Paediatric Metabolic Disease Clinical Nurse Specialist Job Description & Person Specification –

A summary of the role responsibilities and person specification



Why Our Trust?

Terms and conditions

Post - Paediatric Metabolic Disease Clinical Nurse Specialist

Division - Women's and Children's

Department – Paediatric Metabolic Disease

Band – 6

WTE - 1.00

Location - Bristol Royal Hospital for Children

Annual leave – Up to 33 days pro rate dependant on NHS Service

Pension - The NHS Pension Scheme is a defined benefit scheme. Further details and outline of benefits can be found at: www.nhsbsa.nhs.uk/pensions

Job Purpose

The post holder will work as an important member of the Metabolic Multidisciplinary Team within University Hospitals Bristol and Weston NHS Foundation Trust. The post holder will provide specialist nursing advice and support to paediatric metabolic disease patients (in-patient and out-patient) and their family, throughout the care pathway.

The post holder will utilize skills of clinical expertise, education, and management to ensure a seamless service for patients, carers and staff.

They will work closely with the multidisciplinary team in hospital and the community to ensure a coordinated quality service and will be actively involved in education, audit and research.

They will work within the paediatric metabolic CNS team to develop and support the care of metabolic patients including patients with CLN2 Batten's disease, lysosomal storage disorders, Barth Syndrome and many other conditions. They will provide clinical care including inpatient investigations e.g, fasting assessments, administration of infusions e.g. enzyme replacement therapy and outpatient investigations e.g. continuous glucose monitoring.

About us

Our mission is to improve the health of the people we serve by delivering exceptional care, teaching and research every day.

What you'll love about working here

UHBW has been rated by the CQC as 'Good' - our staff are proud to deliver excellent care. As a forward-thinking multi-award winning Trust, our world-leading research and innovations are having a positive local and global impact. Our hospitals are spread across Bristol and Weston-super-Mare, join us and you can enjoy the very best of both worlds; city living within a stone's throw of the countryside or beside the seaside, both with easy access to all that the South West has to offer.

A digital exemplar- Being appointed as a Global Digital Exemplar means we can realise this vision by implementing digital technologies that will help us to transform the way we work and how we relate to our colleagues, patients and partner organizations.

Sustainable healthcare - We have joined the international movement to declare a climate emergency, recognising the impact climate change is having on the world. Climate change is labelled as the greatest threat to health in the 21st century, with a range of conditions related to heat, cold, extreme weather and air pollution predicted to rise. To lead the way in healthcare the Trust has set ambitious goals to become carbon neutral by 2030.

Access to further opportunities with the Trust - Apprenticeships are a great way to learn and earn on the job. UH Bristol and Weston provides a range of apprenticeships to support a huge number of career opportunities in clinical and non-clinical support services with apprenticeships starting at level 2 through to level 7._As an organisation we encourage further development of all employees to progress upward within their chosen field.

Diversity & Inclusion

A core principle of the Trust is to ensure that patients and staff are treated with dignity and respect. Promoting equality, diversity and human rights and challenging any form of inequality, discrimination, harassment or abuse are central to the Trust's Values.

'Committed to inclusion in everything we do' is the ambition set out in the Trust's Workforce Diversity & Inclusion Strategy. The Trust will not tolerate discrimination, harassment or bullying under any circumstances and particularly because of a characteristic protected by the Equality Act 2010.

We are supportive respectful innovative collaborative. We are UHBW.











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Main Duties and Responsibilities

Communication and Relationship skills:

- Demonstrate politeness, courtesy and sensitivity in providing compassionate care for patients, visitors/relatives and colleagues.
- Contribute towards sharing good practice within the multidisciplinary team.
- Promote a positive image of UHBW Trust at all times.
- Work cohesively with all members of the multidisciplinary team and promote effective liaison with the team in ensuring that the very best services to patients are provided at all times.
- Communicate effectively within the multidisciplinary team, participate in motivating and supporting team members and maintain confidentiality with patients and carers. Give written and verbal advice/teaching to patients and carers.
- To develop links and work closely with relevant charities and patient networks.
- Gives clear and consise information on the management of the unwell child with metabolic disease, escalting the wider MDT for support and guidance.

Patient Care:

- To provide patients and staff with specialist advice to manage complex symptoms
- To develop, improve, and promote the service ensuring the delivery of high quality, cost effective care utilising the support and guidance of senior colleagues
- To develop and share expertise within the multidisciplinary team
- To develop the skills to act as a resource in the care of patient's needs, ensuring an optimum level of service to patients and their carers.
- To work closely with other hospitals and community staff to ensure an effective seamless service.
- To build up a skill set to embed patient and public involvement within the sphere of specialist nursing practice.
- To ensure that all patients and families are aware of all treatment options, including clinical trials
- To work as patient advocate, to help negotiate the patient journey and ensure optimum care is provided to each patient.

Organisational Structure

Lead Paediatric Metabolic disease Clinical Nurse Specialist

Paediatric Metabolic Clinical Nurse Specialist

Key Relationships

Lead Paediatric Metabolic disease CNS, Metabolic CNS team, Paediatric Metabolic MDT-Consultants, CNS team, pharmacist, dietitians, biochemists. Neurometabolic junior doctors. Ward nursing staff and ward sister. Paediatricians, community children's nurses.













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- To adhere to infection control guidelines and procedures.
- To act as a positive role model for nurses in the hospital through the demonstration of excellent communication and clinical skills.
- To work clinically, as part of the nursing team, to share experience, knowledge and expertise
 and role modelling to more junior staff..
- Through supervision and support develop the skills to analyse and respond to complex clinical situations utilising specialist knowledge to assess a range of options to formulate solutions and recommendations.
- To support patient investigations and care including CNS led investigations and patient infusions e.g. enzyme replacement therapy
- To coordinate and plan patient assessments as per care plans and national monitoring e.g.
 NICE managed access agreements
- To provide cross cover to the Paediatric Metabolic, Batten's and Barth Syndrome CNS service
- To assist with monitoring of patients undergoing intraventricular infusions
- Administer medicines in accordance with trust policy
- Promote a clean environment and the prevention of hospital acquired infections
- Respond positively and act promptly to resolve problems/issues for patients/carers utilising complaint procedure and PALS where appropriate
- Identify, record and report all incidents/complaints involving staff, patients and visitors in accordance with the UHBW NHS foundation trust policies and assist in any investigations as required

Professional Development and Education Responsibilities:

- To participate in the planning and delivery of formal and informal education programmes for patients, carers and all staff.
- To participate in education forums locally.
- To participate in individual performance review annually.
- To ensure that professional knowledge and practice is constantly updated
- Takes personal responsibility for life-long learning and personal development through clinical supervision, appraisal and Knowledge and Skills Framework
- To participate in CNS team development

Leadership and Management:

- Planning the provision of day to day organisational tasks
- With support, manage a caseload based on flexible principles, prioritises and the care needs of patients.
- In conjunction with their line manager develop the skills to provide an initial response to complaints and queries, and have a working awareness of the UHBW NHS Trust's complaints procedure.
- Maintain accurate and concise records that produce statistical data for the purpose of evaluation and development of the service.
- To keep accurate and up to date patient records.
- Actively engages with appropriate agencies to contribute expertise and experience
- In partnership with the line manager develop the skills to provide specialist nursing advice and support to patients including their families.
- To assist in the development of evidence based policies and procedures relating to the speciality
- To assist in the development of quality initiatives such as audit, evidence based practice and risk management within a culture of continuous quality improvements.
- To practice in accordance with current policies and procedures of UHBW NHS Trust
- To act as a change agent, using appropriate communication skill that will motivate and reassure staff through negotiation and training, to facilitate the change process.
- The post holder may be required to order supplies as advised and/or safely use equipment
- To record all patient related work to ensure this is commissioned correctly.
- To actively contribute to trust wide and divisional CNS work e.g. PANDORA, CNS away days, annual job plan reviews, and annual reports













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University Hospitals Bristol and Weston NHS Foundation Trust

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Research Responsibilities:

- Demonstrate and promote an understanding of the interplay between research and practice to ensure patient care is supported by good evidence and continues to improve
- Demonstrate the ability to access up-to-date evidence and critically analyse this to inform care practices
- Learn to identify gaps in knowledge and discuss these with relevant teams as possible areas for research or clinical audit
- Contribute to an ethos of striving for excellence through promotion of an enquiry-based culture
- Be informed regarding the research studies being undertaken within clinical specialty and support these through:
 - knowledge of inclusion/exclusion criteria and referral of suitable patients to research team
 - provision of appropriate space for research team to see patients
- Facilitate patient and staff involvement in research studies where appropriate as part of promoting excellent care through research, by:
 - assisting in the collection of research data when part of usual clinical care, following relevant training
 - ensuring the delivery of research intervention when part of usual clinical care, following relevant training













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Personal Profile - (E) = Essential (D) = Desirable

Knowledge and Experience

- Appropriate post registration experience in nursing E
- Appropriate post registration speciality experience D
- Appropriate proven leadership and management experience E
- Proven commitment and experience, evidence in teaching E
- Experience of undertaking research or audit projects D
- Evidence of commitment to research based practice or evidence of project work undertaken
 D

Aptitudes

- Respecting Everyone E
- Embracing Change E
- Recognising Success E
- Working Together E

Qualifications and Training

- RSCN/ RN Child Branch- E
- Current NMC Registration E
- 1st Degree In nursing or health related subject, willing to undertake/ working towards E
- Relevant accredited post registration qualification at level 3 E
- · Qualification in Teaching and Assessing E
- Willingness to work towards Masters level academic study D
- Clinical skills e.g. venepuncture, cannulation D

Skills and Abilities

- Organisation and management skills E
- Teaching E
- Ability to work effectively under pressure E
- Ability to problem solve E
- Flexibility, adaptability to meet needs of a changing service E
- Ability to work alone or as part of a team E
- Ability to cope with emotional issues presented in the course of work, and to support others E
- Knowledge of national and local specialty specific issues E
- IT skills including use of email and Microsoft office packages E
- Act as a role model and as a mentor/assessor E
- Innovative and participates with practice and policy change E
- Awareness of professional responsibilities to self and others E
- Commitment to the development and provision of high quality nursing care E
- Excellent interpersonal and communication skills E
- Awareness of current national changes in nursing / NHS E
- Ability to develop own clinical skills and a willingness to participate in continuing professional development – E
- Recognition of own limits E

Public Sector Language Competency

- Be able to speak fluent English to an appropriate standard E
- (E) = Essential
- (D) = Desirable













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Transforming Care

Delivering sustainable healthcare services to our patients, which are effective, efficient and driven by excellence, is at the heart of our organisation. Transforming Care is the Trust's overarching programme of transformational change. It enables staff to use a structured approach to continuously improve and innovates their services, strengthen our capability, and deliver our Trust's mission to improve the health of the people we serve by delivering exceptional care, teaching and research, every day.

Our Quality Improvement Academy is open to all staff and leaders across the Trust, and provides training to lead or take part in improvement and transformation activities in their departments and across the Trust. We will support staff to develop the skills and tools to improve services to deliver the best care to our patients and public.

Information Governance

It is the responsibility of all staff to respect the confidentiality of patients and staff, as specified in the Caldicott Principles, Data Protection Act 2018 and the Human Rights Act. It is the duty of every employee to:

- Only access person identifiable information as required in the execution of their duties.
- Disclose information appropriately, in line with the Data Protection Act 2018.
- To ensure good quality data by recording, promptly and accurately, clinical and non-clinical information within agreed timescales to PAS, the health record or the appropriate clinical or nonclinical information system
- Always trace patient notes on the Patient Administration System

Maintain the confidentiality of their passwords / usernames and if in possession of a 'Smartcard' abiding by the terms and conditions of its use.

Workplace Wellbeing

The Trust Workplace Wellbeing Framework encourages all colleagues to look after their own wellbeing as well as supporting the wellbeing of colleagues. Line managers will oversee the wellbeing of their team, making wellbeing a priority when considering ways of working and will undertake regular health and wellbeing conversations that are supportive, coaching-style one-to-one discussions focused on building team resilience. To assist this, the Trust offers comprehensive wellbeing provision for employees, students, volunteers and managers.

Safeguarding Children and Vulnerable Adults

The Trust is committed to safeguarding and promoting the welfare of all children, young people and vulnerable adults, and as such expects all staff and volunteers to share this commitment.

Quality and Clinical Governance

Quality in the NHS has three core dimensions: Patient Safety, Patient Experience and Clinical Effectiveness. Clinical Governance is about the systems, processes and behaviours to ensure that high quality services are provided to patients. Every member of staff has a role to play in striving for excellence: it is important that everyone is aware of and follows policies and procedures that govern their work; and if something goes wrong, everyone has an obligation to report it so lessons can be learned from mistakes, incidents and complaints. If any member of staff has concerns on any clinical governance matters, they should raise them with their line manager, professional adviser, or a more senior member of management. Reference should be made to the Trust's guidance on Raising Concerns about provision of patient care.

Health and Safety

Under the provisions contained in the Health and Safety at Work Act 1974, it is the duty of every employee to:

- Take reasonable care of themselves and for others at work
- To co-operate with the Trust as far as is necessary to enable them to carry out their legal duty
- Not to intentionally or recklessly interfere with anything provided including personal protective equipment for Health and Safety or welfare at work.

Everyone has a responsibility for contributing to the reduction of infections.

Senior Management is responsible for the implementation throughout the Trust of suitable arrangements to ensure the health, safety and welfare of all employees at work and the health and safety of other persons who may be affected by their activities. Where health and safety matters cannot be resolved at Senior Management level the appropriate Executive Director must be notified.

Line Managers are responsible for the health and safety management of all activities, areas and staff under their control. This includes responsibility for ensuring risk assessments are completed and implementation of suitable and sufficient control measures put in place. Health and safety issues are dealt with at the lowest level of management practicable. Where health and safety matters cannot be resolved at a particular management level the appropriate Senior Manager must be notified.











