk and Norwich
- Plans to develop South Yorkshire transition

Website

- www.emeesykidney.nhs.uk
- Old website now redirected
- Developed by Volute with one year further support
- Development and ongoing charitably funded
- 3-monthly editorial board meeting



Monthly history



Month	Unique visitors	Number of visits	Pages	Hits	Bandwidth
Jan 2014	0	0	0	0	0
Feb 2014	0	0	0	0	0
Mar 2014	164	266	6,642	33,253	790.35 MB
Apr 2014	244	416	5,440	31,304	905.02 MB
May 2014	246	435	5,531	33,618	825.42 MB
Jun 2014	352	488	3,193	15,803	500.15 MB
Jul 2014	497	759	3,939	16,574	647.71 MB
Aug 2014	730	1,125	9,086	32,380	1010.26 MB
Sep 2014	18	18	90	490	15.94 MB
Oct 2014	0	0	0	0	0
Nov 2014	0	0	0	0	0
Dec 2014	0	0	0	0	0
Total	2,251	3,507	33,921	163,422	4.58 GB

Opportunities and challenges

opportunities

- Lots!
- For example:
 - Patient prep for biopsies etc
 - Virtual tour of E17
 - Video clips

challenges

- Need to update regularly to prevent stagnation
- Getting feedback
- Time to update pages and develop new ones

Workplan for 2014-15

- Overhaul of E17 pages
- Sort out electronic access for our own Nottingham patient information
- Develop some transplant/biopsy preparation material, possibly with pharma funding
- Engage all the time with ownership and ideas!

Education

Autumn meeting 2013

Senior medical staff (consultants/speciality doctors)	23
Junior medical staff	6
Nurses	3
Dietitians	5
Pharmacists	2
Total	39

Spring meeting 2014

Senior medical staff (consultants/speciality doctors)	31
Junior medical staff	11
Nurses	10
Dietitians	8
Pharmacists	-
Total	60

Facebook page

It's been a busy week for our renal clinics in South Yorkshire - Barnsley, Sheffield and Doncaster all visited this week. We are looking for feedback and would love to talk to families who attend local clinics rather than coming to Nottingham. Please let us know if you would be willing to have a chat on the phone!

[LikeLike](#) · [Share](#)

Information

Sarah We're seen at LRI by dr Malik. Very happy with my daughter's care and happy to have a chat on the phone.

[17 hours ago](#) · [Like](#)

Feedback

Lisa We are seen at Rotherham and although very happy with her care I am getting increasingly worried of the consequences of my daughters illness for her future and would love to be directed to maybe a chat forum etc where I can learn more from people who have been through similar situations.

[17 hours ago](#) · [Like](#)

Identify concerns

Zoe Lisa ^^have u tried the British kidney patient association Facebook page?? I've found that helpful

[16 hours ago](#) · [Like](#)

Suggestions

Laura I would be happy to chat,would also love to hear from anyone else who's little one has nephrotic syndrome

[16 hours ago](#) · [Like](#)

Peer support

EMEESY Thanks Sarah and Laura. We will be in touch next week to arrange a time to call you. Lisa, we will also give you a call next week - we may be able to put you in touch with other families. Zoe, great suggestion as always! Here's a

link<https://www.facebook.com/bkpa.alton>**Bkpa Alton**

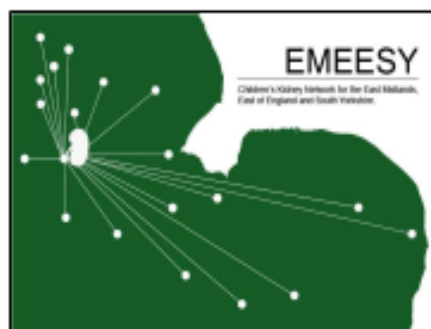
[14 hours ago](#) · [Like](#) · [Remove Preview](#)

<https://www.facebook.com/emeesynuh>

New SLAs

- Reversing activity/reimbursement flow
- Newly-established clinics have asked for this model
- Allows all clinics to be badged as “specialist activity” for accounting
- Appropriately costed tariff

Education meetings 2015



EMEESY Paediatric Nephrourology Symposium

Friday 27th March 2015, Eastwood Hall, Eastwood, Notts

Nephrourology at the Fringes: antenatal and transitional care

Overnight packages available again. Multi-professional streams available.

For more information and a registration form please see website updates

www.emeesykidney.nhs.uk

Autumn meeting 2015: proposal 1: renal biopsy

- Clinical sessions on:
 - Introduction to renal pathology
 - Investigation of haematuria/proteinuria
 - Acute glomerulonephritis
 - Steroid resistant nephrotic syndrome?
- Use of biopsy in HSP nephritis
- Nursing care aspects of renal biopsy
- Opportunity to launch biopsy preparation material on website

Is this enough to fill a whole day?

Combine with another topic?

Autumn meeting 2015:

Proposal 2: Renal genetics

- Opportunity for geneticists from Nottingham, Sheffield, Leicester and Cambridge to share their services
- Who needs to see a geneticist?
- Introduction to genetics
- Update on genetics testing available
- Specific sessions on:
 - Renal cystic disease
 - Haematuria/Alport's
 - Steroid-resistant nephrotic syndrome

Peer review

- Halted in March 2014
- Restarted August 2014
- Currently waiting to know if adopted
- Timetable – 2015?

Audit

- Discussion about NICE quality standards for UTI as pilot network audit
- Lead: Simon Rhodes

Governance

- Risk register sitting on Nottingham Children's Hospital risk register
- Accountability?
- Planning parent feedback in 2015
- Piloting BAPN outcome measures?

Research update

- PREDNOS
- PREDNOS2
- RaDaR

PREDNOS2

Hospital Name	Current Number Recruited 07/10/2014
Nottingham Children's Hospital	6
Sheffield Children's Hospital	0
Addenbrookes Hospital, Cambridge	0
Kettering General Hospital	2
Peterborough City Hospital	3
Barnsley General Hospital	1
Norfolk & Norwich University Hospital	0
Lincoln County Hospital	1
Derbyshire Children's Hospital	N/A
James Paget Hospital	0
King's Mill Hospital	1
Leicester Royal Infirmary	5
Rotherham General Hospital	N/A
Pilgrim Hospital, Boston	N/A
Doncaster Royal Infirmary	1
West Suffolk Hospital	0
Grantham Hospital	N/A
Bassetlaw Hospital	0
Queen Elizabeth Hospital, King's Lynn	N/A
Chesterfield Royal Hospital	0
Hinchingbrooke Hospital	N/A

Disease specific guidelines

- Available now on website:
 - Antenatally detected urinary tract abnormalities
 - Nephrotic syndrome
 - Hypertension
 - HSP
 - Hyperkalaemia
 - Acute kidney injury (coming soon)