

## Role of the Adult Congenital / Congenital Heart Disease (Specialist) Nurse in Level 3 centres

### Background and vision of the Network

The South Wales and Southwest Congenital Heart Disease Network (SWSWCHD Network) was formed in 2016 in response to the NHS England “*Congenital Heart Disease Standards and Specifications*”. [Congenital-heart-disease-standards-and-specifications.pdf \(england.nhs.uk\)](#)

The report set out adult and paediatric standards and service specifications for congenital heart disease services in England agreed by the NHS England Board in July 2015 and effective from 1 April 2016.

The standards cover adult and paediatric care in the Level 1 specialist surgical centre (Bristol), the Level 2 specialist cardiology centre (Cardiff) and the Level 3 (peripheral clinics across the Network) local cardiology centres.

Our vision is to be a Network where:

- Patients have **equitable access** to services regardless of geography
- **Care is provided seamlessly** across the Network and its various stages of transition (between locations, services and where there are co-morbidities)
- **High quality care** is delivered, and participating centres meet national standards of CHD care
- The provision of **high-quality information** for patients, families, staff and commissioners is supported
- There is a strong and **collective voice** for Network stakeholders
- There is a strong culture of collaboration and action to **continually improve** services

The role of the ACHD/CHD nurse in the level 3 centre is key in supporting the Network to deliver this vision.

### Definition of role

The postholder of ACHD/CHD Nurse in a level 3 centre will be a registered nurse with a proven interest in congenital heart disease, working with either adult or paediatric patients. This could be a development post, with progression towards a specialist nurse role and will be at band 6 or 7, depending on competency and experience.

The nurse will develop relationships with staff in the specialist centre (level1), improving communication channels for patients, families and the local teams.

This role outline reflects the NHS England CHD standards and specifications and will normally be part time. The hours required will be dependent on the size of the service and patient caseload.

## Clinical

The ACHD/CHD Nurse will:

- Support or participate in the congenital cardiology clinics, working alongside the visiting specialist and local consultants to provide additional support with onward treatment plans, and enable the cardiologists to see more patients. The nurse will also provide support for patients between appointments as appropriate.
- Provide high quality information and support to patients with CHD and their families and ensure that they are signposted to and can access up to date relevant information and websites which would be available in level 1 and 2.
- Ensure that patients can have appropriate tests carried out at the local hospital and have access to local teams for support to ensure care is delivered as close to home where possible.
- 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 and signpost to support for patients with learning disabilities.
- Be able to identify and support the high-risk congenital heart disease patients in the local centre and signpost to appropriate additional support.
- Support in-patients with CHD and their families, if admitted to the level 3 centre, and liaise with the team at the Specialist Cardiology or Surgical Centre (Cardiff or Bristol), to ensure that the teams have access to specialist advice.
- Provide a point of contact for local patients for non-urgent advice. This could be by means of a telephone advice line, mobile phone or email. If this is a part time role, patients will be given contact details of the Clinical Nurse Specialist team at the Specialist Centre (see below).
- Provide contact details to patients and families for Clinical Nurse Specialist, paediatric or adult teams in the Specialist Cardiology or Surgical Centre who will be able to provide more specific advice and detailed support such as: pre-pregnancy counselling and contraception for CHD patients, lifestyle advice and support and also support for patients and families with end-of-life care which will build on the initial advice given in the Level 3 centre.

- Participate in the Transition and transfer pathway from age 12yrs to 24yrs to ensure a seamless transfer of care and minimise lost to follow up. In addition to clinical information, Lifestyle advice and support will be given.
- Provide information about the Youth Worker and psychology services as refer as appropriate for additional support, working with them for the best outcomes for the patients.

### Education

The ACHD/CHD nurse will:

- Develop their knowledge and skills by visiting the Level 1 Centre, CHD outpatient clinics, paediatric or adult congenital joint cardiac case conferences and cardiac wards. This will enable them to have a broad understanding of the patient pathway. Virtual opportunities for participating in meetings and joint cardiac conference are available
- Participate in educational opportunities on the diagnosis and treatment of congenital CHD conditions as offered by the Specialist Surgical Centre, CHD network, national conferences, university run CHD masters modules, and stand-alone paediatric and adult congenital study days
- Be able to access the network website for up-to-date clinical guidelines and education opportunities [www.swswchd.co.uk](http://www.swswchd.co.uk). Ensure these are shared with, and available for the local teams
- Demonstrate a level of clinical competence and knowledge about congenital heart disease. Competencies for this role should be completed and can be found on the website,
- Deliver education to local colleagues and teams and engage with their local cardiology teaching programmes to develop the skills of the wider team and raise awareness of this speciality.

### Management

The ACHD/CHD Nurse will:

- Participate in service developments in the local congenital heart disease service
- Facilitate local education opportunities for other nurses working in the level 3 centre. Communicate with the Lead Nurse for the Network & the Cardiac CNS who supports the level 3 centres

- Work closely with the local clinical educators to facilitate education of staff
- Develop resources for local staff such as teaching boards, education resources and signposting to relevant web-based materials
- Assist in setting up and maintaining a simple, lesion specific database to keep a record of CHD patients in the level 3 centre
- Support and share practice with other link nurses within the local area through network led activities and events
- Support /lead on local service development in line with network protocols and national guidance, ensuring that local patients receive a high standard of care.

### Professional support

ACHD/CHD Nurses will be offered professional support relating to CHD by the Lead Nurse for the Network, Cardiac CNS' and PEC(s) (Paediatrician with Expertise) /Adult Consultant with an Interest in CHD). This would be offered via:

- Network nurse study days
- Opportunities for shared learning/debrief
- Rotation/shadowing at the Specialist Cardiology/Level 2 and/or Surgical Centre/Level 1 centre
- Regular contact with the local PEC or Adult Consultant with an Interest in CHD

### Audit

- Respond to Network requests for local information and data
- Undertake/lead on basic audit with the local team
- Obtain local patient feedback and use for service development