

# **Developing the Novel Role of Renal Genetics Nurse Specialist: A New Way of Working**



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# Background

- ❖ White paper “Our inheritance, our future – realising the potential of genetics in the NHS”(2000)
- ❖ Renal NSF .....“ to provide our patients with tailored information that will empower them to make informed decisions about their care”
- ❖ Single gene disorders account for up to 10% of adult patients requiring renal replacement therapy, but currently there is no specialist provision for this group of patients or their families

## Renal Genetic and Tubular Disorders: Case mix

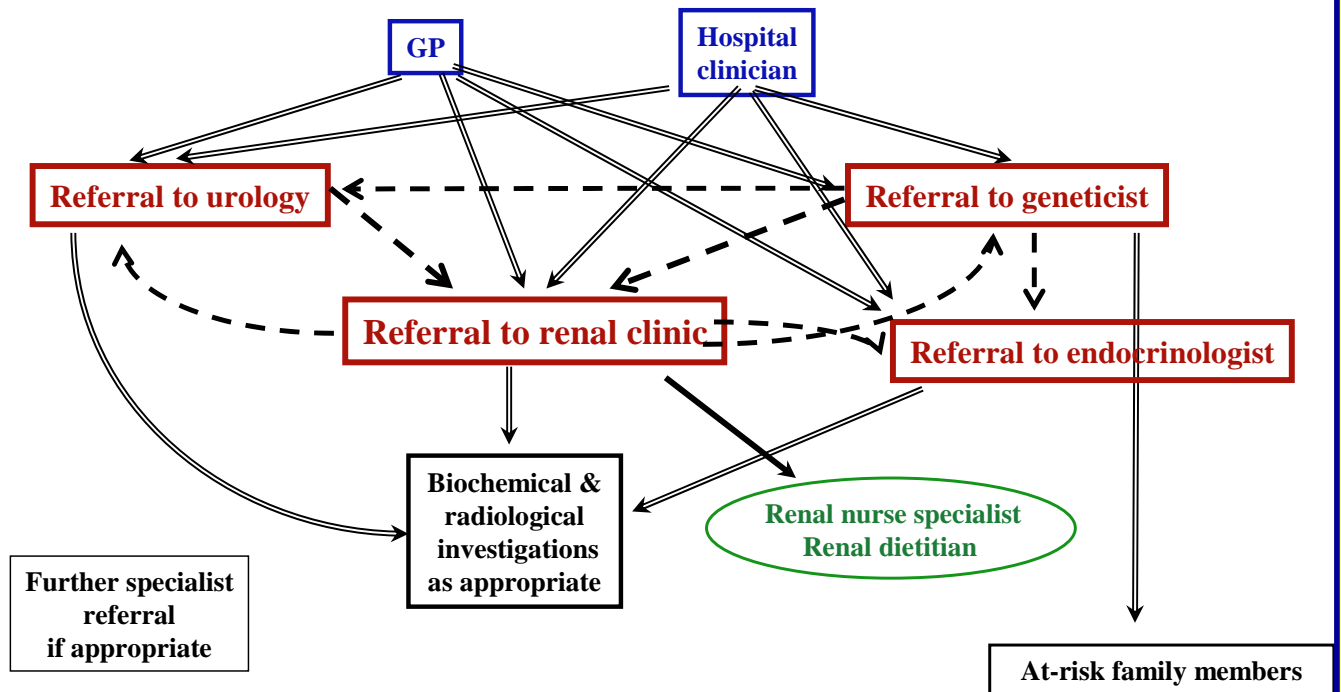
### *Known genes*

- ❖ Polycystic kidney disease
- ❖ Alport’s disease
- ❖ Gitelman and Bartter syndromes
- ❖ Liddle syndrome
- ❖ FSGS
- ❖ Renal tubular acidosis

### *High heritability*

- ❖ Recurrent kidney stones
- ❖ Nephrocalcinosis
- ❖ Early onset hypertension with a family history
- ❖ Other tubular disorders e.g. hypo- or hyperkalaemia
  
- ❖ At risk relatives of patients with the above conditions

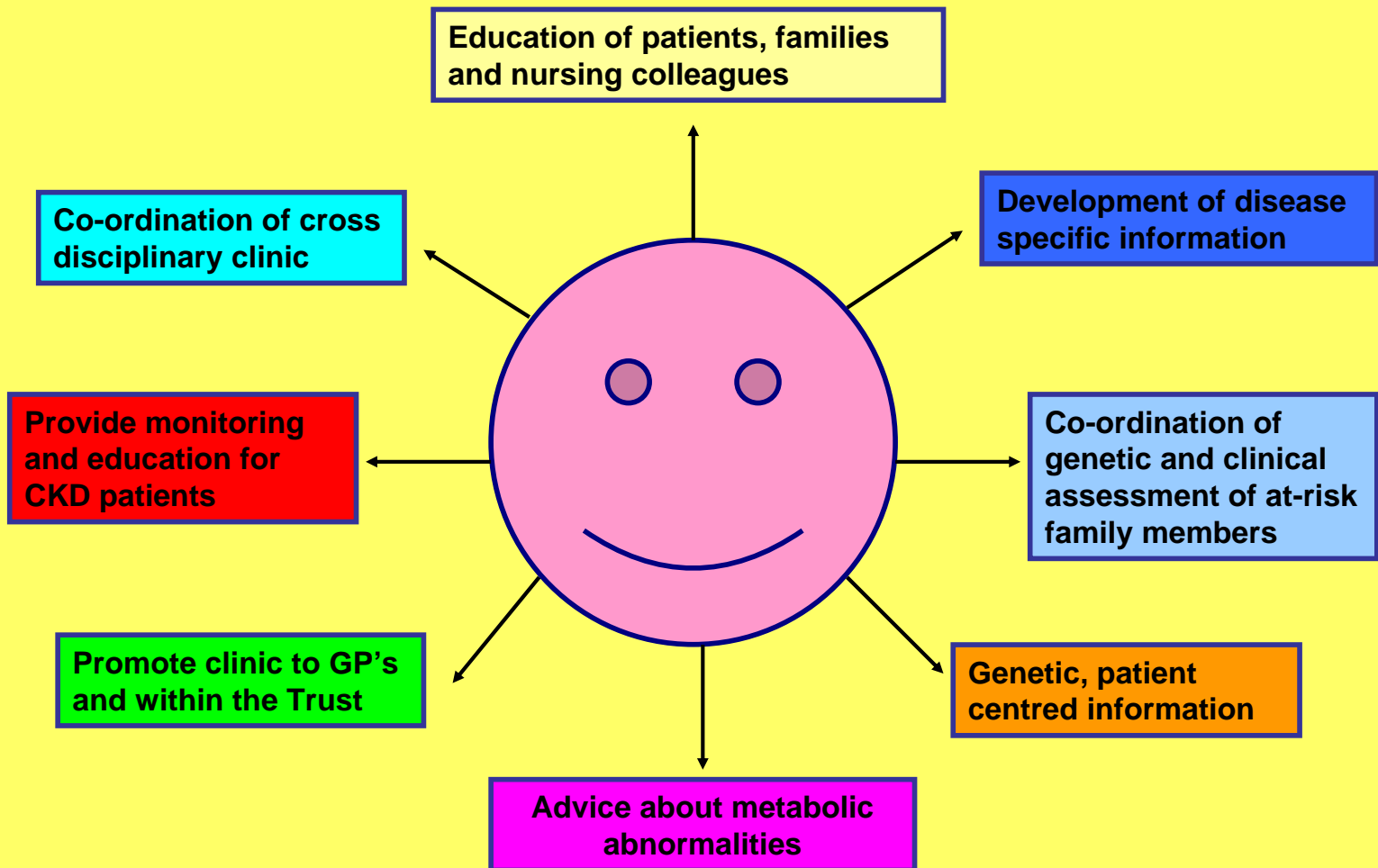
# Previous referral pathway



## *Problems:*

- ❖ Haphazard referral patterns
- ❖ Insufficient consultation time
- ❖ Inconsistent provision of information
- ❖ Inadequate screening and genetic testing
- ❖ No provision for at-risk family members

# The Specialist Nurse Role



## *Advantages*

- ❖ Facilitates effective communication between specialities
- ❖ Ensures a smooth, seamless patient pathway
- ❖ Provides holistic care to patients with hereditary renal disease
- ❖ Acts as a resource for other members of staff

- Manage paperwork
- Co-ordinate clinic with 3- 4 consultants
- Perform routine and PH urine testing
- Take BP, weight and height
- Administer audit questionnaire
- Liaise with clinic staff

- Monitor blood and urine results
- Provide information about CKD, medications, blood and urine results
- Act as contact for patients and other health care staff
- Educate about treatment options and progression of disease
- Ensure knowledge of patient pathway
- Provide tailored information for patients

- Increase personal knowledge of genetics
- Attend clinics with genetic counsellor
- Develop competencies for renal genetic nurses
- Attend relevant study days and network with colleagues
- Ensure the use of current research
- Collaborate with National Genetics Education Centre and Cambridge Genetics Knowledge Park

- Develop patient information
- Promote clinic information leaflet to describe the clinic
- Liaise with communications department to ensure correct corporate guidelines used
- Produce disease specific leaflets

- Develop web page for Trust web site
- Provide details about referral for GP's
- Provide online patient information
- Give links to other websites
- Promote service locally and nationally by presenting to AKPA and conferences

- Educate patients and relatives in clinic
- Act as a contact for queries and information
- Ensure inclusion of hereditary renal disease in local renal course
- Educate nursing colleagues within the renal unit

- Review clinic blood results and advise about medications
- Provide advice about potential symptoms
- Liaise with biochemistry and research staff about specific investigations

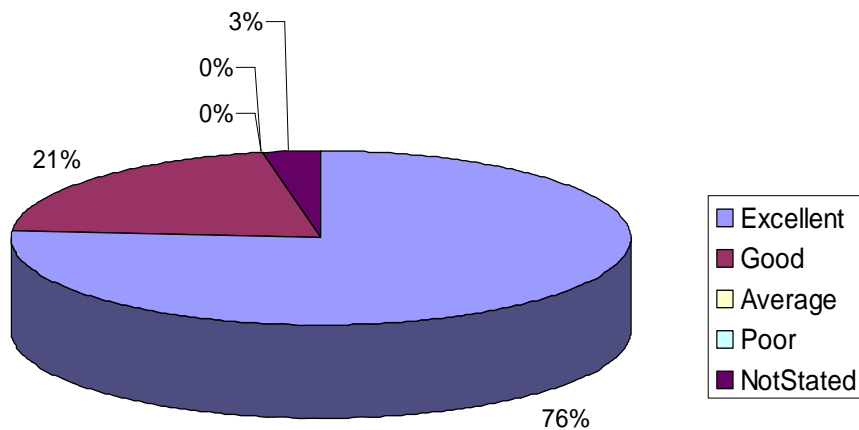
- Liaise with patients to obtain family history
- Produce family pedigrees
- Obtain information about affected family members
- Collect relevant historical documents
- Liaise with other renal units



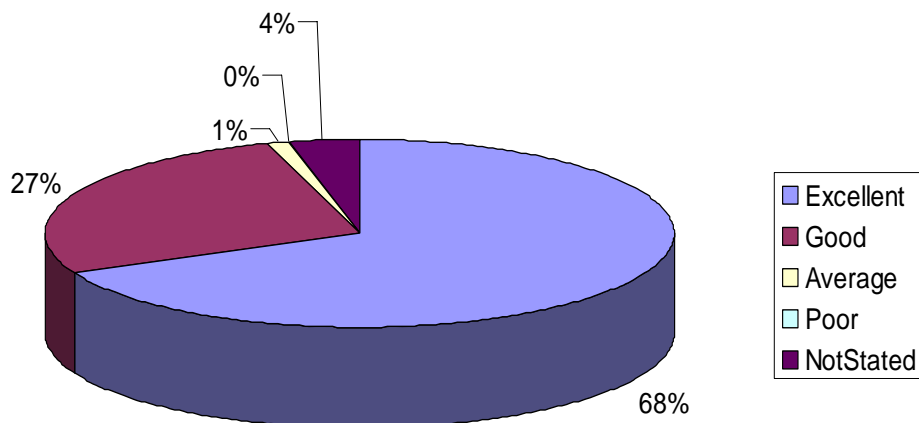
# Patient Satisfaction Survey

180 audit questionnaires administered, 170 returned

Patient Satisfaction - Clinic Staff



Patient Satisfaction - Information Given



## ***Acknowledgements***

- ❖ Department of Health – Service Development Award
- ❖ Addenbrooke's Foundation Trust
- ❖ Addenbrooke's Kidney Patients Association (AKPA)
- ❖ Cambridge Genetics Knowledge Park (CGKP)
- ❖ National Genetics Education Centre

# Information and Communication

Website – [www.addenbrookes.nhs.uk](http://www.addenbrookes.nhs.uk) - Renal Genetics and Tubular disorders

The screenshot shows a web browser window displaying the website for Addenbrooke's Hospital. The page is titled "Renal Genetics and Tubular Disorders Clinic". It includes a navigation menu with links for "About us", "Patients", "Visitors", "Press", "Services", "Research", "Teaching", "Careers", and "A to Z". The main content area provides information about the clinic, including its location (TBox: 118, Tel: 01223 256318), a description of the clinic's services, and a list of typical diagnoses or problems. The page also lists key contacts, including the clinic PA, consultants, and a renal nurse specialist. The browser's address bar shows the URL: [http://www.addenbrookes.nhs.uk/ser/clin/med/renalgenetics\\_clinic.html](http://www.addenbrookes.nhs.uk/ser/clin/med/renalgenetics_clinic.html).

**Renal Genetics and Tubular Disorders Clinic**

TBox: 118  
Tel: 01223 256318

**About the clinic**

This Clinic brings together staff from Addenbrooke's Hospital: Nephrology, Medical Genetics, Urology and Clinical Biochemistry to see patients whose disease usually needs to be looked after by one or more of these specialities.

The Clinic was set up in February 2005 with initial funding for two years from the Department of Health as part of its Mainstreaming Genetics programme.

Patients may be referred by their general practitioners (GPs) or by hospital doctors from Addenbrooke's, from local hospitals or from further away if there is no local centre.

**What does the clinic offer?**

- The clinic has a consultant nephrologist, medical geneticist, urologist and chemical pathologist and a specialist renal nurse.
- We have the expertise in the clinic at a single visit to evaluate fully and care for the patient, which should lead to better and more efficient care.
- We have access to genetic counselling and can arrange diagnostic mutation screening for selected conditions where the causative gene is known.

**Which patients are referred to us?**

We can provide services to:

- Adults who have all types of renal tubular diseases including polycystic kidney disease; the cause may be acquired, hereditary or unknown.
- Patients who have recurrent kidney stones and/or a family history of kidney stones.
- We are also happy to see 'at-risk' relatives of patients.

Typical diagnoses or problems include:-

- Autosomal dominant polycystic kidney disease
- Bartter Syndrome
- Cystinuria
- Dent's disease
- Familial hypertension
- Gitelman syndrome
- Hypercalcaemia (of unknown cause)
- Hypomagnesaemia (of unknown cause)
- Medullary cystic kidney disease
- Nephrocalcinosis
- Nephronophthisis
- Recurrent hypokalaemia or hyperkalaemia (of unknown cause)
- Recurrent kidney stones
- Renal tubular acidosis (definite or possible)
- Severe gout with renal impairment

**Key contacts**

Clinic PA Tel: 01223 256 318; Fax: 01223 586 506

**Consultants:**

- Prof Fiona Karet (Nephrology) Tel: 01223 762 617
- Dr Anthony Norden (Clinical Biochemistry) Tel: 01223 586 820
- Dr Richard Sandford (Clinical Genetics) Tel: 01223 762 616
- Mr Nimish Shah (Urology) Tel: 01223 257 215

**Renal Nurse Specialist:** Sr Deborah Spencer Tel: 01223 257 194

**For referring doctors**

To make referrals, please contact the Clinic PA, RGTD Clinic, Box 118, Addenbrooke's Hospital, Hills Road, Cambridge CB2 2QQ; Tel: 01223 256 318; Fax: 01223 586 506

If you are a referring doctor, please feel free to discuss patients with the clinic staff listed above.

## Leaflets –

- ❖ Clinic information leaflet
- ❖ Disease specific leaflets – Polycystic disease, Bartters, Gitelmans

## Talks –

- ❖ Renal course – Homerton College
- ❖ East Anglian Renal Meeting
- ❖ Addenbrooke's Kidney Patients Association
- ❖ GP liaison committee

## Promotion –

- ❖ Communications Department – 'Addenbrooke's Matters'
- ❖ Local Press