

## Role of the Paediatric Nurse with an Interest in Congenital Heart Disease

### Network

The North West, North Wales and Isle of Man Congenital Heart Disease Network, together with all providers of CHD care are striving towards meeting NHS England CHD Standards (2016). They are responsible for ensuring that all patients receive care from staff who have the appropriate skills and training to ensure a high level of care is delivered as close to the patients home as possible.

### The vision and aims of the network are:

- For all individuals and families affected by CHD to have equal access to high-quality specialist CHD care over their whole lifetime pathway, in accordance with the accepted NHSE CHD standards.
- For as much of this care as possible to be delivered locally, provided the same standard of care can be achieved, through a seamless network model according to established best practice guidelines.
- To facilitate evidence-based improvement in quality of care and patient/family experience across all patient pathways, through collaborative research and clinical audit against published standards.
- Effective communication between all network partners to facilitate shared learning and problem solving on all aspects of service delivery, including clinical governance and patient safety.
- Best use of NHS resources through streamlined, cost-effective care with reduction of duplication.
- Effective engagement as partners with other CHD networks and external bodies in the interests of the national CHD service.

The CHD Network Board acts as the body responsible for overseeing the implementation of the national CHD review, as agreed with NHS England.

### Definition of Role

Paediatric Cardiac link Nurses are defined as qualified nurses, working in clinical areas within the Network who take responsibility for participating in the care of patients with congenital heart disease. They will develop relationships with staff in the specialist centres, with the aim of improving communication channels and facilitating education of other staff within their area of work.



The Paediatric Cardiac Link Nurse's usual place of work may be a hospital ward, neonatal unit, community, outpatients or palliative care environment and they will encounter patients with congenital heart disease and their families.

## The Paediatric Cardiac Link Nurse responsibilities will include:

### Clinical

- Participate in congenital cardiology care. They will not be expected to undertake the role of a Clinical Nurse Specialist (CNS) but have a role providing advice, support, signposting and an understanding of the congenital heart disease network
- Be confident in undertaking the assessment of a patient with congenital heart disease in terms of clinical observations as appropriate - blood pressure, oxygen saturations, height, weight, NYHA classification
- Work alongside the Cardiac Nurse Specialist, Congenital Cardiologist and/or Paediatrician with clinical expertise in cardiology (PEC) and will provide additional support with regards to the patient's onward treatment plan. This may be in the community, at the clinic or on the ward.
- Work as a core member of the cardiac team, liaising with young people, their parents/carers, Paediatric CNS, Adult Congenital Heart Disease (ACHD) team, and wider MDT to facilitate the effective and timely transition from paediatric to adult services.

### Provide high quality information and support to patients with CHD & their families

- Ensure patients and families can access up to date relevant cardiac information and signpost to available websites
- Provide information about facilities and resources at the specialist surgical centre relating to cardiac surgery, cardiology interventions, transition and transfer from paediatric to adult services.
- Provide support for patients with learning disabilities.
- Provide contact details to patients & families for CNS teams in the specialist cardiology or surgical centre as appropriate who will be able to provide more specific advice and detailed support.
- Be able to identify congenital heart disease patients in the network and provide appropriate support.

### Education

- The Paediatric Cardiac Link Nurse will develop their knowledge and skills by visiting the specialist cardiology and/or surgical centre, congenital heart disease



outpatient clinics, multidisciplinary team meetings and the cardiac ward for a minimum of 30hrs per year.

- Training may be via a mixture of CHD specific education including CPD and onsite training at the specialist surgical or cardiology centre. This will enable the Link Nurse to develop a broad understanding of the patient pathway.
- Participate in educational opportunities on the development, diagnosis and treatment of congenital cardiac conditions.
- Attend specialist training hosted by the specialist surgical and/or cardiology centre, Congenital Heart Disease Network, national conferences and stand-alone paediatric congenital study days.
- Be able to access the network website for up to date clinical guidelines.

## Management

- Participate in service developments within the CHD Network.
- Facilitate educational opportunities for other nurses working in their area of practice.
- Work closely with the local clinical educators to facilitate CHD education for staff in their centre.
- Develop resources for local staff such as teaching boards, education files & signposting to relevant web-based materials.
- Support and share practice with other Paediatric Cardiac Link Nurses by attendance at the Network Link Nurse Forum hosted by the Network.

## Professional Support

Paediatric Cardiac Link Nurses will be offered professional support relating to congenital heart disease by the Lead Nurse for the Network, Cardiac Nurse Specialists and senior ward staff based at the specialist surgical and cardiology centres. This would be offered by:

- Study days
- Opportunities for shared learning/debrief
- Rotation/shadowing at the specialist cardiology and/or specialist surgical centre
- Learning bursts/short teaching sessions from the CNS and/or Lead Nurse for the Network
- Regular contact with the Network Specialist Cardiologist and/or local PEC
- A named mentor to be allocated to support progress through the link nurse competencies

The designated point of contact for the Paediatric Cardiac link Nurse will be via a named mentor which may be either a Clinical Nurse Specialist, Lead Nurse for the Network or a senior nurse from the specialist surgical or cardiology centre.

## Relevant Sections of National CHD Standards 2016

[www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf](http://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf)

A17 (L3)	Each Local Children's Cardiology Centre must have identified registered children's nurses with an interest and training in children's and young people's cardiology	Within 1 year
B2 (L3)	Local Children's Cardiology Centres must have locally designated registered nurse with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people	Within 1 year
B4 (L3)	Each Local Children's Cardiology Centre must have a locally designated 0.25WTE registered children's nurse with a <b>specialist interest</b> to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice	Within 1 year
E6 (L3)	Nurses working within Local Cardiology Centres must be offered allocated rotational time working in the Specialists Children's Surgical Centre to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place	Immediate
17 (L3)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate

Document originally written September 2018 updated June 2020

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