

Job Title	Haemoglobinopathies Clinical Nurse Specialist
Band	7
Responsible to	Clinical Lead For Haemoglobinopathies
Accountable to	Head of Clinical Services
Base	TBC

Job Purpose

The Clinical Nurse Specialist (CNS) role is pivotal to the delivery of high quality, effective and compassionate care to a defined group of clients with haemoglobinopathies. The CNS will work as an autonomous practitioner with a caseload of complex patients within a team structure to provide a supportive, advisory, educational and evidence-based service to patients with haematological disorders, in addition to their families, carers and other healthcare professionals. The post holder will be primarily responsible for the adult or paediatric pathway but will be expected to provide cover for the alternative. The CNS will work in close partnership with the haematology Consultants and their teams continually developing the Haemoglobinopathy service.

They will also liaise, where appropriate, with other healthcare professionals in primary and tertiary care settings and other relevant agencies. They will assist with the coordination of clinical care and other supportive therapies. This will involve the education and monitoring of sickle cell and thalassaemia patients with the documentation of accurate patient data.

This is a broad summary of the role detailing key areas of operation and responsibilities – further detail will be provided in the Main Duties and Responsibilities section, below, which provides more granular detail.

The post holder will be responsible for:

- To be responsible for providing a culturally sensitive, and evidence based Haemoglobinopathy service in the community setting
- To be able to communicate highly sensitive and complex information to professionals, patients and to those who are important to them, often as a lone worker in the community. This communication could be about diagnosis, treatment or prognosis.
- Lead in providing a person-centred holistic approach to assess the mental, physical, psychological and social wellbeing abilities and needs of the person, their families and carers.
- To be responsible for providing advice and support to all patients in the borough with a haemoglobinopathy and their families.
- To ensure that patients and their families are fully informed and supported by providing clinical and support.
- To establish clear lines of communication within the specialty team supporting a comprehensive service with a multi-disciplinary team approach for patients and their families.
- To demonstrate effective leadership and actively promote and contribute to learning activities across the care group and the Trust.
- To remain clinically and professionally up-to-date with current trends and developments in the clinical specialty.
- To link and provide support to healthcare teams in order to increase knowledge and facilitate the care of this group of patients in the community or in their local healthcare setting.
- To be responsible for the auditing and effective management of this service
- Provide advice, information and support on the haemoglobinopathies to Community Health professionals, GP's ,teachers, social workers, and to other interested persons.
- Compile and maintain a register of all known clients living with a Sickle Cell Disorder and Thalassaemia in a specific borough/ defined population.
- Responsible for developing quality standards for the services by evaluating and monitoring programmes of care.
- Participate in professional/multi-professional meetings and conferences as required
- Develop protocols, standards and clinical audit mechanisms to ensure the delivery of high quality service and standards of care.

- Liaise with the haemoglobinopathy laboratories where appropriate in order to obtain and convey accurate results of babies to their parents, so that they can be given counselling, advice and information about findings.
- Make referrals as necessary, in line with the local protocol.
- Provide telephone or virtual support and advice

Clinical & Counselling Skills

- To support the team to promote a culture of independence, self-care, self-management and enablement for patients/clients
- Lead on the delivery and promotion of evidence-based practice in line with local, regional and national guidelines.
- Be proficient in carrying out effective physical assessment and be able to order diagnostics in a succinct and logical manner using this information to guide the level of intervention offered to patients.
- Manage a clinical caseload effectively.
- Demonstrate in-depth knowledge of the options for achieving symptom control and be able to advise the primary health care team appropriately.
- Participate in patient counselling and provide support when appropriate.
- To prescribe medication within nurse prescribing formulary if appropriate. If qualified as an independent prescriber, prescribe in accordance with the local non-medical prescribing policy. It is expected that all prescribers will prescribe within the limits of their individual competence.
- Ensure that clinical knowledge of haemoglobinopathy is up to date and in line with any national or governmental guidance
- To assess, plan, implement and evaluate programmes of care for patients with Haemoglobinopathies and their families, actively seeking evidence based practice, which will support clinical outcomes as appropriate.
- Develop and implement, as an intrinsic part of the role, a variety of counselling strategies in a range of very different situations, presented by patients and relatives coping with haemoglobinopathy disorders
- Liaise as necessary with medical, nursing staff and other professionals with regard to the management of discharge planning from inpatient to community.
- To follow-up patients in the outpatient setting and as appropriate and ensure all relevant information is available to enable patients to make an informed choice about their treatment.
- Support the development and implementation of health promotion activities and to participate in the development of literature and information
- Participate in multi-professional meetings, supervisory sessions and case conferences as required
- To have good verbal and written communication skills so that professional advice or care guidance and instructions are well understood by patients, their relatives and/or carers, and members of the multi-disciplinary team.
- To be responsible for own patients caseload, monitor their treatment and ensure that they have up to date care plans and keep accurate records that are accessible and disseminate across the MDT.
- To co-ordinate and develop care plans for patients with Haemoglobinopathies who require frequent hospital admission for pain relief, in collaboration with the acute pain service.
- To support the transition of adolescents to the adult services within the Trust.
- To participate in the process of operational policies review annually in accordance with national standards
- To work with key staff members to maintain nurse led pre-assessment/assessment and out patient follow-up services. Providing detailed baseline patient assessment and education and support to patients and their families
- To liaise with the discharge coordinator and ward staff to ensure appropriate and timely discharge/follow-up arrangement in place for patients
- To liaise with local community, social services, paramedics and voluntary organisations in order to develop existing services for clients, carers and health professional
- To actively involve service users in providing feedback of their experience of the current service and suggestions for improvements.
- To participate in relevant forum at Care Group, Trust or ICB level to represent the service and patient perspectives

Professional Practice

- Promote and raise awareness of the Haemoglobinopathies in the local community
- Act as a key resource of authority and knowledge on clinical issues and develop clinical expertise in this speciality
- Formulate policy and care delivery strategies for the specialist area, including the development of Integrated Care Pathways for Major Haemoglobinopathy within the Trust
- Implement and evaluate innovations in this specialist area across the trust.
- Recognise through qualification, experience and practice, which is appropriate and reflect the needs of this speciality
- Ensure that record keeping and maintenance of records is undertaken in accordance with NMC guidelines/ Produce and maintain accurate records and statistical data for clerical, managerial and research purposes

Further information and general responsibilities

- The post holder will demonstrate responsibility and professional and managerial accountability, which includes management of staff, quality and standards of practice of all members of the team by enhancing systems such as clinical supervision, personal development and competency planning and monitoring, clinical audit, policy compliance checks etc.
- To have overall responsibility to ensure that a personalised service to clients/service users is delivered in accordance with Trust standards
- Lead, participate in and cooperate with concerns, complaints and investigations as required.
- Communicate with colleagues, patients and visitors in a polite and courteous manner at all times
- Have responsibility for the health, safety and welfare of self and others and to comply at all times with the Health and Safety regulations.
- Ensure confidentiality at all time, only releasing confidential information obtained during the course of employment in an official capacity
- Attend any mandatory training and induction courses as designated by management
- Report all clinical and non-clinical accidents or near misses promptly and when required, to co-operate with any investigation undertaken
- To ensure student learners on clinical placement are appropriately supervised and assessed and have an effective learning experience.
- To lead and provide education to system partners as well as internal staff members on Sickle cell and Thalassaemia.
- Accepts designated responsibilities from senior leaders and actively contributes to performance review and the appraisal process.

Key Working Relationships

- Promote and raise awareness of the Haemoglobinopathy Service in the local community.
- Work in partnership with the surrounding Haemoglobinopathy Services, local Hospitals, GPs, the regional Laboratory and other health professionals and agencies in delivering a seamless and equitable service.
- Ensure contact continues with haemoglobinopathy coordinating centres (HCC), including voluntary organisations and charities.
- Ensure that all relevant information regarding patients are documented in keeping with Trust policy and where appropriate reported and acted upon immediately.
- Ensure effective communication with patients and their carers, including the provision of patient education and opportunistic health promotion where appropriate.
- Assist with the education and training of community and acute/hospital staff in the problems of sickle cell disease and thalassaemia e.g. health needs of affected families, uptake of screening/counselling facilities and evaluation of the neonatal screening programme
- Further research opportunities may be available when the service is fully established.

Person Specification Job Title: Haemoglobinopathies Clinical Nurse Specialist

Factors	Criteria	Assessment Method
Education/Qualification		
Essential	<ul style="list-style-type: none"> • Appropriate NMC registration • > 2 years Community experience • Genetic risk assessment and counselling in Haemoglobinopathies - • Advancing client centered care – Haematology • Advanced assessment skills • Medical prescribing -NMC recorded Non-Medical Prescribing qualification or has successfully completed the Non-Medical Prescribing qualification and is awaiting annotation with the NMC OR • If the individual does not have the Non-Medical Prescribing Qualification, they must be willing to undertake and successfully complete it within 2 years of appointment to the role. • Evidence of relevant continued professional development • Haemoglobinopathies advancing client centred care – if not, willingness to work towards 	IV/AF
Desirable	<ul style="list-style-type: none"> • Teaching qualification • People Management • Recruitment and appraisal training • Leadership course • Paediatric nursing or health visiting school nursing SCPHN qualification for the Paediatric Nurse specialist or district Nursing qualification for the adults 	IV/AF
Experience		
Essential	<ul style="list-style-type: none"> • Community experience as an autonomous practitioner- 2 years • At least 2 years of working in the specialty (such A&E , Critical care or Haematology) - at band 6 • Counselling skills • Experience of supporting patients through difficult and potentially upsetting news • Experience of teaching within the clinical field. 	IV/AF
Desirable	<ul style="list-style-type: none"> • Experience of change management-Awareness of Service improvement activities 	IV/AF
Skills & Knowledge		
Essential	<ul style="list-style-type: none"> • Excellent written, verbal and presentation skills • Demonstrates effective communication and interpersonal skills in complex situations • Ability to lead team and work effectively with others • Demonstrates initiative and ability to work independently, able to problem solve and prioritize own and others work • Demonstrates planning and organisational skills • Clinical Leadership skills • Advanced Decision Making Skills • Clinical skills in relation to management of sickle cell & Thalassaemia emergencies • Able to demonstrate excellent interpersonal skills • Approach sensitive and challenging situations with a strategic outlook • Analytical and problem solving skills 	IV/AF

	<ul style="list-style-type: none"> • Understanding of audit, clinical governance and service delivery procedures • Time management skills • Basic computer literacy • Demonstrate excellent organisational skills and ability to self-direct • Client advocacy skills 	
Desirable	<ul style="list-style-type: none"> • Knowledge of nursing governance principles 	IV/AF
Key Attributes		
Essential	<ul style="list-style-type: none"> • Ability to relate to people from diverse backgrounds and cultures • Motivated • Committed and enthusiastic • Able to use own initiative • Works well within a team • Adaptable and flexible approach to work • Willingness to develop new clinical skills • Demonstrate understanding of the relevance and application of nursing research 	IV/AF
Desirable	<ul style="list-style-type: none"> • Excel spreadsheet skills 	IV/AF
Assessment will take place with reference to the following AF – Application Form, IV – Interview, P – Presentation, T-Test, C Certificate		