



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

Annual Report 2022/23



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 Objectives

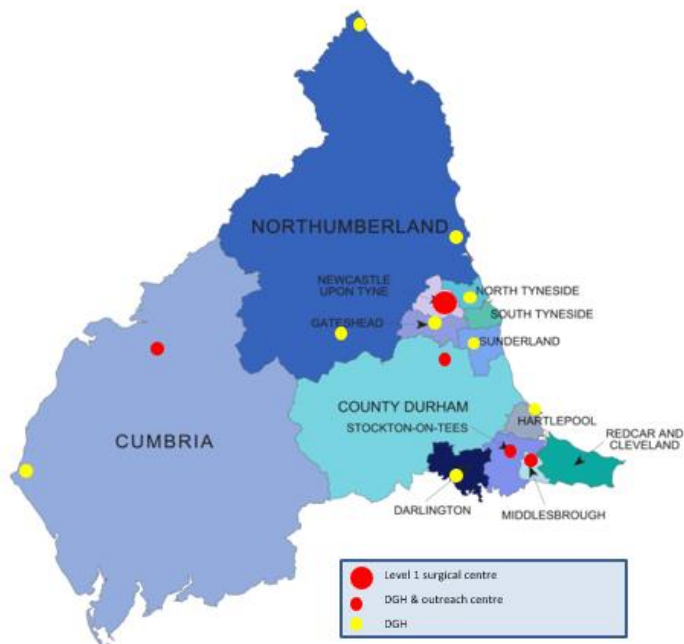
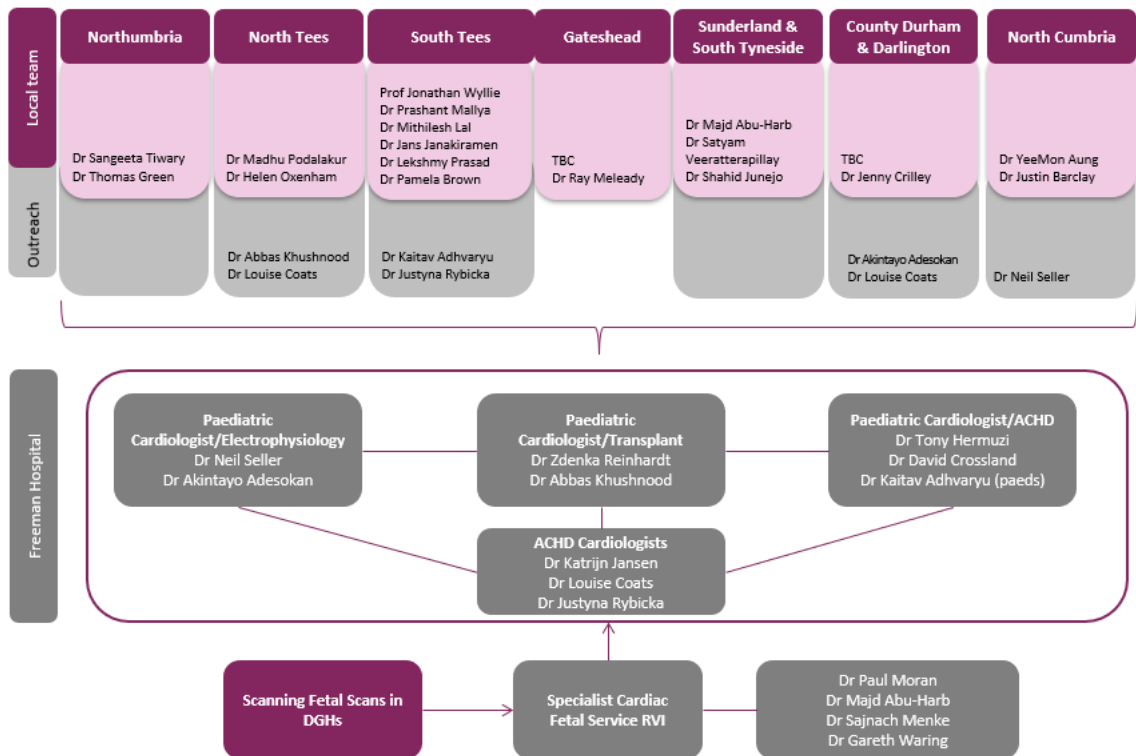
1. Increase patient and stakeholder **engagement** to improve inclusivity and listening.
2. Ensure equitable and lifelong access to **holistic services** for all CHD patients.
3. Provide **strategic direction** for high-quality care throughout the CHD network.
4. Promote **inclusive** and **innovative**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

Network Strategy

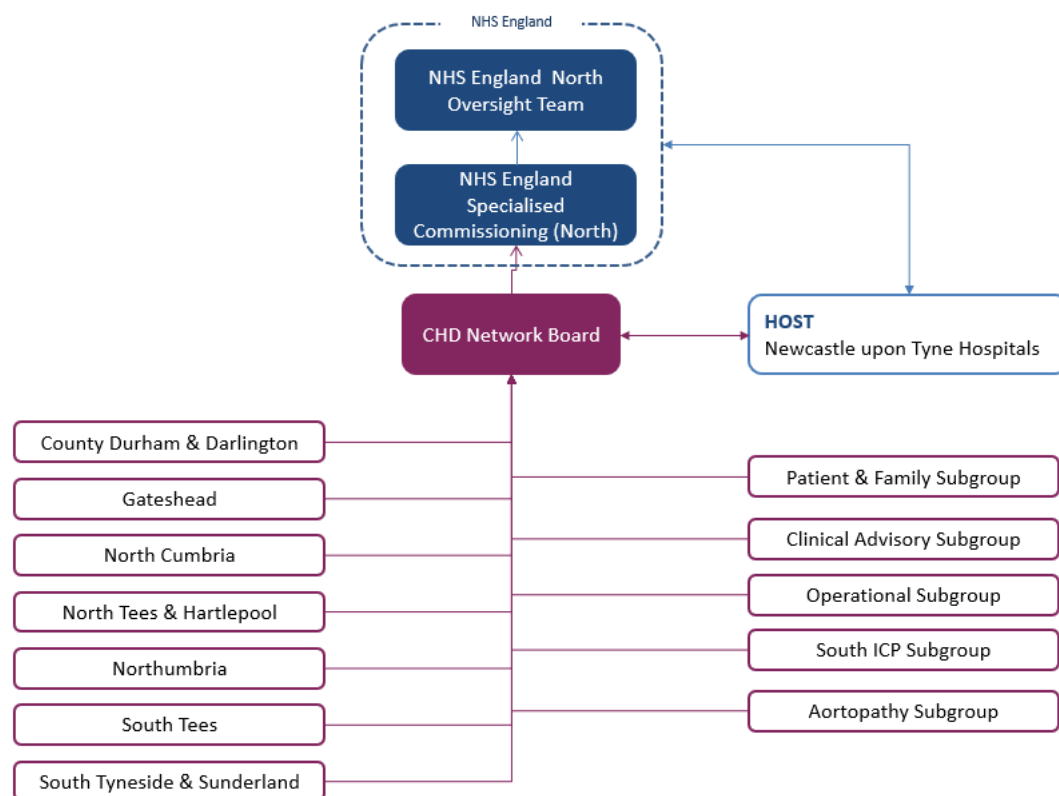
In March 2023 we hosted a meeting to begin the process of outlining a 3 year strategy for the Network. The meeting was very well attended and generated useful discussion. We will present our draft strategy at the Network board meeting in June 2023.

Congenital Cardiac Service North East and North Cumbria

Congenital Cardiac Service North East & North Cumbria



Network Structure & Oversight



New Network board members

Mark Overton – patient representative
 Lisa Davidson – parent representative
 Claudia Meloni – midwife sonographer
 Gareth Waring – fetal medicine
 Claire Boag – consultant midwife

Network board meetings

Following the success of the first face-to-face meeting in October 2022 and the strategy meeting in March 2023, the board meetings will primarily be held face-to-face with a virtual meeting in January via Teams.

The time of the board meetings will be between 10am and 12 noon, the dates and venues for 2023/24 are listed below.

- 14/06/2023 Teams (virtual)
- 18/10/2023 James Cook Hospital
- 17/01/2024 Teams (virtual)
- 27/03/2024 Freeman Hospital

Board meeting attendance

Attendance at board meetings remains challenging despite several meetings being delivered virtually. Of the 12 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

Trust	# meetings
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 2022/23

➤ Education and training

Training events

During 2022/23 we hosted several virtual and face-to-face education events, one of which was a collaboration with the Yorkshire & Humber CHD ODN (Heart Disease in Pregnancy).

- Paediatric Congenital Heart Disease Echocardiography Course May 2022
- NENC-CHDN Study Day May 2022
- Heart Disease in Pregnancy December 2022
- Cardiac rehab training session at Northumbria September 2022
- Paediatric ECG and arrhythmia education day October 2022
- CHD Awareness week Melissa Bus February 2023
- Cardiac Rehabilitation for adults living with CHD March 2023

All of the events were very well attended and we continue to receive positive feedback regarding our education programme.

Simulation

SimBaby continues to enhance the network education programme, Kaye and Elaine have been to a number of Trusts to provide live simulation education with scenarios tailored to the needs of the local teams. This type of education enables staff to confidently manage the care of children with CHD and heart dysfunction, ensuring a safe pathway of high-quality care.

The SimBaby simulator looks and acts like a 9-month-old paediatric patient and provides a highly realistic mannequin that meets specific learning objectives focusing on initial assessment and treatment. 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.

Our thanks go out again to [CHUF](#) for supporting the purchase of SimBaby.

Congenital course

The Newcastle Hospitals skills academy are offering a Certificate of Achievement in Improving Clinical Practice in Congenital Heart Disease here in the North East. The development of this course has been led by Kaye Walsh, the network lead nurse, and is the culmination of a number of years of dedication and hard work.

The course will be run over 4 consecutive Fridays in June 2023 at the Freeman Hospital education centre. 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.

eLearning for health modules

Last year we contributed to the development and launch of the ELHP online congenital heart disease modules which was a collaborative national CHD project to enhance CHD education provision <https://www.e-lfh.org.uk/programmes/congenital-heart-disease/>.

This year Newcastle Hospitals NHS Foundation Trust has added these modules to their skills platform and they are now mandatory training for new staff working with congenital heart disease patients.

➤ Patient and family engagement

Congenital Heart Disease transitional care workshop

We held virtual workshop for CHD patients of transition age in September. The workshop was very well attended and generated a lot of discussion providing education sessions to support patients into adulthood living with CHD. The workshop included a live tour of the adult services within the Freeman. It also provided attendees with an opportunity to ask questions, hear from other patients and meet the adult team who will be managing their care from the age of 18 years.

PICU/HDU video

Together with the staff at Newcastle Freeman Hospital and CHUF, vCreate have created a virtual tour of the paediatric intensive care unit at the Freeman Hospital. The video takes you on a tour of the PICU and HDU to help prepare patients for their hospital stay.

The Network have created business cards for colleagues to hand to patients and families to access in their own time. You can find the video on our YouTube channel [Virtual tour of the PICU at Freeman Hospital - YouTube](#).

TinArts Heart to Heart Shout Out

In January we helped to run two workshops in collaboration with TinArts, Graffiti with Frank Styles and Animation with Sheryl Jenkins. This was an opportunity for young people aged between 12 and 17 years with congenital heart disease to come together to discuss their shared experience and highlight what is important to them.

CHD Awareness Week February 2023

During CHD awareness week in February the team took a road trip on the [Melissa Bus](#) to Carlisle, Stockton and Ashington. The week was a great success and we are hoping to carry out a similar event next year.

Kaye and Elaine were able to carry out some simulation education with A&E staff, paramedics and medical students during the events. We were also joined by the new transition nurse specialists who had the opportunity to discuss the development of this part of the service with patients and staff.

We were also very privileged to be able to discuss some patient stories, which can be found on our website [Patient Stories | NENCCHDN \(nenc-chdnetwork.nhs.uk\)](#).

PPI board strategy meeting

Colocation of paediatric cardiology. The first meeting of the PPI group took place in January 2023. The group reflected on the letter from Dame Jackie Daniel and agreed the principles of patient engagement have not been fulfilled by the Trust regarding colocation of paediatric services to GNCH. The workshop designs were not representative of the lifespan of CHD and the consultation referred to in the letter was dated 2017, did not deal with colocation, and therefore not appropriate as a reflection of current service user engagement. Overall it was agreed that Trust engagement to date appeared to be tokenistic.

All activity of the Trust engagement group is currently 'on hold' until a decision has been made regarding the business case submitted by the Trust in October 2022. There has been recent improved engagement by some members of the Newcastle Hospitals NHSFT team assessing the practicalities of future CHD surgical service provision with the Network. However, at the time of writing, no firm decision, process, or plan has been communicated.

Transition from paediatric services to adult services. Significant concerns were raised around the lack of information or insight into the strategic planning for adult services within the context of co-location. The group raised concerns around the planning for a centre of excellence for paediatrics at the detriment of the adult congenital service. Concerns were raised around the possible down grading of adult services to level 2 as an outcome of co-location of paediatric cardiology.

Safe staffing. The future of congenital heart services in the region after co-location was discussed with particular concern regarding the current staff pressures in many areas of the service. Concerns were also raised around bed shortages, the number of patients on the waiting lists and cancellations of surgical and intervention procedures.

The group would like to see plans for the sustainability of the service at Newcastle with clear patient pathways covering the full lifespan of this patient group, and some reassurance on how the quality and safety of the service will be maintained across two sites.

The Trust and the Network need to agree and produce clear joint plans regarding the long term recruitment and retention of staff in the service, with particular regard to skills development and training to ensure a high quality, safe service before, during and after the planned service move.

Research

Our research colleagues at Newcastle University have successfully recruited 200 patients to Approach IS II (ACHD PROMS, www.approach-is.net/) study and completed a national clinician interview study about ACHD ambulatory care presently submitted for publication. Whilst Newcastle led these studies both have network and national relevance.

The network are also supporting a number of pilot studies, for instance A&E attendance of ACHD patients, and with further data analysis several themes are emerging which will generate hypotheses for network wide projects.

➤ Service Improvement

Clinical psychology support for ACHD patients

The Network funded a nine-month project to explore the regional psychological needs of both transition and adult patients in the North East and North Cumbria region. NHS England standards specify that each Level 1 Surgical Centre for ACHD should employ a minimum of 1 WTE practitioner psychologist (with experience in ACHD) and 1 WTE practitioner psychologist should be employed for each network.

There is no dedicated psychological service for ACHD patients who have relied on local primary care mental health services or general health psychology services. A needs assessment was conducted using group concept mapping methodology, the provision of a pilot clinical psychology service and informal discussions with staff to explore the needs of patients and staff.

The results of the group concept mapping found the main themes centred around anxiety and fears of future treatment, physical deterioration, and the impact on the patient and their family. The most important were worries about the impact of the patients' ACHD on family and friends.

The outcome of the clinical psychology pilot service was well received and attended, with a preference for face to face and some video conference individual appointments. Main problems discussed were anxiety, low mood and symptoms of trauma.

An inequity was identified in the NENC network across the lifespan with the paediatric CHD service currently providing a psychology service therefore leaving young people who transition to adult services without a dedicated psychology service.

South Paediatric Cardiology Pathway

The Network continues to work with local teams to develop the paediatric cardiology service in the south of the region. We have made some progress in accessing data to better understand the number and complexity of the patients with CHD in this area of the region.

Plans were developed to provide more equitable access to early cardiological clinics in Durham and Darlington but events and staff change and movement pre-empted these. Future plans will depend somewhat on the configuration of services with merging of services across the North Tees & Hartlepool NHSFT and South Tees NHSFT for whom a single joint CEO is being appointed.

Nutrition Clinic

The Network continued to fund a weekly nutrition clinic for paediatric cardiology patients needing nutritional support. The nutrition clinic is paediatric dietitian and nutrition nurse specialist led and is based at Freeman outpatient department. The clinic appointments are face to face or over the phone.

The nutrition clinics enable the team to monitor children's nutrition when they are home or in the community and intervene in a timely manner to allow both optimal nutritional care at home as well as early intervention of a deteriorating patient.

Suboptimal nutrition in this group is associated with poor growth and poor brain development. It can affect post-operative outcome; increase in length of hospital stay, longer periods of ventilation and increased risk of developing a hospital acquired infection and mortality.

NCARDS Data

Following our application to NCARDS we have recently received data of patients on the register since 1985. The data will be used to help compile the CHD database for the region, together with data from the Level 1 centre and provider trusts.

National/Regional collaborations

➤ National collaborations

CHD Networks National meeting

The CHD networks national meeting takes place monthly and is chaired by the national lead, Marion Eaves (Programme of Care Manager, Women's and Children's services). Monthly waiting list data is presented at the meeting, and this has been revised to include information about cancellations and average waiting times.

The meeting is an opportunity to identify areas where additional aid and support is required for services and also to share best practice and collaborate on work plans and national projects.

National CHD workforce strategy

The Network have been working with the NHSEI national team on a demand and capacity project. The project is comparing the number of adults with CHD in each regional population with the number of WTE cardiologist with specialist training in CHD and the number of ACHD nurse specialists. These figures are compared with the minimum requirements as outlined in the NHSE CHD National Specifications¹ to estimate the current and future shortfall in workforce capacity.

Current figures for the North East and North Cumbria show a shortfall of 6.6WTE ACHD cardiologists based on current population of 2.9 million². Based on this population figure, the current ACHD population is estimated to be 13,686 (based on a prevalence of 4 per 1000

¹ <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

² <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates>

adults³). However, it has been suggested that this prevalence figure is significantly less than experienced.

This work has since been expanded to include paediatric workforce and all healthcare professionals looking after CHD patients in level 1, 2 and 3 centres. This work is ongoing and will be included in the next update. Initial findings show that there are significant insufficiencies in workforce in adult cardiology (3.6 WTE cf. 7.8 WTE), psychology (0.8WTE cf. 2.9WTE) and clinical education (0.8WTE cf. 2.0WTE) across our region as recommended in the national standards, which is reflected across the country.

CHD Service Specifications Review

The national CHD specification and standards developed in 2016¹ are to be reviewed in 2024/25, the detail of which is yet to be outlined.

CHD data

We are working with CHD Network colleagues across the country on the development of a CHD national dashboard, led by Patrick Uriot (Manager for West Midlands). Slow progress due to difficulties in accessing data within our Network providers.

ODN Specification

A new draft specification for operational delivery networks was published by NHSE in 2022 and provides updated guidance on deliverables for ODNs. This new network specification template will bring a more consistent approach and emphasises the role of networks in supporting ICBs to deliver the triple aim: driving clinically led change and service improvement, improving value, taking greater responsibility for tackling inequalities and for improving population health.

From April 2023, all regions and ICBs will have arrangements in place for networks to be commissioned collaboratively. While the specification for each type of network will remain nationally determined, the annual work programmes will be agreed locally between networks and their commissioners and would be expected to include local, regional and national elements.

Regional collaborations

Cardiac rehabilitation

The Network team have been working with the cardiac clinical network on improving access to cardiac rehabilitation for adults with CHD. Face-to-face and webinar training has been arranged with location centres and a half-day training event is planned for January 2023.

Aortopathy Service

Initial discussions have taken place led by Nic Child from North Tees & Hartlepool NHS Foundation Trust to outline a proposal for developing an aortopathy service across the North East and North Cumbria. The project is still at the service requirements gathering stage and progress will be updated at the quarterly board meetings.

This collaboration includes the cardiac clinical network, cardiologists from across the region and the Northern Genetics service.

Regional HDU provision - cardiac patient care pathway

With the PIC/SIC network we are developing a project to look at the possibility for discharge of patients to a HDU care setting at the JCUH, specifically looking at provision and usage of HDU beds across the region.

This project would explore specific criteria for discharge, which group of patients (if any) are appropriate to be managed in the HDU for ongoing care. Also, the fitness for transfer criteria for this group of patients (NECTAR).

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

The network will support data collection for the project. We can look at the number of patients (once criteria identified) and the number of days spent inpatient at the Freeman.

We can look explore together if any of those patients would have been suitable patients to be cared for in HDU at JCUH. This project would support care closer to home and potentially relieve bed pressure at the Freeman centre.

Challenges

➤ CHD Data

Regional CHD data

The Data Protection Impact Assessment is in the final stages, a standard operating procedure (SOP) and data template have been drafted. A data sharing agreement for the Network board members has been drafted which will enable teams across the region to submit clinic data in order for the Network to have a better understanding of the number, location and complexity of CHD patients in our region.

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.

Work carried over to 2023/24

➤ CHD Database

Work on the development of a regional CHD database continues as challenges remain in outlining an agreement and process for data submission to the CHD network. The DPIA and Data Sharing Agreement are in the final stages and we are hopeful will be signed off at October 2023 board meeting.

➤ South ICP Paediatric Cardiology Service

Work on developing the paediatric cardiology pathway in the south of the region will continue in 2023/24 and will form a central part of our 2023/24 workplan. Deferred underspend from NHSE non-recurrent funds will support clinical time to help design this service.

One output from this will be a regional CHD workforce strategy and service specification for CHD services across the North East and North Cumbria.

➤ 2023/24 workplan

In January 2023 NHSE issued new guidance on network work plans, our plan for 2023/24 is outlined below. Progress will be monitored quarterly and annually by NHSE.

Table 2. CHD Network work plan for 2023/24⁴

Area	Objective	Expected Benefit
Workforce	<i>To review current workforce and complete skills assessments</i>	<i>Identify current shortages across the region, identify areas for staff development, formulate training and education strategy, improve patient access/experience</i>
Governance	<i>Identify an audit lead, develop an audit strategy for the region, establish clinical advisory group</i>	<i>Establish a clear inclusive governance structure, ensure pathways and guidelines are up to date</i>
Understanding CHD Services	<i>Data flows in place across providers, monitoring capacity and demand, regular reporting.</i>	<i>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</i>
Service development	<i>Improve outreach support to CDDFT, develop south ICP pathway, develop a formal aortopathy service, develop a cardiac rehab service including mental health support</i>	<i>Improved patient access/experience, develop PECSIG roles in region, join up services across the region</i>
Health Inequalities	<i>Monitoring of WNB and DNA appointments, deep dive into demographics of service users, review of offered appointment times to patients.</i>	<i>Understand the CHD patient demographics, reduce the number of WNB and DNAs to increase efficiency, reduce LTFU to improve patient experience</i>
Reducing Variation	<i>Establish clinical advisory group, outline pathway and guidance review process</i>	<i>Harmonisation of pathways across the network</i>

⁴ Subject to change following the output from the strategy development

Financial Summary

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**.

Table 3. NENC CHD Network budget 2022/23

Post	Grade	Salary rate	Gross cost	WTE	Gross cost
Clinical Lead - Paeds	Consultant	£ 55,179.85	£ 73,566.11	0.1	£ 14,563
Clinical Lead - ACHD	Consultant	£ 55,179.85	£ 73,566.11	0.1	£ 14,563
Lead Nurse	Band 8a	£ 51,668.00	£ 68,250.58	1.0	£ 67,331
Network Manager	Band 8a	£ 51,668.00	£ 68,250.58	1.0	£ 67,331
Admin & Clerical	Band 3	£ 21,142.00	£ 25,793.00	0.6	£ 16,096
Total expenditure					£ 179,885
Network Budget 22/23					£ 199,920
Total Income					£ 199,920
Surplus					£ 20,035

Table 4. Expenses against the 2022/23 budget underspend

Category	Cost	% of total
books	£ 46.16	0.29%
conference	£ 1,948.30	12.29%
course	£ 2,568.00	16.20%
education	£ 1,124.40	7.09%
equipment	£ 625.24	3.94%
marketing	£ 1,148.50	7.24%
project	£ 3,250.00	20.50%
software	£ 180.06	1.14%
stationary	£ 199.59	1.26%
venue	£ 4,766.17	30.06%
Grand Total	£ 15,856.42	100.00%

In 2021/22 financial year the network was awarded non-recurrent funds from NHS England, the remainder of which was pushed forward into the 2022/23 financial year. An outline of expenditure against these non-recurrent funds are outlined in **Table 5**.

Table 5. NHSE non-recurrent funds 2022/23 (brought forward from 2021/22)

Post/expense	Grade	WTE	Gross cost
Total brought forward			£153,314
Carlisle paediatric outreach clinic	Consultant	1 PA	£ 10,500
Durham/Darlington paediatric outreach clinic	Consultant	1 PA	£ 16,000
Nutrition nurse	Band 7	0.13	£ 7,500
Network Nurse Educator	Band 6	0.8	£ 31,200
Clinical Psychologist - 7 months (Jul22-Mar23)	Band 8b	0.6	£ 37,695
Total expenditure			£ 102,653
Surplus			£ 50,919

The host provider (Newcastle Hospitals NHS Foundation Trust) has approved the request to defer the remainder of the non-recurrent funds to the current financial year (2023/24). Expenditure against these funds is outlined in **Table 6**.

Table 6. NHSE non-recurrent funds 2023/24 (brought forward from 2021/22)

Post/expense	Grade	WTE	Gross cost
Total brought forward			£50,919
Clinical Psychologist (12 months)	Band 8b	0.4	£ 32,959
PA time PECs (North & South Tees)			
Total expenditure			

New for 2023/24

➤ Certificate of achievement in improving clinical practice in congenital heart disease

Kaye Walsh has been developing a programme of education for nurses, ODPs and AHP's for some time. This is being launched in November in collaboration with the Newcastle Hospitals Skills Academy and will provide a quality assured qualification for healthcare professionals involved in the care of patients with congenital heart disease.

This course aims to provide learners with the knowledge and skills necessary to manage the care of a patient with congenital heart disease throughout their lifetime, allowing healthcare professionals to develop vital skills and knowledge to manage the care of patients with complex anatomy and physiology.

The course is being delivered at the Education Centre at the Freeman Hospital each Friday in June and covers the following topics;

- Introduction to congenital heart disease
- The sick child with CHD
- Diagnosis and management of CHD
- The failing CHD circulation
- Psychosocial impact of living with CHD / Moving into adulthood

➤ ACHD Simulation

Kaye Walsh has designed an adult CHD patient simulation scenario which will assess and plan the care of a patient with ACHD presenting acutely at the emergency department with infective endocarditis. We are planning to roll this out later this year commencing with an in situ session at Whitehaven.

➤ Video engagement project

We have been working with TinArts on a patient experience video which Kaye will be presenting at the BCCA Annual Scientific Meeting in November.

➤ Young people engagement event - exercise programme

This year we will be organising a physical activity and exercise fun event for young people aged between 12 and 16 years. It will be a day filled with activities to bring together young people from across the region living with heart disease. It will be an opportunity to meet others of the same age, share their lived experience, learn new things, and have their voice heard. We will be asking for their views throughout the day to help shape future services for young people.

We are hoping this event will be the springboard for a young persons exercise programme in collaboration with the cardiac rehabilitation team at South Tyneside and Sunderland with the support of the [Children's Heart Federation](#).

➤ Family education days

Families and adult patients have requested opportunities to engage in 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 will be delivered over three days across the region in 3 locations. Locations will be accessible public buildings with licencing to deliver public events.

This project will be supported by CHUF, CHF (Childrens Heart Federation) and First Aid North East.

➤ Parent workshops

These workshops will focus on 'The teenage years living with CHD. We are in this together', and will bring parents and carers together in a fun interactive workshop where we can learn from the experts and from each other.

A psychologist will start the session with a fun and informative introduction to the adolescent brain. We will provide a safe space to explore the challenges and shared experiences of family life with CHD and discuss what additional challenges present with CHD and how to navigate them. Our end goal is to produce a 'top tips' resource for parents which will be available on our website and social media channels.

➤ Somerville Heart Foundation patient conference

The Somerville Heart Foundation conference is an annual event for young people and adults born with a heart condition to come together and meet others who have ACHD. The conference will include talks from healthcare and industry professionals, with a focus on wellbeing, social interaction and peer support bringing congenital hearts together from all over the country.

This year the conference is being held in Newcastle with input from the clinical and nursing teams at the Freeman Hospital.

➤ Clinical psychology support for ACHD patients

Continuing with the work carried out last year described above, the Network will continue to fund two clinical psychologists to support adults with CHD for further 12 months. The Network will provide updates at board meetings.

➤ Dental digital PIL (D-PIL)

The team at the Freeman Hospital are developing a digital patient information leaflet to raise awareness of the key oral health messages for children and young people with congenital heart disease. They will be embracing new technology to ensure that children and young people will be more engaged and will be achieved via an innovative digital publishing platform.

The e-book will include core content supplemented by animation and audio files. During the development stage, feedback will be sought from end users to ensure it is accessible for the target audience. Input from the National Paediatric Dentistry – Clinical Excellence Network will be sought.

➤ 3 Year Network Strategy

In March 2023 the Network hosted a strategy development meeting to outline the priorities for the Network over the next 3 to 5 years. The meeting was very well attended with great collaboration and discussion. The Network team will present a draft strategy at the board meeting in June 2023.