

## Role of the Link Nurse with an Interest in Adult Congenital Heart Disease (ACHD)

### Network

The North West, North Wales and the Isle of Man Congenital Heart Disease Network, together with all providers of ACHD 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 ACHD to have equal access to high-quality specialist ACHD 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

ACHD 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 adult 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 ACHD Link Nurse's usual area of work may be a hospital ward, specialist cardiology teams such as EP or heart failure, community, outpatients or palliative care teams etc. They will be nurses who come into contact with patients with congenital heart disease and their families as part of their normal practice.

## **The ACHD Link Nurse responsibilities will include:**

### **Clinical**

- Participate in ACHD care. They will not be expected to undertake the role of a ACHD 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 as part of their normal role and may include clinical assessment of the patient. All nurses should be able to perform basic observations as appropriate.
- Work alongside the ACHD nurse specialist, ACHD Cardiologist or Cardiologist with a special interest to 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, ACHD CNS, and wider MDT to facilitate the effective and timely transition from paediatric to adult services

### **Provide high quality information and support to patients with ACHD & 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.
- Provide support at the time of transition and transfer of care from paediatric to adult services.
- Provide support for patients with learning disabilities.
- Provide contact details to patients & families of the ACHD team as appropriate and who will be able to provide more specific advice and detailed support.
- Be able to identify ACHD patients in the Network and provide appropriate support.

### **Education**

- The ACHD Link Nurse would develop his/her knowledge and skills by visiting the Specialist Cardiology and/or Surgical Centre(s), ACHD outpatient clinics, multidisciplinary team meetings and the cardiac ward for a minimum of 30hrs per year,



- To access education specific to ACHD including CPD and onsite training at the specialist ACHD surgical or ACHD cardiology centres. This will enable the Link Nurse to have a broad understanding of the patient pathway.
- Participate in educational opportunities on the development, diagnosis and treatment of congenital cardiac conditions as offered by the Specialist ACHD Surgical Centre, Congenital Heart Disease Network, national conferences and stand-alone paediatric and adult congenital study days.
- Be able to access the network website for up to date clinical guidelines.

## Management

- Participate in service developments in the ACHD service
- Facilitate educational opportunities for other nurses working in their area of practice by communicating with the Lead Nurse for the Network & the identified ACHD Nurse Specialist who supports the local services.
- 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 ACHD Link Nurses within the network

## Professional Support

The ACHD Link Nurse will be offered professional support relating to congenital heart disease by the Lead Nurse for the Network, ACHD CNS, ACHD Cardiologists and Cardiologists with a special interest in ACHD. This would be offered by:

- Study days
- Opportunities for shared learning/debrief
- Rotation/shadowing at the specialist cardiology and/or surgical Centre
- Learning bursts/short teaching sessions from the ACHD nurse specialists or Lead Nurse for the Network

The designated point of contact for the ACHD Link Nurse will be via an appointed and named mentor from within the Network.



## 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)

<b>B2(L3)</b>	Each Local ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
<b>B3(L3)</b>	Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
<b>B4(L3)</b>	ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.	Immediate
<b>E5(L3)</b>	Each Local ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Local ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
<b>E6(L3)</b>	Nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.	Within 1

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