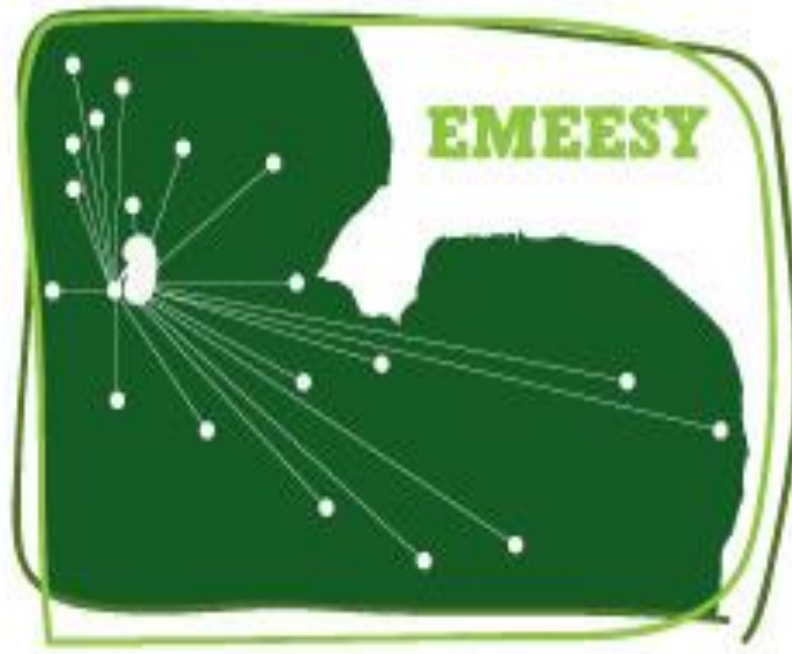
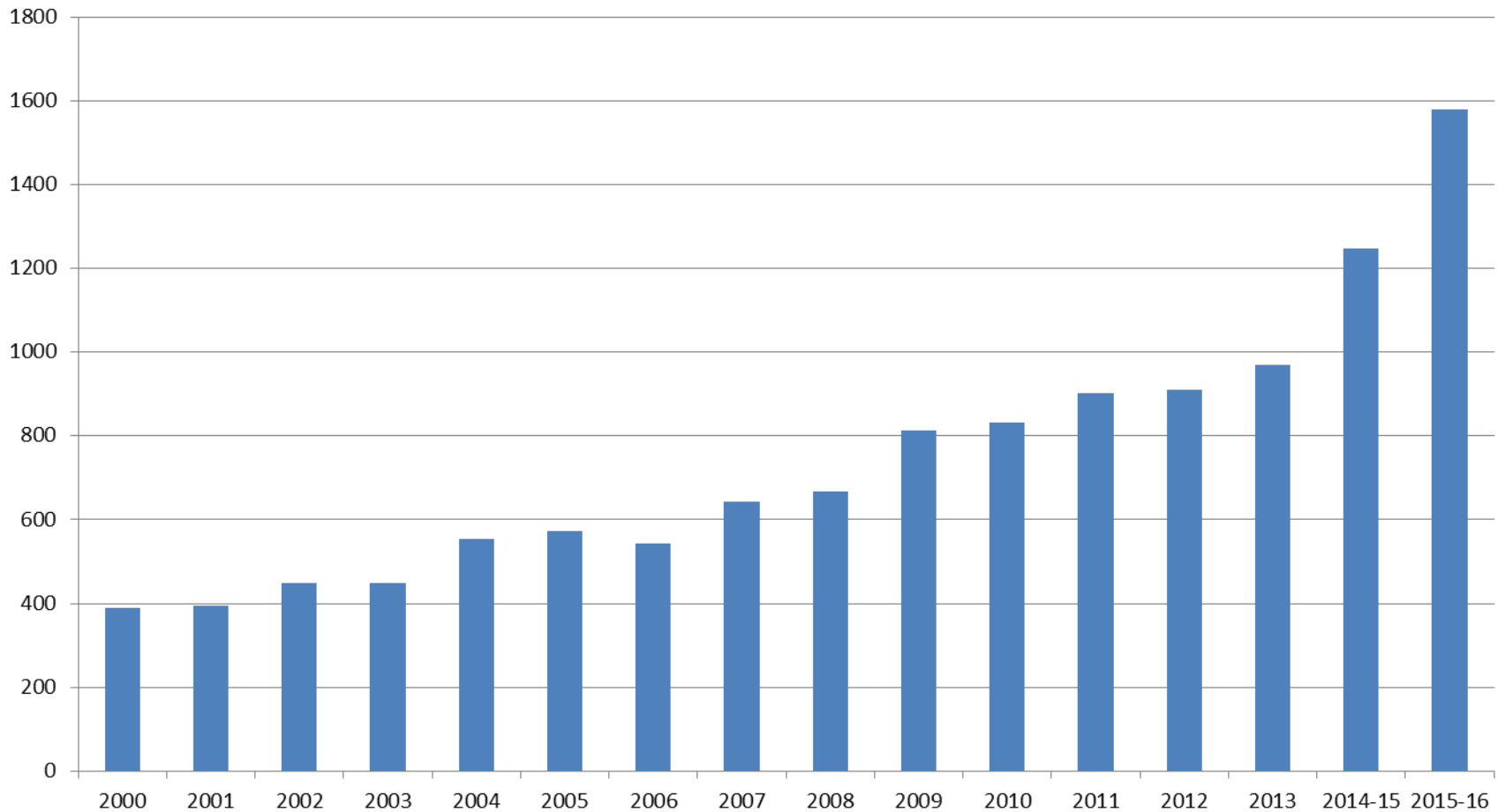




**EMEESY Children's Kidney Network
Annual General Meeting 2016**

Shared-care clinic numbers



Dialysis

Haemodialysis

Year	Total patient number	Patients under 5
2015-16	22	5
2014-15	15	6
2013-14	15	4
2012-13	22	7

Peritoneal dialysis

Year	Total patient number	Number of families trained
2015-16	15	7
2014-15	13	5
2013-14	15	5
2012-13	18	12

Transplantation

- 13 transplants 2015-16
- 3 LRD transplants
- Likely to be more overall and LRDs in 2016-17

CKD

- Need all SCC patients registered on EMED to get accurate numbers of CKD 3-5.
- From 2016, all CKD4 patients should also be reported to UKRR but this can only happen if they are registered on EMED
- CKD guidelines and pathway in preparation

Nephrotic syndrome

- Nephrotic specialist nurse, Monique Burgin attending regular SCC
- Over 150 patients with NS identified across EMEESY
- Rituximab experience in process of write-up
- NS guidelines about to be revised as network guidelines



Feedback from specialised commissioners' meeting

Website plans

- Glossary
- On-line booking/payments for education meetings
- Advice referral form

Network peer review/benchmarking

1. Local link paediatrician available in clinic
2. Link nurse identified
3. Link dietitian identified and available during SCC
4. Same-day phlebotomy service available (or bloods done before clinic)
5. Mechanism in place for specialist blood tests (e.g. white cell cystine, tacrolimus level, rituximab profile)
6. Letters to be typed within 1 week of clinic
7. Results to be viewed next day by link paediatrician
8. Clinic list preview discussion 1 week before clinic
9. Discussion about investigation results within 1 week
10. Corrected letters available to send out within 2 weeks

Education meetings

- Nephrourology
 - March 2017, date tbc
 - Second year of conundrums
- Annual education meeting
 - October 6th or 20th
 - Venue? Overnight package?
 - Electrolyte disturbance
 - Acid-base balance
 - Multi-professional cases
 - Nephrogenic DI
 - Pseudohypoaldosteronism

Network guidelines

- NUH guidelines to become network guidelines as they require review
- Any new guidelines needed?
- Comments?

Network research

- RaDaR
- ECUSTEC

IT support

- The gold standard option:
 - Able to access all Nottingham information at shared-care clinics, including:
 - Patient letters
 - NotIS (for investigation results)
 - Radiology imaging
 - EMED – to be able to input
 - Able to access wifi for Nottingham emails
 - Able to access local hospital information from Nottingham, for:
 - Interim blood results mainly
 - Patient letters
 - Radiology imaging
 - More comprehensive access to Nottingham information from Leicester and Sheffield

Local dietetic/nursing update

Pharmacy updates

Dietetic updates

Nursing updates

Network evaluation

Any other business?

Remember to complete your
evaluation forms please!