



**NORTH EAST AND NORTH CUMBRIA  
Congenital Heart Disease Network**

Annual Report 2023/24



## Document History

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## Introduction

The North East and North Cumbria Congenital Heart Disease (CHD) Network management team was formerly established in January 2020. The key priorities and work of the Network team is determined by the Network Board which has representation from all 8 Trusts from across the North East and North Cumbria.

The Network 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 Trust.

Our 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.

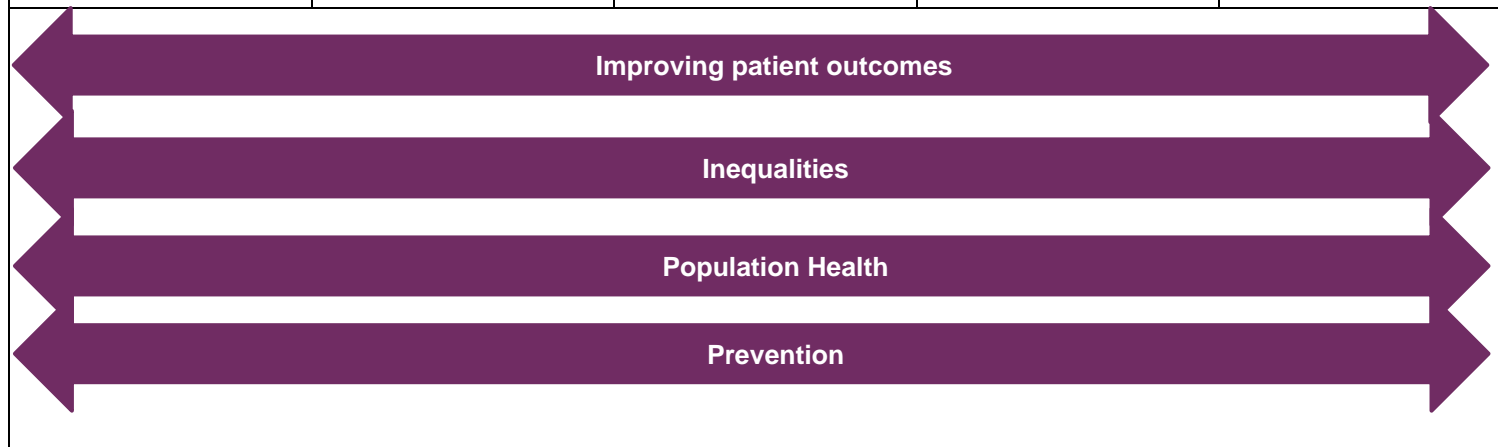
## Network Strategy

In March 2023 we hosted a meeting to begin the process of outlining a 3 year strategy for the Network. The meeting was very well attended and generated useful discussion. Our strategy was presented at the Network board meeting in June 2023 which included a revision of our six key objectives are:

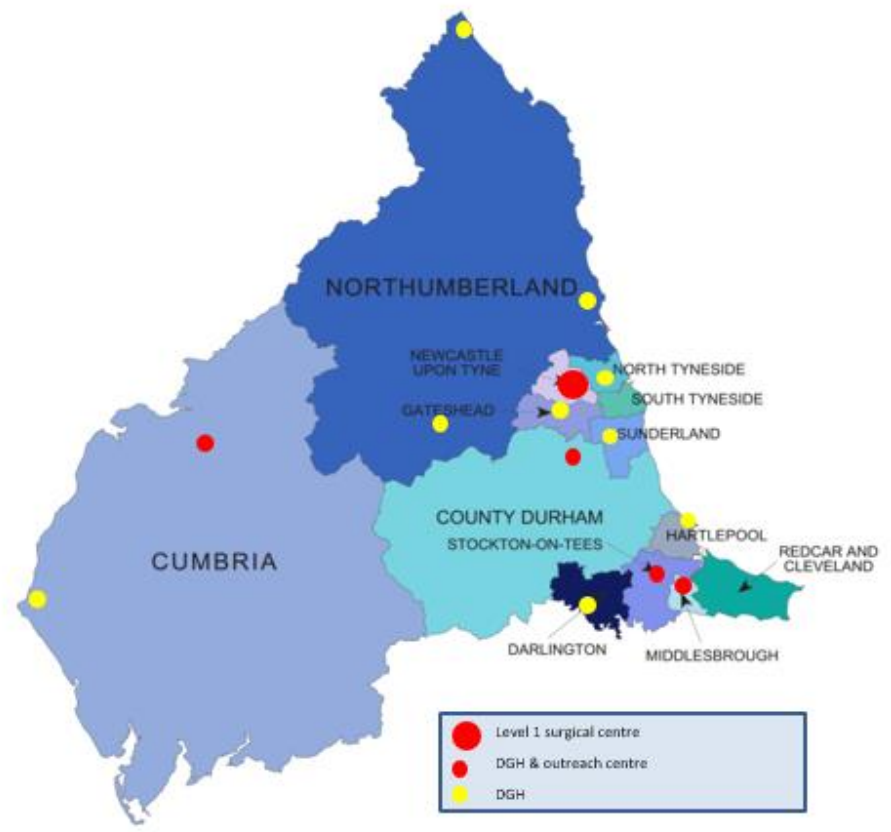
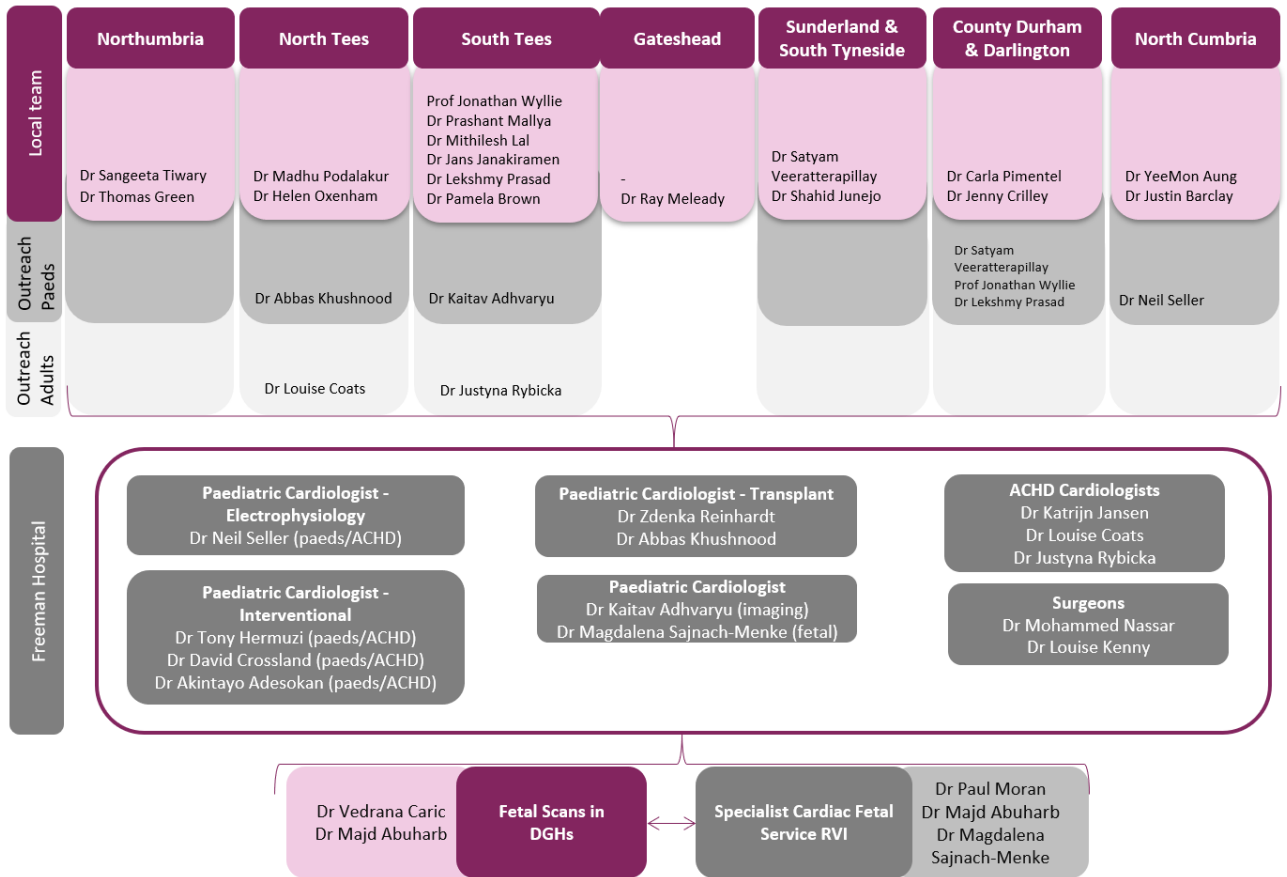
1. Increase patient and stakeholder engagement to improve inclusivity and listening.
2. Ensure equitable and lifelong access to holistic services for all CHD patients.
3. Provide strategic direction for high-quality care throughout the CHD network.
4. Promote inclusive and innovative CHD research initiatives.
5. Enhance "global" collaboration to increase the CHD network's impact.
6. Support ongoing workforce education and training, increasing general awareness.

The key theme for the strategy is greater collaboration and integration between stakeholders across the geography of this CHD network. Together with a drive for skills development, training, and a focus on innovative research, it will steer us towards a more sustainable, high-quality service for congenital heart patients and their families in the North East and North Cumbria.

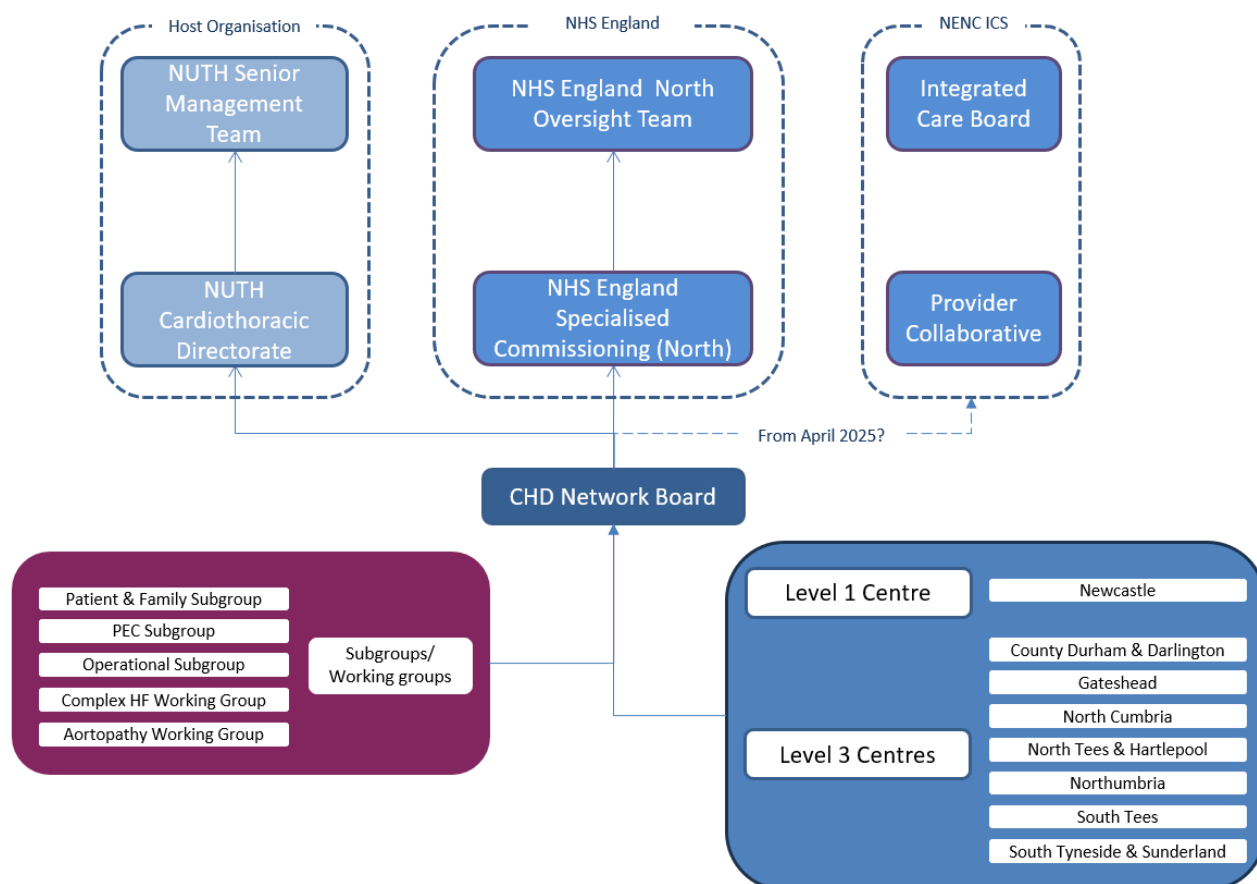
objective	fetal	neonatal	children	adults
1. Increase patient and stakeholder engagement to improve inclusivity and listening.	Develop parent and family feedback mechanisms for fetal medicine and fetal cardiology services.	Review and improve communication with families in the antenatal period.	Develop comprehensive referral guidelines, pathways and follow-up protocols for PEC and joint clinics.	Develop an on-line support group for patients. Link with national peer to peer network
2. Ensure equitable and lifelong access to holistic services for all CHD patients.	Develop regional guidelines and pathways.	Standardize delivery pathways for CHD babies.	Develop a consistent Network strategy for tertiary, primary to home care (eg. INR).	Establish pathways for wider aspects of care (ambulatory, personal and local care).
3. Provide strategic direction for high-quality care throughout the CHD network.	Develop a multi professional case review process.  Engage in joint working between fetal and paediatric services.	Undertake a neonatal CHD audit based on place and time of delivery focused on both fetal and maternal outcomes, as well as maternal CHD outcomes.	Ensure involvement of relevant healthcare professionals from across the network in JCC meetings.  Create learning opportunities and identify common themes that may influence future CHD care.	Support clinicians to present cases at JCC.  Develop an ACHD surveillance programme to implement standardised approaches (eg. Hypertension)
4. Promote inclusive and innovative CHD research initiatives.	Establish an audit process to identify common themes that may influence future service delivery.	Align with other Networks on research initiatives.	Support PEC involvement in research opportunities.	Develop a learning curriculum for ACHD nurses and adult cardiologists with an interest in ACHD.
5. Enhance collaboration to increase the CHD network's impact.	Explore use of telemedicine for immediate CHD advice on 20 week scans.	Engage in joint working with other Networks to prioritise access for CHD babies.	Ensure timely communications between all stakeholders.  Promote GNCR adoption with stakeholders.	Investigate better engagement and collaboration with Primary Care.
6. Support ongoing workforce education and training, increasing general awareness.	Deliver targeted training for obstetric sonographers.	Develop guidelines for CHD place of delivery.  Develop guidelines to streamline multiple outpatient appointments.	Promote and support the Link Nurse role to be the focus point for education and communication.	Develop Top Tips for patients to help them get the most out of their follow-up consultations.



# Congenital Cardiac Services North East and North Cumbria



## Network Governance Arrangements



### New Network board members

This year we were joined by Dr Akintayo Adesokan who is the new paediatric lead for the network.

### Network board meetings

The time of the board meetings will be between 10am and 12 noon, the dates and venues for 2024/25 are listed below.

- 17/07/2024 Teams (virtual)
- 18/11/2024 University Hospital of North Tees
- 20/01/2025 Teams (virtual)
- 27/03/2025 Sunderland Royal

### Board meeting attendance

Attendance at board meetings remains challenging and in-person meets ultimately become hybrid meetings. Of the 16 meetings held since October 2019 only 4 of the 8 providers had at least one clinical lead attend at least half the meetings.

**Table 1. Provider representation at Network board meetings**

<b>Trust</b>	<b># meetings</b>
CDDFT	2
Gateshead Healthcare	1
Newcastle	11
North Cumbria	5
North Tees & Hartlepool	9
Northumbria	5
South Tees Hospitals	11
South Tyneside & Sunderland	8

## Summary of the work 2023/24

### ➤ Education and training

The network continues to support the regional workforce with education and training through structured and bespoke learning both virtually and face-to-face.

#### Training events

During 2023/24 we hosted the following in-person events;

- Nurse Practitioner Day April 2023
- CHD Study Day December 2023
- CHD Awareness week Feb 2024

The team also delivered bespoke teaching to Queen Elizabeth Hospital Gateshead, James Cook University Hospital and RVI Emergency Department.

The network team have focussed on hosting case review days alongside the board meetings to provide a more clinical focus. These have been well-attended and have attracted a wider clinical audience.

#### Simulation

SimBaby continues to enhance the network education programme. An adult manikin (Dave) has been developed to complement the paediatric manikin. Dave runs through endocarditis & tattoo-based scenarios. This type of education enables staff to confidently manage the care of children & adults with CHD and heart dysfunction, ensuring a safe pathway of high-quality care. Controlled by a trained educator, the new technology can simulate real life scenarios, allowing healthcare professionals to work effectively as a team to deal with life threatening situations.

#### Congenital course

The Newcastle Clinical Skills Academy continue to offer a Certificate of Achievement in Improving Clinical Practice in Congenital Heart Disease and are currently advertising for their June 2024 cohort. The development of this course was led by Kate Walsh, the network lead nurse, and is the culmination of several years of dedication and hard work. The programme offers nurses, ODP's and allied health professional colleagues the opportunity to advance knowledge and skills in the care of patients living with congenital heart disease.

#### Paediatric ECG fortnightly meetings

We have set up fortnightly virtual meetings for paediatricians from across the region to discuss arrhythmia cases with the electrophysiologist from the Level 1 centre. The fortnightly meetings are a forum to discuss specific cases and provide an opportunity for shared learning, and identify themes to inform our network education and training programme.



## ➤ Patient and family engagement

### **Heart to Heart film**

The network commissioned a short film (<https://youtu.be/ibm-liM0cRI>) which puts a spotlight on the authentic lives of five extraordinary young people living with CHD. Produced by TIN Arts, 'Heart to Heart' has been crafted by lead creatives, Laura Lindow and Laura Degnan. 'Heart to Heart' is a profound testament to resilience and shared experiences.

### **Family Fun Days**

In July 2023, the network hosted 3 family fun education days across the region. These events provided an interactive day full of activities for families living with CHD to learn together and have fun. Some of these activities included basic CPR and first aid training provided by First Aid North East, and physical activity sessions provided by an instructor from North Tyneside Council. The events were supported and attended by CHUF and CHF.

### **CHD Awareness activities**

For this year's CHD Awareness Week in February the network planned for another Melissa Bus roadshow with stops at Whitehaven, Sunderland and Stockton. Unfortunately, due to inclement weather, the final 2 destinations had to be rearranged with spaces booked on-site.

We attended the Long Term Conditions Education Day in March run by the South Tyneside and Sunderland rehabilitation services. This was a great opportunity to engage with patients with congenital heart disease and raise awareness of the network.

### **Patient & Parent Participation Group (PPPG)**

At the beginning of 2024 the network began recruiting for the PPPG. Several people have registered their interest and our initial meet-up is scheduled for June where the group will be renamed, and decisions made as to when and where the group will meet going forward. This should allow for further varied patient and parent input into the continual development of the network services.

### **ACHD Mental Health Webinars**

We hosted a series of webinars for adult CHD patients discussing mental health issues including Low Mood, Stress and Resilience, and Understanding Anxiety. The evening sessions were well attended and the recordings are available on our website and YouTube channel for others to view.

## ➤ Service Reviews

Building on some initial work on developing a South ICP paediatric cardiology service we have started service reviews to assess how providers in our region compare with the Level 3 standards of care for CHD.

We have had an initial review with South Tyneside and Sunderland with a follow up review planned for May 2024. From this we have outlined an action plan to help facilitate an integrated CHD service development at the trust.

An initial service review at the Level 1 surgical centre in Newcastle has been carried out with a clear action plan based on both the CHD service specification and 2019 peer review. A follow-up review is scheduled for early 2024 with the aim to submit this to NHSE regional and national commissioners.

## **National/Regional collaborations**

### ➤ National collaborations

### **National CHD Networks**

We meet with the national CHD networks monthly and are involved in several workstreams; NENC currently lead the National CHD workforce review workstream and co-lead the CHD data workstream. We are leading the nursing workforce review on behalf of the CHD Clinical Reference Group.

We attended the National Network PPV workshop in Leicester March together with patient and family representatives from NENC.

We attended and presented at the National CHD Networks meeting in Bristol in November 2023.

### **Childrens Heart Federation**

We sit on the Childrens Heart Federation Professionals steering group and contribute to the activities of the CHF board.

### **Somerville Foundation**

We co-hosted the Somerville Foundation Hearts Together event in May 2023.

### **British Heart Foundation**

We have been selected as a pilot site for the BHF Under 18s Peer Support event which will take place in November 2024. This is described in more detail in [BHF Under 18s Peer Support Event](#).

## ➤ Regional collaborations

### **Cardiac rehabilitation**

We attended the *Long Term Conditions Education Day* hosted by South Tyneside and Sunderland NHS FT rehabilitation team.

### **Regional Paediatric ECG meetings**

We have established a fortnightly virtual meeting for paediatric consultants from across the region to discuss arrhythmia cases with Dr Seller, paediatric cardiologist and electrophysiologist at the Level 1 centre. The purpose of the meetings to is ensure regular contact between the Level 1 centre and regional colleagues, reduce the email 'traffic' to Dr Seller, ensure timely response to queries, identify common themes and learning opportunities to incorporate into the Network training programme. We have received very positive feedback since the sessions started.

### **Aortopathy Service**

We have been working with tams across the region to develop a regional thoracic aortopathy service aligning pathways, protocols and guidance increasing collaboration and integration of services across teams. We are planning an education event in February 2025.

### **Chuf**

We successfully secured funding from Chuf to run a Psychological Care Scoping and Awareness/Education Project. The funding will enable the appointment of a clinical psychologist to work with the network in developing a strategy for the delivery of good psychological care, and identify NHS business cases to support this. The aim of the project is to have delivered and evaluated interventions to increase awareness and provide education, have developed resources that can continue to be used, and to have contributed to the network strategy for education.

### **PCC/SIC Network**

We sit on the board for the PCC/SIC network and attend the Paediatric Regional Update meetings.

### **Cardiac Clinical Network**

We sit on the clinical advisory group for the cardiac clinical network and attend monthly meetings. We work with the cardiac network on projects that encompass adult CHD patients.

## **Challenges**

### ➤ CHD Data

#### **Regional CHD data**

Progress, albeit very slow, is being made regarding DPIA. Contact has been made with other Network's as to how they brokered a data agreement with the Trusts across their regions.

#### **NCARDRS data**

The Network have successfully submitted an NCARDRS data request application and have recently received historical data submitted to NCARDRS dating back to 1985. Together with other data sources, this will form the basis of the regional CHD database.

All data, either submitted by regional Trusts or NCARDRS, will be held on NuTH network and will only be accessible by the Network Manager and CHD Data Analyst. All requests for aggregate data can be made to the Network Manager as per the SOP.

### ➤ Outreach Clinics

Establishing outreach clinics with some providers remains a challenge. Clinic space, equipment and tertiary consultant PA time are limiting factors when setting up clinics. Chuf continue to offer support for equipment and have approved the purchase of several echo machines for teams across the region.

Workforce challenges within the Level 1 centre has impacted the level of support available for outreach clinics, however the network team are in discussions with the directorate on how to approach this in the future. This also factors in establishing a regional strategy for CHD making the best use of available resources across our region.

## **Work carried over to 2024/25**

### ➤ Service Reviews

Work on developing the paediatric cardiology pathway in the south of the region will continue in 2024/25 and will form part of a wider regional strategy for CHD. Service reviews will be scheduled with South Tees and North Tees in the autumn of 2024.

➤ 2024/25 workplan

The workplan for 2024/25 aligns with the 3-year network strategy and is outlined below.

**Table 2. CHD Network work plan for 2024/25<sup>1</sup>**

Area	Objective	Expected Benefit
Workforce	To review current workforce and complete skills assessments, develop PEC roles across the region	Identify current shortage; identify staff development opportunities; regional education strategy & training programme; regional workforce strategy
Governance	Identify audit lead, develop an audit strategy for the region, establish clinical advisory group	Establish network clinical governance structure; establish pathway and guideline review programme
Understanding CHD Services	Establish data flows across providers, monitoring capacity and demand, regular reporting.	Access to accurate data, inform decision making across the network, highlight pressure points, develop mitigation protocol, meet the 23/24 guidance on recovery to reduce waiting lists
Service development	Improve outreach support, develop south ICP pathway, develop a regional aortopathy service, develop a cardiac rehab service (including mental health support)	Improve patient access/experience; maximise resources
Health Inequalities	Monitoring of DNA appointments, deep dive into demographics of service users, review of appointments offered to patients	Understand the CHD patient demographics; reduce DNAs to increase efficiency; reduce LTFU to improve patient experience
Reducing Variation	Establish clinical advisory group, outline pathway and guidance review programme	Harmonisation of pathways across the network

<sup>1</sup> Subject to change following the output from the strategy development

## Financial Summary

### ➤ Network Budget

The CHD network budget covers the salary costs for the network team and is outlined in **Table 3** below. Regional commissioners have approved any underspend to be used for the purposes of delivering the network workplan and is outlined in **Table 4 and 5**.

**Table 3. NENC CHD Network budget 2023/24**

Post	Grade	Salary rate	Gross cost	WTE	Gross cost
Clinical Lead - Paeds	Consultant			0.1	£ 14,713
Clinical Lead - ACHD	Consultant			0.1	£ 14,713
Lead Nurse	Band 8a	£ 57,349	£ 72,254	1.0	£ 68,250
Network Manager	Band 8a	£ 57,349	£ 72,254	1.0	£ 68,250
Admin & Clerical	Band 3	£ 22,816	£ 27,990	0.6	£ 17,962
<b>Total staff expenditure</b>					<b>£ 183,889</b>
Network Budget 22/23					£ 199,920
Budget Surplus					£ 16,031
Deferred Budget from NHSE non-recurrent funds 22/23					£ 60,919
<b>Total Surplus</b>					<b>£ 76,950</b>

**Table 4. Expenditure against the 2023/24 budget underspend**

Post/expense	Grade	WTE	Gross cost
<b>Total Surplus</b>			<b>£ 76,960.00</b>
Carlisle paediatric outreach clinic	Consultant	1 PA	£ 7,000.00
Durham/Darlington paediatric outreach clinic	Consultant	1 PA	£ 7,000.00
Clinical Psychologist (Jul22-Mar24)	Band 8b	0.4	£ 34,632.00
General expenses (see <b>Table 5</b> )			£ 26,937.31
<b>Total expenditure</b>			<b>£ 75,569.31</b>
<b>Remaining balance</b>			<b>£ 1,390.69</b>

**Table 5. General expenses for 2023/24**

Category	Cost	% of total
learning aids*	£5,473.25	20.32%
travel	£4,476.55	16.62%
patient engagement	£4,140.96	15.37%
educational	£3,699.00	13.73%
venue	£3,035.00	11.27%
marketing	£2,710.14	10.06%
consultation	£1,225.00	4.55%
PEC clinic	£1,042.00	3.87%
stationary	£492.29	1.83%
website	£443.11	1.64%
books	£165.02	0.61%
electronic	£34.99	0.13%
<b>Grand Total</b>	<b>£26,937.31</b>	<b>100.00%</b>

\* includes 2 year warranty for SIM baby which made up the bulk of this expense

### ➤ Funding applications

This year we have applied for additional funding to support the work of the network and support teams to deliver care and innovation to our CHD patients.

#### **Q Exchange application**

This project is to investigate barriers to accessing healthcare services for adult CHD patients. We will partner with an acute provider organisation with connections to primary care to understand how and when patients become lost to follow up. We will reach out to patients to promote living well with CHD and raise awareness of the network and CHD services available to them. Project value: £36,119.

#### **Cardiac Transformation Programme – Cardiac Rehab (ACHD clinical psychologist)**

This project will address the need for psychology provision for adult CHD patients. Currently access to mental health support is very limited and a recent survey of adult patients highlights the importance of timely access to psychology support. Project value: £59,064.

#### **Cardiac Transformation Programme – Cardiac Rehab (Cardiac Transplant psychologist)**

This project will address the increased demand on the cardiac transplant service by improving access to psychology support, decreasing waiting times and enable more 1:1 sessions. Project value: £51,441.

#### **Managing Heart Failure @Home Programme – Milrinone@Home**

This project will allow us to expand on a successful case study implemented during the covid-19 pandemic. While HF@Home is provided for cardiology patients this is not offered to adult CHD patients residing at the Freeman Hospital for substantial periods of time, up to a year, awaiting heart transplant. The project will enable complex ACHD patients from the Newcastle area to reside at home and those from further afield to reside in rented accommodation with family and friends with a milrinone pump, biweekly visits from a nurse specialist and weekly outpatient appointments with the congenital cardiologist. This will significantly improve their mental wellbeing and prevent them from becoming deconditioned while experiencing a sedentary lifestyle as an inpatient. Project value: £41,110.

## **New for 2024/25**

### ➤ ECG one day course

Kaye Walsh has developed a one-day *Paediatric ECG and Arrhythmia* course. This interactive course is designed to provide a safe and engaging learning environment for healthcare professionals seeking to enhance their skills in paediatric ECG interpretation and recognition of arrhythmia. The course has been designed with consultant cardiologist/electrophysiologist Dr Neil Sellar, is being held on 18<sup>th</sup> September 2024.

### ➤ ACHD walk-around video

The Network have commissioned the TEL team at Newcastle to create a walk-around video of the adult service at the Freeman Hospital. This will complement the PICU/HDU video launched in 2023 and will provide adult patients with an opportunity to familiarise themselves with the unit prior to admission, particularly useful for those living at a distance. We are hoping to launch this later in 2024.

### ➤ BHF Under 18s Peer Support Event

We have been selected as a pilot for the BHF Under 18s Peer Support event which will take place in October 2024. With the pressing need for peer-to-peer support among young heart patients in the North East, and the prevalence of socio-economic disparities which limit access to social support, British Heart Foundation is looking to collaborate with the NENC CHD network to launch an innovative pilot that supports young people in the area.

Fully funded by BHF we aim to conduct “One-day connection events” for individuals aged (12-18). Our focus on 12–18-year-olds stems from recognising that this a key age range for social

development. Featuring fun activities with skills-based components such as cooking workshops and team-building challenges, these events are designed to offer opportunities for young people of similar age to connect and build meaningful friendships.

These day events will provide young people with a break from parental oversight and everyday “hospital talk” promoting a sense of independence and normalcy. Post-event, young people will have the opportunity to continue their interactions independently from BHF and the hospital via social media. We hope that maintaining connections in this way will help them to build on the friendships they form during the day events and access ongoing support as they navigate living with a heart condition.

### ➤ Family fun day – supported by NuTH Charity

Following the success of the family fun days last summer we are running a single day in July to engage with families of CHD patients. The day will involve crafts, fitness activities, healthy eating and basic first aid and CPR training. The education day will combine this with opportunities for peer support and education which would empower and inform the congenital heart disease community. This year the project will be supported by Newcastle Hospitals Charity and First Aid North East.

### ➤ Service development - Milrinone@Home

Current guidance recommends patients with adult complex CHD who develop heart failure should be managed in specialist centres with adequate experience in ACHD. This management is often for long periods of time and conventional community heart failure services and cardiac rehabilitation programmes are often limited to specific cardiac conditions and therefore not accessible to ACHD patients with heart failure.

This service development proposal outlines a pilot program to provide milrinone at home to address the inequity of access to home monitoring for adults with complex CHD who are waiting transplant. It will outline the service requirements to manage patients on inotropes from across the country who are under the care of the Freeman Hospital in a home environment close to the specialist centre.

### ➤ Service development – Newcastle Complex Adult CHD Centre

This proposal will outline the development of Newcastle Hospitals as a national centre for complex congenital heart disease adult patients. The aim is to establish referral pathways and criteria to ensure adult patients with complex congenital heart diseases and heart failure are referred to the clinical team at the Freeman Hospital. There are a number of elements to this proposal including the milrinone@home programme, outreach clinics in Cumbria to provide easy access for patients from the west of the country, and an outreach hospital in Newcastle to provide a good quality of life away from home for patients waiting long periods of time for transplant.

### ➤ Regional Strategy – System Approach to delivering CHD care

To address the continuing workforce challenges and the increasing demand on services, particularly with a growing adult CHD population, providing a sustainable robust quality CHD service needs to be implemented at a regional level. Better integration and collaboration between providers of CHD services with clear patient pathways and shared care are needed to ensure the right patient has access to the right healthcare professional at the appropriate time on their CHD journey.

During 2024/25 we will outline collaborative working arrangements and describe how these relationships will work; define patient pathways and resource pathways (for instance outreach, ‘moving professionals not patients’); identify gaps in workforce and where future investment is needed; identify new ways of working such as physiology-led and nurse-led clinics, better utilisation of resources such as diagnostic centres, shared clinic spaces and virtual wards.