



Operational Policy

2021/22

Document History

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Introduction

The North East and North Cumbria Congenital Heart Disease Network (NENC-CHDN) covers a population of 2.9 million people in the North East and North Cumbria, and is hosted by the Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH).

NUTH forms part of the national Congenital Heart Disease (CHD) Service commissioned through NHS England Specialised Services and is part of the Cardiothoracic Directorate based at the Freeman Hospital providing care to both adults and children as a Level 1 Specialist Surgical Centre (SSC).

The Network aims to provide services in line with the agreed standards of care which operate within a Network Model encompassing the whole lifetime of care. The Network will support the Level 1 SSC and work collaboratively with the peripheral centres in the region to develop and support national, regional and network arrangements that facilitate mentorship and centre-to-centre referrals.

This document outlines the aims and objectives of the Network, and highlights the priorities to meet the Standards and Service Specification for CHD services in England, as agreed by NHS England¹.

Network Objectives

Our Network vision is;

“to provide high quality, equitable care for congenital heart disease patients wherever they live within our region; provided closer to home when possible, ensuring seamless transition between fetal, paediatric and adult services and providing a holistic approach to care”

We aim to deliver on this vision through a number of objectives to;

- Deliver a formalised CHD Network across the North East and North Cumbria
- Provide direction and develop a Network Strategy
- Ensure equitable access to CHD services for all patients
- Work towards meeting the service standards
- Improve and support patient and family engagement
- Provide a high-quality service and develop a Quality Improvement Policy
- Promote research activities in all centres and affiliated universities within the network
- Effectively communicate within all centres of the network

¹ <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf>

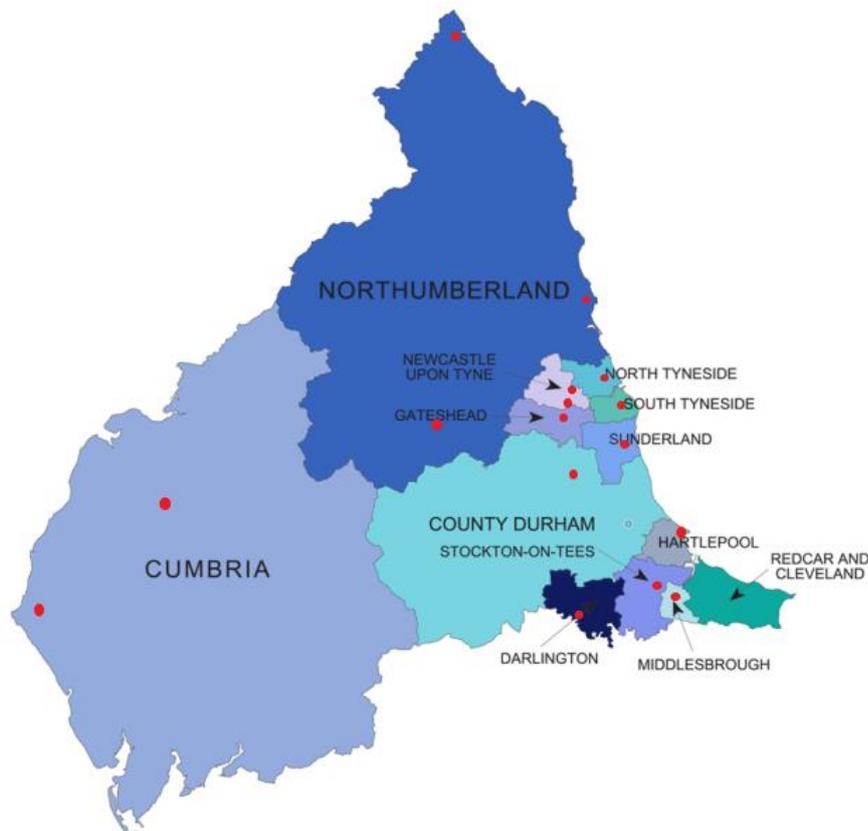
- Support education, training and development of all professionals within the network

Scope of the Network

The Network was formally launched as an Operational Delivery Network (ODN) in January 2020 in line with the NHS England CHD Standards and Specifications², building on a long history of hub and spoke service provision and clinical networking across the region.

As the Level 1 SSC, NUTH will be at the heart of the Network providing support to all referring hospitals across the North East and North Cumbria. Currently there are no Level 2 or Level 3 centres within the Network and it is our focus to assess each centre against the national standards to accomplish Level 2 or 3 status and work with them to achieve their service improvement ambitions.

Regional map covered by the North East and North Cumbria CHD Network



The Network covers the whole lifetime of care of patients with CHD, and their families, including prenatal diagnosis, maternity, obstetric and neonatal services, children's services, transition, adult congenital cardiac services and palliative care; providing a

² <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf>

single network for both children and adults. The Network will work with the host centre to forge close relationships with the relevant specialties across all centres to ensure this is achieved.

Our Population

We provide care for children with both congenital and acquired heart disease and adults with congenital heart disease to a population of 3.2 million across the North East and North Cumbria.

Paediatric Cardiology (<18 years)

Currently there are 11588 children with CHD under the care of NUTH the majority of whom are seen at the Freeman Hospital and a smaller proportion are followed in peripheral joint clinics. Around two thirds have a diagnosis of CHD with others having arrhythmic or myocardial disease or simply being investigated for innocent murmurs or other incidental findings. However, there are a number of children with CHD looked after in the wider network, who never need to be seen at the Freeman hospital. One of the aims of the network is to accurately quantify and support this additional care.

Adult Congenital Heart Disease [ACHD] (18 years or older)

There are 4618 adults under the care of NUTH the majority of whom are seen at the Freeman Hospital and a smaller proportion are followed in peripheral clinics, however the numbers are increasing as those in paediatric clinics transition to adult services and are projected to double over the next decade.

As of September 2020, approximately 2838 paediatric patients were between the age of 11 and 16 years who will be transitioning in to adult services and should be listed on a transition pathway.

Evidence suggests that the best estimates of the prevalence³ of ACHD are 4 per 1000 adults, estimating the overall regional ACHD population would be 9600. The prevalence of complex ACHD is 10% of the ACHD population meaning the number of complex ACHD patients in the region is estimated to be 960.

It is expected that there are a significant number of ACHD patients followed without specialist care in peripheral general cardiology clinics, but it is also well recognised that many are lost to follow-up and that these patients have worse outcomes. Heart failure is the most common cause of death and the most pressing problem requiring management in this growing group. Even relatively minor CHD may have significant detrimental effects in adult life if it is not acknowledged or understood by patients and their care teams.

Our clinics

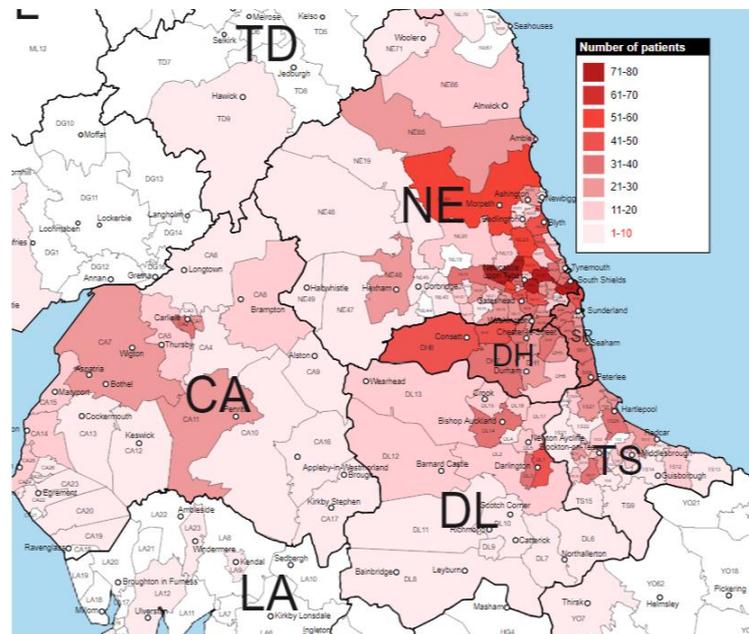
Within the Network there are 4 types of clinic, currently delivered as follows;

- Freeman Hospital (adult and paediatric)
- Freeman outreach

³ <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05/>

- University Hospital of North Durham (paediatric)
- University Hospital of North Tees (adult and paediatric)
- Cumberland Infirmary (paediatric)
- James Cook University Hospital (adult and paediatric)
- Peripheral (PEC)
 - James Cook University Hospital
 - University Hospital of North Tees
- Nurse-led
 - Nutrition clinic (Freeman) (paediatric)

Regional map showing the distribution of Patients by Postcode



The Network Team

Network Chair	Jonathan Wyllie
Adult CHD Lead	Louise Coats
Paediatric CHD Lead	Abbas Khushnood
Nurse Lead	Kaye Walsh
Manager	Terry Phillips
Data Manager	Gwen Taylor
Administrator	Rebecka Nordstrom

Outreach Clinic Specialist Nurses

The North East and North Cumbria covers a vast geographical area and in order to provide adequate support, we propose the region is divided into sub-regions which will be supported by the allocated specialist nurse;

- West (Carlisle, Whitehaven) – Jacqui Laydon
- South (Stockton, Middlesbrough, Northallerton, Darlington) – Debbie Lawson
- North (Alnwick, Hexham, North Tyneside) – Vicky Russell
- Central (Sunderland, South Tyneside, Gateshead, Durham) – Deb Richardson

It is a priority for the Network to work with the Level 1 centre to increase these numbers. The CHD National Standards recommend the following specialist nurse provision;

CHD Standard B29(L1) – Within 3 years

Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum five, and location of these nurses will depend on geography, population and the configuration of the network.

CHD Standard B29(L1) – Within 3 years

Each Specialist Children's Surgical Centre will employ a minimum of 1 WTE children's cardiac specialist nurse per 600 000 catchment population, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum seven, and location of these nurses will depend on geography, population and the configuration of the network.

.....Included in these numbers will be at least 1 WTE Fetal Cardiac Nurse Specialist, shared with the fetal network, to provide expert information and on-going support to parents who have a fetal diagnosis of congenital heart disease and 1 WTE designated Children's Cardiac Transition Nurse to coordinate the transition process across the network.

Based on these recommendations, the Network covering the North East and North Cumbria should have 5 WTE nurse specialists for ACHD and 7 WTE nurse specialists for paediatric CHD (including 1 WTE fetal nurse and 1 WTE transition nurse).

Currently there are 2 ACHD nurse specialists and 5 paediatric nurse specialists in post, two of which are funded by CHUF.

Workforce development is a priority for the Network and an ongoing theme. Recruitment to these nurse specialist posts, developing the link nurse role and training and recruitment of ACHD cardiologists are paramount to improving CHD services in the region.

Network Structure

Host Provider and Level 1 Specialist Surgical Centre

- Newcastle upon Tyne Hospitals NHS Foundation Trust

Peripheral Centres

- County Durham & Darlington NHS Foundation Trust
- Gateshead Health NHS Foundation Trust
- North Cumbria Integrated Care NHS Foundation Trust
- North Tees & Hartlepool NHS Foundation Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- South Tyneside and Sunderland NHS Foundation Trust

Link Nurses

County Durham & Darlington	Tracey Davidson
Gateshead Health	Rebecca Williams/Stuart Adams
North Cumbria	Julie Milburn; Katie Allison, Terri Rae
North Tees & Hartlepool	Andrea Clark
Northumbria	Jayne Moore
South Tees	Tracy Farley
South Tyneside and Sunderland	Paula Mulvaney

Network Partners

Specialist Commissioning Organisation

North East and North Cumbria NHSEI

Integrated Care System

North East and North Cumbria ICS

Affiliated Academic Institutions

Newcastle University

Northumbria University
Teesside University
Sunderland University

Charitable Organisations

Children's Heart Unit Fund (CHUF)

Networks

Northern Neonatal Network
North East Clinical Networks (Maternity, Fetal Medicine, Cardiovascular Disease)

Network Transport

NECTAR
NNETS

Other

Northern Genetics Service

The Wider Network

Heart Failure

Belfast Health & Social Care Trust
Manchester University NHS Foundation Trust

Transplantation

Barts Health NHS Trust (St Bartholomew's Hospital)

Pulmonary arterial hypertension outreach service

Hull University Teaching Hospitals NHS Trust
Belfast Health & Social Care Trust

The Network Board

The Network Board was formalised in January 2020. The Board meets formally three times per year and is chaired by Jonathan Wyllie from South Tees Hospital NHS Foundation Trust. Meetings take the form of two formal board meetings per year and a clinical case review meeting with a network business meeting as an agenda item. The Networks Terms of Reference can be found in Appendix 1.

Chair	Jonathan Wyllie
Paediatric CHD Lead	Abbas Khushnood
Adult CHD Lead	Louise Coats
Primary Care Representative	Dr Ahmet Fuat
Patient & Family Representatives	Ivan Hollingsworth; Michelle Sinclair
NHSE Representative	Steven Duckworth
Network Nurse Lead	Kaye Walsh
Network Manager	Terry Phillips
Network Data Analyst	Gwen Taylor

Trust Representatives (paeds/adults):

County Durham & Darlington	El Mehdi Garbash	Jenny Crilley
Gateshead Health	TBC	Ray Meleady
North Cumbria	Yee Mon Aung	Louise Buchanan
Northumbria	Sangeeta Tiwary	Thomas Green
North Tees & Hartlepool	Madhu Podalakur	Helen Oxenham
South Tees	Prashant Mallya; Lekshmy Prasad	TBC
South Tyneside & Sunderland	Majd Abu-Harb	Raj Mohindra; Shahid Junejo

Network Governance

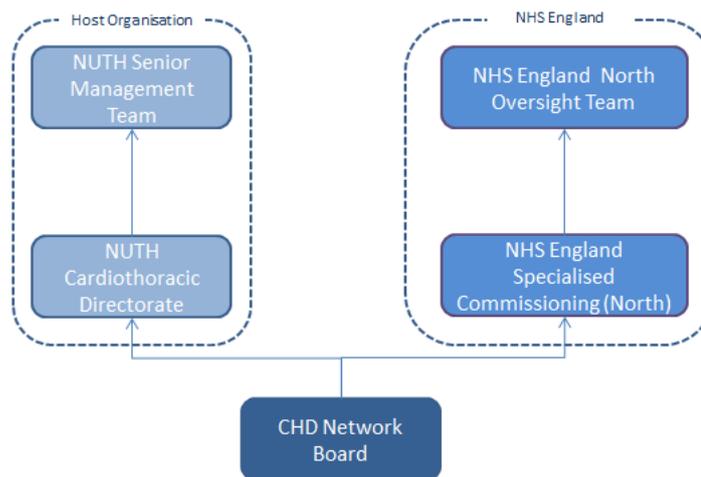
Operational Delivery Networks (ODNs) were launched in April 2013 following the publication of the NHS England strategy to sustain and develop clinical networks. ODNs are focussed on coordinating patient pathways between providers over a wide area to ensure access to specialist resources and expertise. Success factors for ODNs are:

- Improved access and egress to/from services at the right time
- Improved operating consistency
- Improved outcomes
- Increased productivity

ODNs are determined by clinical need as agreed between providers and commissioners and their outcomes and outputs are included in the relevant commissioning service specifications. Responsibility for assuring governance arrangements for ODNs sits with NHS England Specialised Commissioning and responsibility for 'hosting' the ODNs is agreed with a local provider organisation.

The Network is governed by the Network Board, which has representatives from the Level 1 centre, peripheral units, primary care, patients and parent representatives, and regional commissioners. The diagram below shows network accountability with the Network team reporting progress and issues through the Cardiothoracic Directorate to the NUTH Executive Team, and via NHSE Specialised Commissioning to the NHS England North Oversight Team.

Network Governance Arrangements



All strategic/operational issues are managed through the regional commissioning operational governance structure. The Network manager works with the NHS England regional commissioner to create a yearly work plan. This considers local, regional and national drivers and the strategic direction of the ODN and confirms objectives, milestones and deliverables with associated timelines. KPI's will be agreed and monitored via a network dashboard.

The work plan is agreed yearly by the Network Board as part of the network planning and to align with local and regional priorities for CHD services. There is also a well-defined organisational structure to deliver the work of the network providing clear benefits for all patients.

Within the ODN model, commissioners will continue to be accountable for the commissioning of services and providers for the delivery of services. However, patients are best served when the whole system works together and clinical networks are well placed to facilitate collaborative working, bringing together commissioning and providers in the design and delivery of high-quality services.

The Network will work within a collaborative model as described below, which will be reviewed annually.



Performance Management

During 2021/22 the Network will work with Trusts to achieve their service improvement ambitions and identify how these ambitions align with the National CHD Service Standards. The Network manager will work with local teams to establish a programme of work and, together with the Network Chair, will liaise with Trust Boards and regional commissioners for help to progress this work.

Once established these work plans will be reviewed quarterly and collated in a Performance Report for discussion at Network board meetings. This process will facilitate collaboration on service development between neighbouring Trusts, at Integrated Care Partnerships (ICP) level and more broadly at Integrated Care System (ICS) level.

There will be Annual Review meetings with all Trusts in the Network to review work plans, review service developments against the National Standards and to discuss capacity issues and review future plans.

Clinical Governance

The clinical governance process for the Level 1 Specialist Surgical Centre was re-organised to a 'per Trust' approach in 2018/2019 and the governance lead is Dr Vrana. A monthly joint adult and paediatric governance meeting is held and a rolling agenda follows a formatted Trust approach.

While robust processes are in place at the Level 1 centre and within each of the peripheral trusts, work is underway to establish a more coordinated collaborative approach across the region. This will be described in more detail in the Network *Clinical Governance Strategy* which is currently in development.

The National CHD Standards and Specification outline requirements relating to clinical governance for all centres providing care to CHD patients which include;

- a network-wide clinical governance framework,
- reporting of adverse incidents and communicating these within the network,
- a network-wide database of CHD patients within the region
- an audit of clinical practice and linking of similar audits across the region
- participate in national programmes for audit of endocarditis

- discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners

These will be incorporated and addressed in the *Clinical Governance Strategy* for the Network.

Clinical Audit and Quality Improvement

Clinical audits, quality improvement projects and service development projects are undertaken within each centre. As part of the *5 Year Strategy* the Network will be working with centres across the region to develop a coordinated approach to quality improvement and outline a regional programme of work to address quality and service development to benefit CHD patients and their families.

Multidisciplinary meeting

The Joint Cardiac Conference (JCC) hosted at the Freeman Hospital is a combined multidisciplinary meeting involving essential personnel required for diagnosis, treatment and management of patients with significant congenital heart disease regardless of age.

Information presented includes echocardiogram, x-ray, MRI/CT images and written documentation. This includes all patients being considered for a complex catheter intervention or innovative procedures. A signed record of discussion and the final outcome is recorded at each meeting and the minimal attendance is as follows:

- Congenital Cardiologist
- Congenital surgeon
- Specialist Intensivist

Part of the *5 Year Strategy* includes a review of the current provision of multidisciplinary team (MDT) meetings for all healthcare professionals involved in the care of CHD patients across the region. The aim is to ensure wide attendance at MDT to enhance participation in decision making and ongoing training and development.

Patient Outcomes

Outcomes for patients under the care of the Level 1 SSC are discussed on a monthly basis at the Clinical Governance meeting and reported to NHS England through the Specialist Services Quality Dashboards.

Surgical and catheter intervention data is submitted to the national database National Institute for Cardiovascular Outcomes Research ([NICOR](#)) and the results are available on the NICOR Central Cardiac Audit Database ([CCAD](#)) website.

It is the ambition of the Network to broaden this process where appropriate and to identify and discuss cases where shared learning would benefit members of the wider network.

Digital Transformation

The covid-19 pandemic has highlighted the need and benefits of digital technology in connecting clinical teams, with each other and with their patients, across the region and across the country. This has resulted in a great increase in the number of virtual meetings and emphasised the need for further developments in technology to support communication and sharing of digital information.

All Trusts in the Network are signed to Microsoft Teams thus enabling greater collaboration and communication. Due to the geographical challenges of the region, using online meetings has led to greater attendance. It has also provided the Network Board with a forum to share documents and information as well as an online chat function that has aided greater communication.

During 2021 the Network will work with teams across the region to develop a *Digital Strategy* to enhance virtual interactions, increase remote engagement in MDT and develop real-time remote consultations.

Risk Strategy and Risk Register

The risk management objectives for the Network are outlined in the *Risk Management Policy* (currently in development) and *Risk Register*. In addition, the Network are developing an Incident Reporting Tool as part of the Risk Management Policy to encourage stakeholders to report adverse incidents in order for lessons to be learned across the Network.

Communication Policy

Engaging with our patients, families and clinical colleagues throughout the region is essential to the success of the Network. During 2020 the Network team carried out a scoping exercise to engage with patients and their families and clinical teams across the region, in shaping the development of the Network and its objectives. We will build on these initial findings during 2021/22 to establish a Patient and Family Engagement Group, Young Persons Group and Primary Care Engagement Group.

A Network website has been launched to host information relevant to patients and families, clinical teams and the wider public. The Network has also established a social media presence through Facebook, LinkedIn and Twitter to increase awareness of the Network and promote the work of the clinical teams in the region.

The Network Communication procedures and activities are described further in the *Communication Policy*.

Patient Engagement

Patients and families remain at the heart of our Network and their opinions and ideas for the future of the service and how it is delivered is key to the success and longevity

of the Network. Our *Patient and Family Engagement Strategy* outlines this in more detail.

As mentioned previously, during 2021/22 the Network will establish a Patient and Family Engagement Group and a Young Persons Group. The purpose of the groups is to provide a forum for patients and families to influence decisions and services that affect their future, be it via a group event, an online chat, an email survey or a phone call. It is an opportunity to get involved in the Network and CHD services across the region, to meet peers and make a positive contribution to the community of people living with congenital heart disease.

The Network aims to ensure that the voice of the patient is heard, valued and acted upon. Patients and families can contribute in a variety of ways, online, face to face, email, drawings, videos and story-telling.

We wish to empower patients and families so their realities of living with CHD and their experiences can be shared and can make a positive and important contribution to the future of the services that are provided right across the region.

We will strive to ensure that volunteers feel valued and that they receive feedback in relation to the ideas and views that they share.

Clinical Services and Pathways

The Paediatric Cardiology Service

The Network is distinguished by the fact that the Specialist Surgical Centre for both paediatric and adult services are co-located at the Freeman Hospital alongside transplantation, ventricular assist devices and pulmonary hypertension. Many of the cardiology consultants at the unit are dual trained and care for patients from infancy in to adulthood.

The unit is one of the only centres to transplant single ventricle patients in the UK for both adults and children. It is one of only two UK centres for paediatric heart and lung transplantation and Ventricular Assist Devices (VAD) attracting referrals of patients with high risk and challenging cardiac pathology from other paediatric and adult congenital heart centres across the UK.

The Great North Children's Hospital (GNCH) is located on the Royal Victoria Infirmary (RVI) site and houses all the other paediatric specialties including the fetal cardiology service. NUTH has agreed a phased approach with NHS England for the co-location of the paediatric cardiology service to be alongside other paediatric and nephrology services in the GNCH. Work continues to develop design plans for a new building adjacent and linked to the Great North Children's Hospital (GNCH) at the Royal Victoria Infirmary (RVI) to enable the paediatric service to be co-located with other Paediatric services. NUTH have developed a vision of the future service model, with engagement from clinical teams, colleagues from other interconnected specialisms and the broader

estates strategy for the Trust. NUTH continue to work towards a design that prioritises patient flow and safety. NUTH are currently developing a patient and public engagement approach which creates opportunities for patients and families to be actively involved, so that they can share their insight and aspirations. The wider community will also be kept informed on progress. The scheme aims for a completion by the end of 2023/24.

Clinical guideline and pathway development

The Network team have developed a clinical guideline review programme. Clinical guidelines and patient pathways are written and reviewed by teams across the Network and presented to the Board. These are then discussed and adopted at the following Board meeting. The *Clinical Guidelines Policy* is currently in development to establish formal governance processes to manage the development, approval and distribution of network pathways ensuring a network-wide perspective is embedded.

A list of clinical pathways which have been approved can be found in Appendix 2. Clinical pathways fall broadly in o the following categories:

- Specialist Surgical Centre for Paediatric CHD and Adults CHD Services
- Fetal Cardiology Pathways
- Paediatric Referral Pathways
- Transition Services
- ACHD Referral Pathways
- Adult and paediatric outreach services

The Level 1 Specialist Surgical Centre for CHD Services

All specialist surgery and interventional catheterisations, for both adults and children, are carried out in the Level 1 Specialist Surgical Centre (SSC) based at the Freeman Hospital in Newcastle. The Network is committed to providing outpatient care as close to home as possible for all patients with CHD by establishing outreach clinics more locally. Cardiologists from Newcastle work closely with local paediatricians with an interest in cardiology and consultant cardiologists to deliver joint outpatient clinics in centres across the region.

Currently there is only one paediatrician with expertise in cardiology (PEC) in the region and the Network are developing a PEC programme to help establish this role further and build a network of PECs in the region.

Joint referral, care protocols and guidelines have been developed for emergency, acute and routine presentations by children and adults with confirmed or suspected diagnosis of CHD. Emergency transfers for critically ill neonates and children are supported by the North East and Cumbria Transport and Retrieval (NECTAR) team. All validated guidelines are included in Appendix 2.

Patients with *confirmed* CHD

Newcastle will provide CHD services to all referred patients, including elective consultations and investigations for both outpatients and inpatients as well as out of hours and emergency care as required.

Newcastle will provide support and guidance to the CHD teams within the network for patients including weekly multidisciplinary team (MDT) meetings. Complex or significantly unwell patients may require inpatient transfer to Newcastle and these will be discussed on an individual basis.

All patients will be admitted to Ward 23 (Paediatrics), PICU, Ward 24, 25, 27, ITU, 30 and 38 as bed occupancy allows.

Newcastle will ensure that nurses managing inpatients with CHD are aware of any safety issues regarding their care. Any specific training needs are addressed by our clinical educators and a framework of competency based regular training programming is available as outlined in the clinical education section. In addition to this, paediatric nurses have the opportunity to attend GOSH CHD training programme for additional education and training.

Patients with *suspected* CHD

Newcastle will provide the appropriate and timely assessment and investigations for all referred patients with suspected CHD as designated in the services standards.

Newcastle will support the appropriate and timely assessment and investigations for patients referred from any UK centre. A Consultant is available for discussion in Newcastle at all times, and teleconferences/videoconference will be undertaken on a case-by-case basis.

Patients who after assessment are found not to be appropriate for CHD specific treatment will be discharged to other services, or their referring physician, as appropriate.

Transplant Service

The [Institute of Transplantation](#) at the Freeman is one of two national centres offering transplantation to children with cardiac disease, and is the main referral centre for adults with CHD requiring mechanical support or transplantation with specific expertise in the failing Fontan circulation.

Since 2003 the Institute have developed a mechanical heart service for both children and adults, as a bridge for transplant until a suitable donor heart is available or as a bridge to recovery in suitable patients.

Pulmonary Hypertension

The Pulmonary Hypertension (PH) Service is commissioned nationally and run by Great Ormond Street Hospital (GOSH). The service covers England, Wales, Scotland, Northern Ireland, and also co-operates with the Republic of Ireland, working with eight major

regional hospitals in which they perform outreach care in the form of shared outpatient clinics.

The GOSH PH consultants facilitate a clinic at Freeman Hospital quarterly within the outpatient department, however due to the pandemic, these have been suspended for past 12 months.

Clinical Support Services

- Psychology – Together with the psychology support at the Freeman there are two psychologists available to support families, in James Cook University Hospital and Cumberland Infirmary, both of whom are supported by CHUF.
- Physiotherapy
- Dental Services
- Palliative Care and Bereavement Services – the Paediatric Palliative care network brings together representatives of children and young people with palliative care needs, their families, commissioners and providers, voluntary sector social services and education. They work across primary, secondary and tertiary care with the aim of improving co-ordination, availability and delivery of palliative care.

Outreach Clinics

There are two well-established outreach centres across the region, James Cook University Hospital in Middlesbrough and University Hospital of North Tees in Stockton. Both centres offer outpatient appointments for children with CHD seeing consultants and nurse specialists from the Freeman Hospital. From June 2021, adult CHD patients will also benefit from an outreach clinic at University Hospital of North Tees in Stockton.

A paediatric outreach service was established in University Hospital of North Durham in February 2020 which moved to Chester-le-Street Hospital during the covid-19 pandemic. A fourth paediatric outreach clinic is being set up in Cumberland Infirmary in Carlisle in June 2021.

Implementation of the outreach programme ceased during 2020 due to the covid-19 pandemic, however clinics restarted, albeit at a reduced capability due to social distancing restrictions, in May 2021.

The outreach programme until 2023 includes plans to expand the adult service to North Cumbria, County Durham & Darlington, and South Tyneside & Sunderland; and expanding the paediatric service to Northumbria.

New specialised Heart Failure satellite clinic has been set up with Royal Manchester Children's Hospital, the first of which was in May 2021.

Paediatrician with Expertise in Cardiology (PEC) Clinics

Clinics take place in Sunderland Royal Hospital (1 consultant), University Hospital of North Tees (1 consultant) and James Cook University Hospital Middlesbrough (2 PEC consultants and 1 seeing patients <2 years of age). There was until recently a further PEC clinic at North Tyneside General Hospital but this has ceased with the retirement of the PEC. A future Network aim will be to cooperate and assist Trusts to prevent the sudden cessation of such local patient services.

Some patients seen in these clinics enjoy shared care with the Freeman service or outreach joint clinics. However, significant numbers of new referrals are seen locally who either do not have CHD or merely require ongoing local monitoring.

Over 2021/22 it is intended to establish a mechanism to quantify this workload and ensure that the network is aware of all clinical workload such that patients are not lost to follow-up, especially as they transition to adulthood. It is also intended to standardise pathways for involvement of the regional cardiac services from PEC clinics.

Fetal cardiology clinics

Cardiac obstetrics services are rapidly growing, the number of CHD cases identified antenatally is increasing each year with increasingly complex patients. Support for these very vulnerable women is not widely available across the network.

Network pathways/protocols for these patients are currently under review and links with other centres are being formalised as part of the network centre reviews. Leadership within the specialist nursing team is essential in mitigating the increased cardiac risk as a result of unplanned pregnancy as well as the risk of pregnancy complications.

The pathway review will ensure all patients receive appropriate advice and management from preconception, during pregnancy and through to delivery. A list of pathways can be found in Appendix 2.

Transition to adult services

The National CHD Standards and Specification recommend that the process of transitioning from paediatric to adult services must be initiated no later than the 12th birthday taking into account individual circumstances and special needs.

The transition pathway and protocol are currently under review as part of the Transition Project, one aim being to establish the nurse specialist role to lead on the transition programme. The transition nurse specialist will act as a liaison between young people, their family and carers, the paediatric nurse specialists, ACHD nurse specialist and wider multidisciplinary team (MDT) to facilitate the transition process.

An MDT transition clinic will be established to discuss paediatric patients who are due to transition in to adult services. Clinicians from across the network will be encouraged to join this MDT as transitioning patients may come in to contact with other local services.

Social care support

The Freeman Hospital offers a social work service for children who are based on site and work with both inpatient and outpatients across the cardiothoracic services. The service offers a varied supportive role to patients and families and offer information with regards to welfare benefits and community services and offer signposting to services to meet an identified need and are able to facilitate professional referrals where required.

The social work team work with children and their families who are being cared for on PICU, ward 23 and in outpatient clinics. The social workers are integrated into the multi-disciplinary team, working alongside the medical team to help make plans regarding children's care. The social workers have a role in the child's discharge; working across organisation boundaries

To assess the needs of the child and their family coordinating services, continuing care and support to facilitate safe discharge or hospital transfer for those moving to care closer to home.

There are a number of ways a social worker may be contacted. It might be that a social worker visits the child's bed space to provide an initial introduction to the services they can offer or, alternatively, the ward staff may contact the social work team to request support for child and family. The child, parent or a member of the family may also request to meet with a social worker.

The social workers can help by providing emotional support to the child and their family, offer practical support around housing, employment, finances, signposting or referring to other services and advocating on the child's behalf. If you live in the Newcastle area the social workers can provide support once the child has been discharged home. Families who live outside of the Newcastle area and who require support may benefit from the social worker making a referral to local services.

Contact details:

The team is Kerry Walker (Monday-Wednesday) and Julie Eardley (Friday). They can be contacted on telephone number 0191 213 7393. There will be hospital social work cover Monday to Friday 9am until 5pm although this may be a duty worker. Hospital social work involvement is voluntary.

Adult patients assessed for transplant are automatically referred to the transplant social work team to review on admission. Emma Sowerby 0191 2448388

Psychological support

The Newcastle Hospitals offer a chaplaincy service which offers a wide range of both religious and spiritual support. During a patients stay, a member of the chaplaincy

service can visit the ward on request or patients and families are welcome to attend the onsite chaplain facilities.

Within the CHD service specifically psychological support is offered as part of the multidisciplinary team to the patient and family within the paediatric services.

Any adult patient requiring additional psychological support can be referred to the Trust psychology service for review independently. If referred for transplant assessment, patients can see one of the trusts transplant psychologists on admission.

As part of the service review against the National CHD Standards and Specification, the Network are assessing the currently demand for psychology and counselling support for CHD across the region. The team are working with psychologists in the region and CHUF, who currently provide financial support for two psychologists (one in Middlesbrough and one in Carlisle), to assess the need and redesign the mental health provision within the CHD service.

Current Psychology Provision

At the Level 1 SSC, the paediatric cardiology provision equates to 0.8 WTE consultant. The paediatric heart and lung transplant team although not formally part of the network partake informally.

The clinical psychologist based at James Cook University Hospital in Middlesbrough, funded by CHUF two days per week (0.4 WTE consultant), provides a psychology service to children and young people and their families across the areas covered by North Tees & Hartlepool NHS Foundation Trust and South Tees University Hospitals NHS Foundation Trust.

CHUF also fund a clinical psychologist one day per week in Cumberland Infirmary at Carlisle who provides a psychology service to children and young people and their families across North Cumbria.

Research Strategy

The Network recognises the role of research in improving outcomes for patients and benefits from strong links with universities across the region. The Network has a strong academic representation on the network board with Dr Louise Coats, a Clinical Intermediate Fellow within the Reproduction, Development and Child Health Theme at Newcastle University.

The Network is developing a *Research Strategy* and programme of research that describes current and planned research activity across the whole region. This will include a commitment to working in partnership with other regional centres in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of CHD patients.

Education and Training policy

CHD is the most common birth anomaly affecting 8 in every 1,000 babies born in the UK and a great deal of emphasis is placed on the surgical episode which is life saving and life changing. However, for most patients CHD is a lifelong condition with patients and their families needing support and care throughout their lives, for some this will mean continued treatment and further surgery.

While the majority of inpatient care is provided on the Freeman Hospital site at the Level 1 centre, many patients and their families receive a significant amount of their care and treatment from their local hospitals or community services. To ensure that patients receive care of the highest quality it is important that staff working in these areas are skilled and feel confident in delivering care to this complex group of patients.

The Network *Education and Training Policy* outlines the educational activities on offer to all healthcare professionals across the region and beyond, from lunchtime booster sessions and webinars to comprehensive PEC and CHD training programmes.

The Future of ODNs

The NHS Long Term Plan⁴ set out a route map for how health and care will be more joined up locally around the needs of the population. During 2021 this will be further developed by the legislative reforms proposed for Integrated Care Systems (ICSs). NHS England published details⁵ of how systems and their constituent organisations will accelerate collaborative ways of working and establish 'place-based' partnerships.

During the pandemic clinical networks, including Operational Delivery Networks (ODNs) became critical in supporting innovation and system wide collaboration. The proposed ICS reforms will support networks to drive clinically-led change and service improvement with greater accountability for tackling inequalities and for improving population health.

The North East and North Cumbria benefits from a single ICS which comprises of 4 Integrated Care Partnership areas;

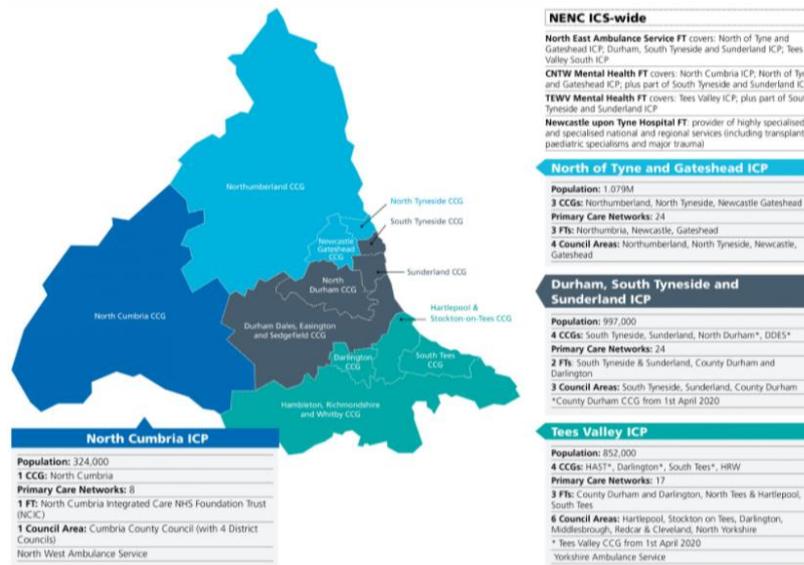
- North Cumbria
- North of Tyne and Gateshead
- Durham, South Tyneside and Sunderland
- Tees Valley

The ICS is a commitment by all NHS organisations along with Local Authorities and other voluntary and third sector organisations, to work together on ambitious plans to

⁴ <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

⁵ <https://www.england.nhs.uk/wp-content/uploads/2021/01/integrating-care-next-steps-to-building-strong-and-effective-integrated-care-systems.pdf>

improve the health of the three million people who live in the region and to improve the quality of their health and care services.



Providers in every system, through partnership or any new collaborative arrangements, must be able to agree proposals developed by clinical and operational networks, and implement resulting changes. These changes include implementing standard operating procedures to support agreed practice, designating services to ensure their sustainability or wider service reconfiguration.

Clinical networks at system, regional and national level have important roles advising on the most appropriate models and standards of care, in particular making decisions about clinical pathways and clinically-led service change.

Place-based healthcare

‘Place’ is an important building block for health and care integration. For most people their day-to-day care and support needs will be expressed and met locally in the place where they live. An important building block for the future health and care system is therefore at ‘place.’

NHS England outlined their ambition to create ‘place-based’ healthcare where possible to ensure everyone is able to;

- access clear advice on staying well;
- access a range of preventative services;
- access simple, joined-up care and treatment when they need it;
- access digital services (with non-digital alternatives) that put the citizen at the heart of their own care;
- access proactive support to keep as well as possible, where they are vulnerable or at high risk; and to

- expect the NHS, through its employment, training, procurement and volunteering activities, and as a major estate owner to play a full part in social and economic development and environmental sustainability.

This aligns with the Network ambitions of equitable care closer to home for all CHD patients and families in our region.

What this means for ODNs in practical terms is still under review and we await further guidance to be published later this year on proposed changes to financial arrangements and accountability for the Network. However, it is clear from published documents that the aims and objectives of the Network align with the future direction of the ICS.

Appendix 1 - Terms of Reference and Governance Arrangements

1. PURPOSE

The North East and North Cumbria (NENC) Congenital Heart Disease Network (hereafter referred to as the Network) encompassing Adult, Paediatric and Neonatal patients will support the provision of high-quality care for CHD patients across the North East and North Cumbria, in line with the requirements of the NHS England standards. The network board will provide clinical leadership and advice to support an integrated approach to high quality care and positive outcomes for patients. It will facilitate the bringing together of clinicians, professionals and organisations, with the patient's voice, to deliver programmes of continuous quality improvement encompassing whole pathways of care (from pre-natal through to end of life care). It will have responsibility for the strategic and operational development and delivery of the whole congenital pathway.

2. MAIN FUNCTIONS

The Network will;

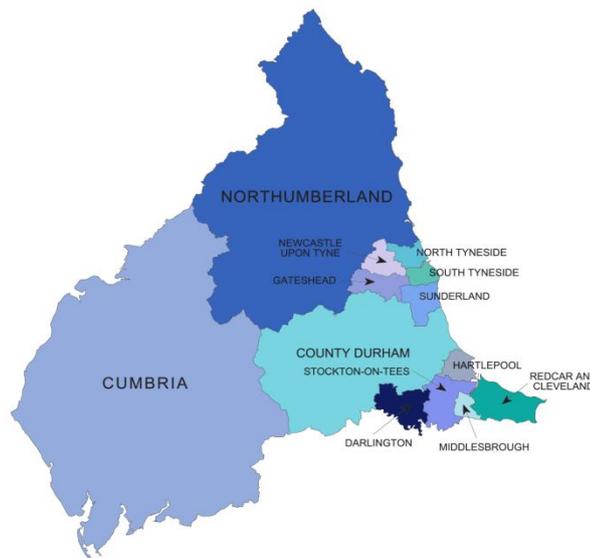
- 2.1. Develop and evolve the congenital cardiac service in line with national policy and the needs of the constituent organisations, ensuring that clinical engagement and influence, and the patient's voice, are at the heart of the Network activities.
- 2.2. Oversee and lead the development and delivery of the Network annual plan to improve quality, productivity and outcomes, ensuring it is in line with national and local priorities.
- 2.3. Promote the development and delivery of best practice, evidenced based care, with an emphasis on equitable, consistent high quality service provision and a seamless transition in care across the whole patient pathway.
- 2.4. Provide support, advice and recommendations to NHS commissioners and providers of NHS services.
- 2.5. Ensure regular continuous clinical audit and quality improvement with feedback from scheduled audit days and resultant action plan.
- 2.6. Reflection of mortality, morbidity and adverse incidents.
- 2.7. Agreement of clinical protocols and pathways across the whole service and by all providers of care.

3. MEMBERSHIP OF THE NETWORK

Membership of the network is open to all North East provider organisations with an interest in CHD. Each provider organisation is asked to nominate a representative in order to ensure appropriate geographical representation. All members of the Network are responsible for taking information back to their colleagues and seeking their opinions to feed into the discussion where appropriate.

- 3.1. The membership of the Network will include the following;
- Network Chair
 - Clinical Director
 - Clinical Lead Adult CHD
 - Clinical Lead Paediatric CHD
 - Network Manager
 - Network Lead Nurse
 - Representative from Maternity/ Fetal services
 - A nominated clinician from each centre with an interest in Cardiology (listed below)
 - Patient representative(s)
 - Commissioner
 - Other members for local determination

- 3.2. The Centres within the Network are:
- County Durham and Darlington NHS Foundation Trust
 - Gateshead Health NHS Foundation Trust
 - Newcastle Upon Tyne Hospitals NHS Trust (Host Provider)
 - North Cumbria University Hospitals NHS Trust
 - North Tees and Hartlepool NHS Foundation Trust
 - Northumbria Healthcare NHS Foundation Trust
 - South Tees Hospitals NHS Foundation Trust
 - South Tyneside and Sunderland NHS Foundation Trust



3.3. Chairing Meetings

The Network meetings are led by the Network Chair.

3.4. Quorum

Network meetings will be quorate when the Clinical Director, at least one NUTH Clinical Lead, at least two external clinicians and one commissioner representative are present.

3.5. Named Substitutes

There may be occasions when members need to nominate a deputy from their organisation or their directorate to attend on their behalf. Such deputies should be notified to the Network Manager prior to the start of the meeting. Deputies will have full voting rights

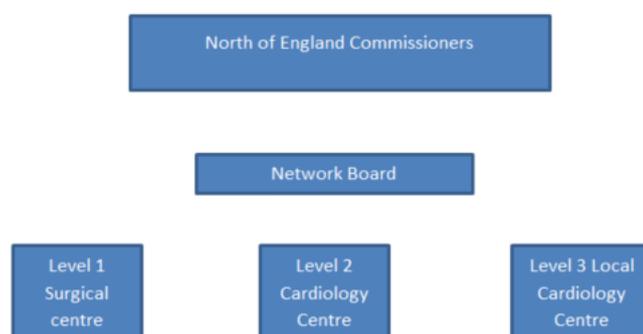
3.6. Declarations of Interests

Objectivity and neutrality will be essential and if any member has an interest, pecuniary or otherwise, in any matter and is present at the meeting at which the matter is under discussion, the member must declare that interest as early as possible and shall not participate in the discussions. The Chair will have the authority to request that the member should withdraw until the item under discussion has been concluded.

4. MEETINGS

- 4.1. The Network meeting will take place bi-annually, normally face-to-face, hosted by The Newcastle Upon Tyne Hospitals NHS Foundation Trust.
- 4.2. In addition to the above, the Chair, and members are authorised to call extraordinary meetings.

5. REPORTING STRUCTURE



6. ADMINISTRATIVE SUPPORT

- 6.1. Support to the Network meeting will be provided by the administration of NUTH. Agenda and briefing papers will be circulated 14 calendar days in advance of the meeting.

7. REVIEW OF TERMS OF REFERENCE

7.1. The Network shall review its terms of reference and membership annually.

Appendix 2 - Clinical Pathways and Guidelines

1. Referral Pathway for Suspected CHD – Paediatric
2. Referral Pathway for Suspected CHD – Adult
3. Routine Adult CHD Referral Pathway
4. CHD Pre-pregnancy counselling, Contraception and Pregnancy Pathway
5. Paediatric Dental Care Pathway
6. Adult Dental Care Pathway
7. Transition Pathway
8. Transplant assessment pathway
9. Fetal cardiology identification to diagnosis pathway
10. 24/7 Specialist Advice
11. Perinatal Planning CHD Pathway
12. Paediatric Catheter Guidelines
 - a. Diagnostic
 - b. Device closure of PFO/ASD
 - c. Interventional catheters
 - d. Transplant biopsy
 - e. EPA studies / RFA
 - f. Pacemaker / ICD / Loop recorder implant