

# Congenital Heart Disease and Paediatric Cardiac Clinical Network Specification



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## Executive Summary

Patients are best served when the whole system works together and Paediatric Cardiac and Adult Congenital Heart Disease networks are well placed to facilitate collaborative working, bringing together commissioners, providers and patients in the design and delivery of high quality services. Services for both children and adults are covered by a single network.

In 2015, the NHS England Board agreed standards for CHD covering the entire patient pathway, for children and adult, from diagnosis through to treatment and then on into care at home. It is a requirement of these standards that these services are delivered as part of an all-age provider network, supported by funded clinical networks. Paediatric Cardiac and Adult Congenital Heart Disease Clinical Networks are, in turn, responsible for ensuring that these standards are implemented so that patients across the country have equitable access to high quality services.

The requirements for these networks are described in this specification.

## 1. Clinical Networks

Specialised services Clinical Networks<sup>1</sup> are a vehicle for specialty level collaboration between patients, providers and commissioners. They should have clear lines of accountability with Integrated Care Boards (ICBs) including providers and provider collaboratives, and to NHS England (NHSE) Regional Teams, to ensure local ownership, alignment and a local mandate.

All networks have an important role in delivering the triple aim, supporting:

- better health and wellbeing of everyone,
- better quality of care for all patients, and
- sustainable and efficient use of NHS resources

This specification sets out the appropriate scope for the work of Paediatric Cardiac and Adult Congenital Heart Disease Networks. This will inform the development of the annual workplans developed in conjunction with the network's commissioners. No network will, or could, focus on all aspects of the scope described, at one time.

In describing the appropriate scope for networks, these specifications refer to the work of the network board and the network's members, supported by the network team. In describing the appropriate scope for networks, these specifications refer to the work of the network board

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<sup>1</sup> While some specialised services Clinical Networks have previously been described as Operational Delivery Networks (ODNs), the range of activity undertaken is now significantly beyond that envisaged for ODNs, reaching into non-specialised services, and in some cases primary and community care and prevention. Some are jointly funded as part of national transformation programmes and have accountabilities outside as well as within specialised services. As a result, as a group they are now referred to as specialised services 'Clinical Networks'.

and the network's members, supported by the network team. Networks are not expected to assume the legitimate accountabilities and responsibilities of providers who are accountable for meeting the needs of the Service Specification. However, network responsibilities inevitably overlap with those of providers, because networks aim to improve the ways in which services are delivered operationally and shape how they develop and because providers are members of networks.

## 2. Strategic Context

In 2015, the NHS England Board agreed standards for CHD are covering the entire patient pathway, for children and adult, from diagnosis through to treatment and then on into care at home. Paediatric Cardiac and Adult Congenital Heart Disease Clinical Networks are responsible for ensuring that these standards are implemented so that patients across the country have equitable access to high quality services.

The standards aim to ensure that:

- Every operation or cardiology intervention for CHD patients will be carried out by specialist doctors with a volume of practice sufficient to develop and maintain their skills.
- Resilience will be enhanced through larger level 1 centres, with bigger teams, providing an assurance of full 24 hour seven day specialist care and the ability to cope with challenging clinical events or fluctuations in specialist staffing.
- Care will be delivered as close to home as possible, through networked specialist level 2 centres, level 3 services and outreach clinics, all co-ordinated by a network team.
- Occasional and isolated practice will no longer be permitted, so low volume surgery or interventional cardiology in institutions without sufficient specialist CHD expertise will cease.

Children with heart disease will receive their care in a holistic children's environment so that they can receive optimum care for any non-cardiac clinical problems without either the child or the specialist having to travel to another hospital with the potential compromises involved. Daily interaction between teams will be facilitated, which is particularly important for children with complex conditions and multiple medical needs.

## 3. Network Scope

### 3.1 Scope

The care pathway is described in detail in Service Specifications E05/S/a and E05/S/b.

Paediatric Cardiac and Adult Congenital Heart Disease Clinical Networks encompass all paediatric cardiac services and adult congenital cardiac services – both specialist services delivered by level 1 and 2 CHD centres (specialised services) and care for children with cardiac disease and adults with CHD provided by general paediatric or cardiac services at level 3 centres and other referring hospitals providing within their catchment (not considered to be specialised services).

Each network will cover the whole lifetime pathway of care including the following service areas:

- Primary care
- Fetal cardiology services
- Paediatric cardiac services for congenital, acquired and inherited heart disease including cardiology, specialist cardiac imaging, cardiac surgery, interventional cardiology and electrophysiology procedures
- Transition to appropriate adult services
- Adult congenital heart disease services including cardiology, specialist cardiac imaging, cardiac surgery, interventional cardiology and electrophysiology procedures
- Care of pregnant women with congenital heart disease
- Palliative care

### Out of scope

Adult acquired and inherited cardiac conditions.

## 3.2 Population Covered

All providers of paediatric cardiac and adult CHD services in England are required to be part of one of nine clinical networks which cover the country. The networks are:

### **NORTH EAST AND YORKSHIRE**

North East & North Cumbria Network

Yorkshire & Humber Network

### **NORTH WEST**

North West, North Wales & Isle of Man Network

### **MIDLANDS**

West Midlands Network

East Midlands Network

### **LONDON, EAST OF ENGLAND AND SOUTH EAST (KENT, SURREY AND SUSSEX)**

One Heart CHD Network

Lifelong CHD Network

### **SOUTH EAST (WESSEX)**

Thames Valley and Wessex Network

### **SOUTH WEST**

South West & South Wales Network

**Wales:** While services in Wales are commissioned separately by NHS Wales, residents of Wales receive their level 1 care in England and for this reason hospitals in Wales are also part of these networks.

**Crown Dependencies:** Residents of the Channel Islands and the Isle of Man receive their level 1 care in England and for this reason hospitals in these territories are also part of these CHD networks.

**Scotland & Northern Ireland:** While some residents of Scotland and Northern Ireland receive their level 1 care in England, hospitals in these countries are not part of these networks.

Further information on population need and demographics may be found in Service Specifications E05/S/a and E05/S/b.

## 4. Network Aims and Objectives

### 4.1 Network Vision and Aims

The aims of the networks are to:

- provide leadership to the development of accessible, sustainable, affordable and high-quality services
- take a lead in implementing the standards agreed by the NHS England Board (in both specialist and non-specialist services) to ensure all patients have equitable access to high quality care
- support the development of appropriate capacity and take a 'real time' role in managing capacity and demand at times of service pressure.

### 4.2 Network Objectives

The objectives of the networks are to:

- Improve the short and long term outcomes for patients
- Improve antenatal detection of CHD
- Improve the quality, safety and experience of care across the pathway through the delivery of the national standards of care embedded in the service specification
- Improve equitable patient access to paediatric cardiac and adult CHD services by identifying the required capacity, better balancing capacity and demand and alerting the system when pressure is compromising timely urgent care.
- Support providers and ICBs in restoring CHD services and reducing waits.
- Improve patient and family experience of care
- Support increasing productivity / efficiency of services

### 4.3 Network Functions

#### ***Service delivery: the network's role in planning and managing capacity and demand***

- Develop an approach within the network to managing capacity and demand that:
  - Ensures efficient and appropriate flow of patients along the pathway, managing system capacity and improving system resilience.
  - Ensures that as much care and treatment is provided as close as possible to home and that the patient and their family travel only when essential, while ensuring timely access and the best possible outcome for the patient.

- Monitors numbers of patients waiting and waiting times (for outpatients, diagnostics and procedures) and ensures a network level response if patients with urgent care needs are unable to access that care in a timely way, working with providers and ICBs to seek mutual aid at regional or supra-regional level.
- Alerts commissioners to L1 centres that are 'under strain' and specifically when a lack of L1 capacity is impacting on the network's ability to provide timely local care.
- Ensure the safe and effective transition of young people from paediatric services to adult services.
- Develop and ensure the operation of common referral, care and transfer pathways and other policies, protocols, and procedures across the network.
- Work with providers to ensure that when services are under pressure:
  - Mutual aid arrangements are in place within network, within region and supra-regionally, including diversion of new admissions.
  - Clear agreements are in place for cross site working of surgeons / interventionists; ensuring continuity of decision making / delivery of care
  - IT/digital provision in place for specialist advice (including patient helplines), triage, consultation and MDT provision
  - Up to date information is provided to patients and Level 3 centres using websites, social media etc.
  - Escalates issues not resolvable at network level to UK network group call.

***Resources: the network's role in stewardship of resources across whole pathway and minimising unwarranted variation***

- Reduce unwarranted variation in pathways and processes that lead to inefficiencies.
- Support consistent, network-wide implementation of new approaches to care that offer greater efficiency e.g. phone/video OP clinics, patient-initiated follow-up, remote patient monitoring.
- Improve effectiveness and appropriateness of use of high-cost treatments and consumables.
- Encourage standardisation of drugs, devices etc. used across the network to achieve best value by facilitating collaborative purchasing arrangements to achieve the best price.
- Work with other related networks, flexing use of resources to find efficiencies, target resources for best effect and share insight and experience.

***Workforce: the network's role in ensuring flexible, skilled, resilient staffing***

- Working with key stakeholders, support workforce planning at network and national level, assessing future workforce needs across the network considering projected demand.
- Advise on succession planning for hard to recruit roles.
- Inform and support the development and implementation of extended roles for non-medical staff groups, supported by training and development and network wide policies and procedures.
- Undertake network training needs assessment (including baseline skills audit and network maturity assessment).

- Develop and agree a network annual training plan for ongoing education and professional development across the network for all healthcare professionals involved in the care of people with congenital heart problems.
- To deliver standardised training and competency-based education programmes across the network.
- Enable the movement of staff through the implementation of a staff passport.

**Quality:** *the network's role in improving quality, safety, experience & outcomes*

- Create a culture of ongoing service improvement, undertaking audit and other service improvement activities including reflecting on and responding to suboptimal outcomes, care and patient experience.
- Reduce variations in access, experience and outcomes within and between networks.
- Establish and maintain systems for the collection, analysis and reporting of key indicators of outcomes, quality of care and patient and family experience and ensure data is submitted as required to NCHDA.
- Regularly review clinical outcomes across the network.
- Benchmark services against national peers and share best practice, including through inter-network peer review.
- Produce an annual network annual audit and governance report.
- Review dashboard metrics, outcomes including risk adjusted mortality, morbidity, adverse events and resultant action plans.
- Manage risks to the delivery of the network's annual work programme.
- Ensure all identified service risks are managed through regional and system quality structures following agreed escalation processes.

**Collaboration:** *the network's role in promoting working together across organisations at local, system and national level*

- Develop agreed working relationships and joint referral, care, treatment and transfer protocols with other relevant networks and services.
- Develop an analysis of the network's data and information needs and a plan, agreed with network members to meet these requirements.
- Develop partnership arrangements with all relevant partners including national and local commissioners, providers.
- Agree a plan for patient and family engagement.
- Link network clinical leadership with system, regional and national clinical leadership cadres to support a collaborative approach and shared aims.
- Share best practice with networks covering the same service across the country.
- Work closely with other clinical networks supporting the care of children and young people through the Children's Strategic Forum (CSF) or equivalent, identifying opportunities for shared solutions and resources.
- Work closely with paediatric and adult critical care and cardiac clinical networks to assure the quality of care provided to paediatric cardiac and adult congenital heart disease patients.
- Actively participate in and support the national network of networks.

**Transformation:** *the network's role in planning sustainable services that meet the needs of all patients*



- Ensure that nationally set specifications and standards of service are consistently met across the network.
- Working with NHSE and relevant ICBs provide recommendations on the need for level 3 services (paediatric and adult) and to support their operation and development.
- Apply improvement and redesign methodologies to all aspects of the network's work to deliver ongoing quality and service improvement.
- Develop an approach to working with patients and families so that patient views inform plans for transformation, to ensure optimal service provision for patients.
- Undertake systematic clinical audits and ensure shared learning across the network.
- Develop a research strategy and programme that documents current and planned research activity.
- Participate in national, regional, and local research and audit across all clinical disciplines and share findings.
- Support the early and systematic adoption of innovation and research across the network.
- Develop and maintain close links with one or more academic department(s) in Higher Education Institutions.

***Population health: the network's role in assessing need, improving inequalities in health, access, experience and outcomes***

- Identify health service needs of children with heart disease and adults with congenital heart disease, taking account of the changing demographic of CHD patients and changing patterns of care.
- Review service provision across the network against identified need and identify gaps.
- Plan and deliver improvements to network services to address identified gaps.
- Develop and implement network pathways, protocols to reduce variation in service delivery.
- Work with maternity services to increase the proportion of congenital heart disease identified antenatally.

## 4.4 Annual workplan

The network board will agree an annual workplan with its commissioners. This will reflect national, regional and local priorities, taking account of the resources available to support delivery. The workplan will describe its expected deliverables and benefits.

The network board will publish an annual report detailing its activities, accounts and delivery against the agreed annual plan.

## 5. Governance

### 5.1 Accountability

#### Hosting

CHD networks are hosted by an agreed lead provider, but operate at arm's length, for the benefit of the network and not the host organisation. Where the level 1 service is split between more than one provider, the identity of the network host will be determined by mutual agreement with regional commissioners.

### Accountability and responsibility

Network footprints reflect patient flows, provider scale and catchments so will often cut across commissioner boundaries (ICB and regional). Governance arrangements must provide clear accountability to commissioners at system level (with links to all relevant ICBs) and region as appropriate for both network delivery and commissioning responsibilities. Local arrangements to achieve this should be clearly documented within the network's terms of reference.

Networks will be responsible to ICBs for the management of local pathways and delivery of locally agreed targets. This should be set out in memoranda of understanding between ICBs, providers and the network.

The network will be accountable to the regional team of NHSE via the appropriate board within the Region including any multi-ICB decision bodies established.

A single network plan and deliverables should be agreed with all ICBs within the network's geography and signed off by the region. Networks will be expected to provide regular reports and have regular reviews with NHSE regional teams.

Paediatric Cardiac and Adult Congenital Heart Disease networks should participate in the relevant Strategic Children's Forum(s) (or equivalent) which ensures strategic alignment across paediatric networks and services.

The network's authority to act on behalf of its commissioners and members will be set out clearly within the network memorandum of understanding and where necessary clarified within the agreed annual plan.

## 5.2 Network governance and architecture

### Members and stakeholders

Networks are required to have a formally constituted governing body or board, which is accountable to the network's commissioners for delivery of the network's agreed programme, with a line of sight to all ICBs whose patients use the services of providers within the network.

Network boards should include balanced representation from member organisations and other relevant stakeholders, including patient representatives and third sector organisations.

Clinical representation should cover the whole multi-disciplinary team and pathway of care.

The network should develop an approach to working with patients and families that ensures patient views inform its whole work programme and ensure optimal service provision for patients.

Patients and families are key partners and should be represented on the network board. Patient and family involvement should be supported to contribute to all aspects of the work of the network.

### The board

The board should meet on a regular basis and operate under the oversight of a suitable chair with agreed terms of reference.

The chair will be an appropriately experienced, impartial leader who is credible across the whole network and will be appointed through a fair and open process.

- The chair should not be the network clinical lead, and ideally should not have the same main employer as the Network Clinical Lead in order to mitigate the risk of (real or perceived) conflicts of interest.
- They could be a board member or senior clinician from one of the provider organisations in the network (ideally not the host, to underpin the collective nature of these arrangements) or a patient representative where a suitable candidate is available.

### 5.3 Risk Management and risk sharing

Networks do not manage risk independently but within a system of national, regional and system level arrangements. Networks support risk identification, assessment, mitigation and may facilitate any agreed response.

Specific local risk management arrangements and governance processes should be managed locally through MOUs/ SOPs etc which are clear and signed off. Escalation processes for risks within a system should be clear and explicit, with any quality concerns escalated through agreed systems and regional processes.

### 5.4 Interdependent Relationships

**Interdependencies** for the service are described in Service Specifications E05/S/a and E05/S/b and the congenital heart services standards.

Paediatric cardiac and adult CHD networks will work closely with a range of networks and services to ensure that consistent, joined up pathways are developed:

- fetal medicine networks
- local maternity services and maternity clinical networks
- neonatal critical care networks including neonatal transport
- paediatric and adult critical care networks
- cardiac networks / The National Cardiac Pathways Improvement Programme (CPIP).
- surgery in children clinical networks
- inherited cardiac conditions services
- cardiothoracic transplant centres
- the national pulmonary hypertension service

community paediatric services in their network.

## 6. Resources

Network funding provided to the host is ring-fenced for the network programme of work.

Each network should have a team to support its work that provides clinical leadership, management and administrative support. Networks should also have arrangements for

analytical and business intelligence support. Commissioners must ensure as part of the annual planning process that the scale of resource made available to networks is sufficient to support the agreed programme of work. The capacity of the network to deliver its programme of work does not reside solely in the network team but also in the support of all network members including its commissioners.

As part of the annual planning process, commissioners must ensure that:

- the scale of resource made available to networks is sufficient to support the agreed programme of work
- networks have access to the data they need and the analytical capacity and capability to turn this into actionable improvement programmes

Roles such as administration, network management and analytical support may be appropriately combined across CYP networks, with further opportunities to increase the value from these investments, share learning across networks and improve the sustainability of networks through the provision of a pool of staff to support specialised services Clinical Networks across a region.

## 7. Deliverables, Service Indicators & Outcomes

Indicators and metrics of network performance come from three principal sources:

### 1. Generic indicators of a well set up, well-functioning network

- There is an appropriate network management team in post with the skills to deliver the specification
- The network board meets at least three times per year, is quorate, and minutes, actions and risks are recorded
- There are regular network specialist Multi-Disciplinary Team (MDT) meetings
- There are IT facilities in place that enable communication across the network, supporting image transfer and remote participation in the MDT.
- There is an annual workplan agreed with the network's commissioners
- There is an agreed plan for PPV engagement
- There is an analysis of the service needs of the population served by the network, a gap analysis and a plan, agreed with the network's commissioners to meet those needs
- There are network agreed patient pathways, procedures and protocols
- There is an analysis of workforce requirements and a plan, agreed with network members to meet these requirements
- There are arrangements (for example passporting) that enable workforce flexibility between providers within the network.
- There is an analysis of training needs, and an annual network training plan agreed with network members
- There is an analysis of the networks data and information needs and a plan, agreed with network members to meet these requirements
- There is a network agreed research strategy including access and participation in clinical trials

- The annual workplan includes at least one quality improvement initiative
  - An annual report is produced, summarising the work of the network and its outcomes. The report includes a financial statement
  - The network participates in the national network of networks
2. Nationally agreed indicators and outcomes for all networks of this specialty, for example as defined by a national transformation programme, or included in the service specification and delegated to network leadership.

Each network should have a comprehensive set of agreed joint referral and care protocols:

- Elective referral for cardiac surgery
- Elective referral for cardiac catheter intervention and diagnostic procedures
- Elective referral for cardiac electrophysiology or pacing procedures
- Urgent referral for management of patent ductus arteriosus (PDA) in premature babies
- Emergency balloon atrial septostomy and temporary pacing outside of a L1 provider
- 24/7 specialist advice including pre-operative risk assessment for patients requiring anaesthesia for non-cardiac surgery or other investigations.
- Management of patients who self-refer out of hours.
- Access to second opinions and referrals to other centres/services.
- Collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.
- Retrieval, transfer and repatriation arrangements for neonates, children and adults with suspected or confirmed congenital heart abnormality
- Referral to advanced heart failure and cardiac transplant services
- Referral to national pulmonary hypertension service
- Network access to cross-sectional imaging.
- Arrangements for the early (pre-natal) diagnosis of congenital heart disease that meet the relevant NHS Fetal Anomaly Screening Programme Standards.
- Arrangements for care of women whose fetus has been diagnosed with a major congenital heart abnormality including delivery at the most appropriate unit
- Arrangements for urgent dental assessments for congenital heart disease patients as required
- Establish formal policy for transition from paediatric to adult services across the network
- Evidence of monitoring of lost to follow up rates and response (2 years)
- Palliative care arrangements
- Care of the woman with CHD who is pregnant

3. The network's individual locally agreed annual workplan, which should build in metrics and indicators for each element.

The network board will agree an annual workplan with its commissioners which will include the expected in year deliverables along with the indicators that will demonstrate effective network operation.

## 8. Further support and information

Paediatric cardiac and adult congenital heart services service specifications and standards, NHSE, 2016 available at: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05/>

Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements, NHSE, 2017 available at: <https://www.england.nhs.uk/wp-content/uploads/2017/11/06-pb-30-11-2017-congenital-heart-disease-services.pdf>

The full suite of materials covering what clinical networks do, commissioning of specialised services clinical networks and the clinical networks operating model together with model materials for use by networks and their commissioners can be found on the Future NHS website here:

<https://future.nhs.uk/NationalSpecialisedCommissioning/view?objectID=34094320>

Access requires membership of the site and permission to access the workspace. This is straightforward for all NHS employees.