

**Clinical Guidelines for a Clinical Nurse
 Specialist (Renal Genetics) led Follow-Up Clinic
 for Patients with a Family History of Genetic
 Renal Diseases**

CONTROLLED DOCUMENT

CATEGORY:	Guideline
CLASSIFICATION:	Clinical
PURPOSE	These clinical guidelines support a clinical nurse specialist (CNS, Renal Genetics) working in Renal Outpatients to lead the CNS-led follow-up clinic for patients with a family history of genetic renal diseases.
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Controlled Document Sponsor:	Associate Director of Nursing Division B Clinical Guidelines Group
Controlled Document Lead:	Clinical Nurse Specialist (Renal Genetics)
Approved By:	Clinical Guidelines Group
On:	February 2016
Review Date:	February 2019
Distribution:	
<ul style="list-style-type: none"> • Essential Reading for: • Information for: 	<p>The CNS (Renal Genetics) who currently leads the CNS-led follow-up clinic for patients with a family history of genetic renal diseases.</p> <p>All clinical staff who provide care to patients with genetic renal conditions.</p>

1.0 Aim of the guidelines

These guidelines support and provide guidance for clinical nurse specialists (CNSs) in renal genetics working in the Renal Outpatients Department, who are competent in the provision of a CNS-led follow-up clinic for patients with a family history of genetic renal diseases.

2.0 Evidence for practice

2.1 A review of the Department of Health White Paper 'Our inheritance, our future' (2008) emphasised the importance of continuing to strengthen specialist genetic services. A joint renal genetic clinic was started in 2006. The specialist genetic registered nurse-led clinic has increased access for patients, with a family history of genetic renal disease, to counselling, advice, clinical and psychological support.

2.2 A review of the guidelines has been undertaken to ensure the practice covered by this document remains up to date and changes have been made to the indications and contraindications for the registered nurse-led follow up clinic.

3.0 Indications for the registered nurse-led follow-up clinic

3.1 The clinic must only take place when there is a consultant available within the Trust to contact for advice, if necessary.

3.2 The CNS (Renal Genetics) must only see patients in the CNS-led follow up clinic with the agreement of the lead consultant. Patients are referred by a consultant nephrologist or renal registrar, by email or letter. Referral letters are scanned onto Portal.

3.3 Only patients of families with a confirmed diagnosis and nephrology involvement will be referred to the specialist genetic registered nurse-led clinic. The CNS (Renal Genetics) will:

- Provide genetic counselling.
- Provide a route onto screening for identified at-risk relatives.
- Monitor the patient's blood values which include-creatinine levels, Full Blood Count (FBC), urea and electrolytes and estimated glomerular filtration rate (eGFR).
- Perform urine analysis.
- Monitor the patient's blood pressure and weight.
- Monitor cholesterol control and angiotensin-converting enzyme (ACE) inhibitors.
- Provide psychological support and advice to the patient.
- Organise monitoring of blood tests for the patient's next appointment.
- Offer health and diet advice.
- Provide research trial information.
- Document all interventions and advice given in the patient's records.

- 3.4** In addition, following the clinic and in discussion with the lead consultant nephrologist, the CNS (Renal Genetics) will:
- Complete a list of the patient's current medication. Any changes that are required are documented in a letter for the patient's General Practitioner (GP) which is completed by the nephrologist.
 - Arrange referral of the patient to the consultant nephrologist as required.
 - Arrange the follow up appointment for the patient.

4.0 Contraindications for the CNS-led follow-up clinic

- 4.1** The following patients must not be referred to the CNS-led follow-up clinic:
- Patients with capacity who refuse to be seen at the CNS-led follow-up clinic.
 - Patients under the age of 16 years.
 - Patients not seen by a Trust nephrologist in the first instance.
 - Patients with an eGFR of 20 ml/min or below.

5.0 Limitations for the specialist genetic registered nurse-led follow-up clinic

- 5.1** The CNS (Renal Genetics) must refer the patient to the consultant nephrologist immediately when:
- The patient presents with pain, which may be related to or impact on their renal condition/treatment.
 - There is change in the patient's condition for example, a rise in blood pressure.
 - The patient's serum creatinine levels are 30% higher than baseline measurement or reduction in estimated GFR.
 - The patient's liver function tests (LFTs) are 50% higher than baseline measurements.
 - The patient's systolic blood pressure is higher than 200 mmHg.
 - The patient's diastolic blood pressure is higher than 100 mmHg.
 - The patient is presenting with urine infection, haematuria or dehydration.
 - The patient is non-concordant with any treatment.

The appropriate Health and Safety risk assessments must have been completed for the clinical area.

6.0 Competencies

- 6.1** The CNS (Renal Genetics) who has undertaken the appropriate training as recognised by the consultant nephrologist in the joint renal genetics clinic and will be required to complete satisfactory supervised practice and be assessed as competent (Appendices 1 and 2).
- 6.2** The CNS (Renal Genetics) must be competent to take medical pedigrees.
- 6.3** The CNS (Renal Genetics) must demonstrate a working knowledge of clinical genetics.
- 6.4** Any CNS (Renal Genetics) new to the Trust, who has been performing the skill elsewhere, must read, understand and be signed off as competent against these guidelines. Evidence of appropriate education and competence must be provided and checked by their line manager before undertaking this practice at the Trust. The decision whether the CNS (Renal Genetics) needs to complete Trust training and competence will be at the discretion of the CNS's line manager.
- 6.5** In accordance with codes of professional practice, the CNS (Renal Genetics) has a responsibility to recognise, and to work within, the limits of their competence. In addition, the CNS (Renal Genetics) has a responsibility to practise within the boundaries of the current evidence based practice and in line with up to date Trust and national policies and procedural documents. Evidence of continuing professional development and maintenance of skill level will be required and confirmed at the CNS's annual appraisal by the CNS's line manager.
- 6.6** A list of CNSs (Renal Genetics) who lead the specialist genetic registered nurse-led follow-up clinic will be kept by their line manager.

7.0 Audit of the specialist genetic registered nurse-led follow-up clinic

- 7.1** A CNS (Renal Genetics) competent to lead the CNS-led follow-up clinic will lead the audit of these guidelines with the support from the Practice Development Team. The audit will be undertaken in accordance with the review date and will include:
- Adherence of staff to these guidelines.
 - Clinic activity.
 - Any untoward incidents.
 - The number of specialist genetic registered nurses competent to lead the specialist genetic registered nurse-led follow-up clinic.
- 7.2** All audit activity must be logged with the Risk and Compliance Unit.
- 7.3** Audit results will be reported back to the Matron for Nephrology and an action plan will be developed as the audit results indicate. The Risk and Compliance Unit will be informed of any resulting changes in practice.

8.0 Incident reporting

- 8.1 Any untoward incidents and near misses must be dealt with by the appropriate management team. An incident form must be completed and in addition the Risk Management Team must be notified by telephone of any Serious Incidents (SI).

REFERENCES

Department for Health 2008 **Our Inheritance, Our Future. Realising the Potential of Genetics in the NHS. Progress Review.** HMSO, London.

University Hospitals Birmingham NHS Foundation Trust Risk Assessment Documentation <http://uhbhome/Resources/RiskAssessmentDocs/Home.aspx> [accessed 18.08.15]

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Department of Health (2009) **Reference Guide to Consent for Examination or Treatment** 2nd edn. HMSO London

Mental Capacity Act 2005,
<http://www.legislation.gov.uk/ukpga/2005/9/contents>
[accessed 18.08.15]

Burke, S. Bennet, C. Bedworth, J. and Farndon, P. (2007) **The Experiences and Preferences of People receiving Genetic Information from Healthcare professionals.** National Genetics Education and Development Centre.

University Hospitals Birmingham NHS Foundation Trust (current version) **Policy for consent to examination or treatment,** University Hospitals Birmingham NHS Foundation Trust <http://uhbpolicies/consent-to-examination-or-treatment.htm> [accessed 18.08.15]

University Hospitals Birmingham NHS Foundation Trust (current version) **Procedure for consent to examination or treatment.** Birmingham: University Hospitals Birmingham NHS Foundation Trust <http://uhbpolicies/consent-to-examination-or-treatment.htm> [accessed 18.08.15]

GUIDELINE SUBMISSION DETAILS

Guidelines reviewed by:

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Guidelines submitted to and approved by Clinical Guidelines Group

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EVIDENCE OF SUPERVISED PRACTICE

To become a competent practitioner, it is the responsibility of each CNS (Renal Genetics) to undertake supervised practice in order to lead the CNS-led follow-up clinic for patients with a family history of genetic renal diseases.

Name of CNS (Renal Genetics):

DATE	DETAILS OF CLINIC	SATISFACTORY STANDARD MET	COMMENTS	PRINT NAME, SIGNATURE & DESIGNATION
		Yes / No		
		Yes / No		
		Yes / No		
		Yes / No		
		Yes / No		
		Yes / No		

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CRITERIA FOR COMPETENCE

END COMPETENCE: Clinical guidelines for a CNS-led follow-up clinic for patients with a family history of genetic renal diseases.

Date(s) of Education and supervised practice:

Name of CNS (Renal Genetics):

Name of Supervisor:

Element of Competence To Be Achieved	Date Achieved	CNS (Renal Genetics) Sign	Supervisor Sign
Demonstrate knowledge and be aware of the indications, contraindications and limitations for practice according to these guidelines.			
Demonstrate knowledge and understanding of the genetics of hereditary renal diseases.			
Demonstrate accurate assessment of the patient's current health status to include social, psychological and physical components in relation to renal disease.			
Demonstrate a working knowledge of ACE inhibitors and medication most commonly prescribed in renal medicine.			
Demonstrate provision of accurate advice for patients with families with genetic renal diseases.			
Describe the importance of obtaining verbal consent from the patient prior to any investigation or treatment in line with the Trust's policy and procedural document and the Department of Health's requirements for consent to examination or treatment.			
Demonstrate a working knowledge of The Mental Capacity Act (2005).			
Describe when the patient should be referred to the medical staff.			

Appendix 2

Element of Competence To Be Achieved	Date Achieved	CNS (Renal Genetics) Sign	Supervisor Sign
Demonstrate accurate provision of information and education to the patient in a way the patient understands.			
Discuss how to maintain the patient's privacy and dignity at all times.			
Demonstrate accurate record keeping.			
Demonstrate an understanding of the incident reporting process.			
Demonstrate the ability to check the patient's infection status on PICS and practise safe infection prevention and control practices throughout the CNS-led follow up clinic. To include: <ul style="list-style-type: none"> • Standard precautions 			

I declare that I have expanded my knowledge and skills and undertake to practise with accountability for my decisions and actions. I have read and understood the **clinical guidelines for a CNS-led follow-up clinic for patients with a family history of genetic renal diseases.**

Signature of CNS (Renal Genetics): **Print name:**.....

Date:

I declare that I have supervised this CNS (Renal Genetics) and found her/him to be competent as judged by the above criteria.

Signature of Supervisor: **Print name:**.....

Date: **Designation:**.....

A copy of this record should be placed in the CNS's personal file, a copy must be stored in the clinical area by the line manager and a copy can be retained by the individual for their Professional Portfolio.