



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

Annual Report 2024/25



## Document History

<b>Title</b>	Annual Report for NENC-CHDN 2023/24
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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

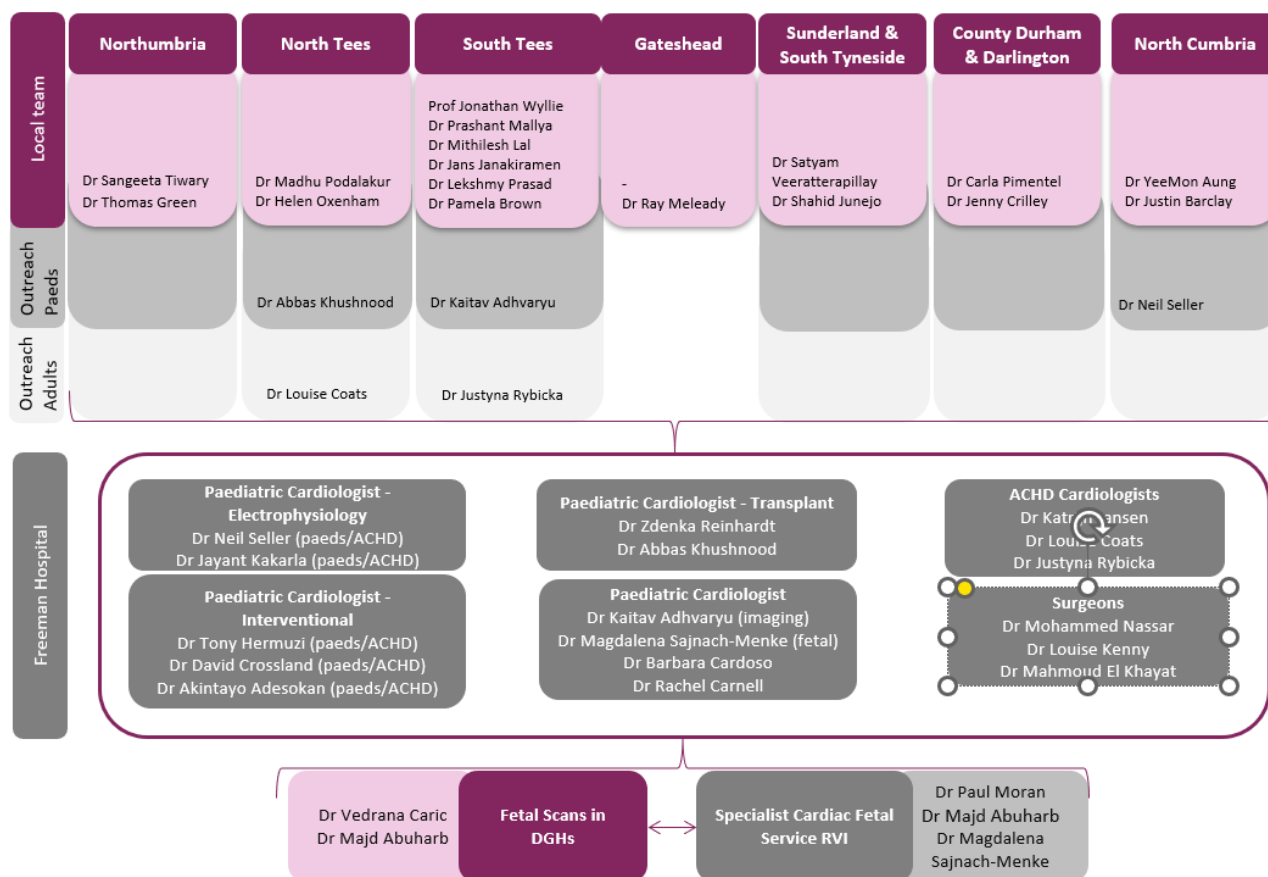
In March 2023 we hosted a meeting to begin the process of outlining a 3 year strategy for the Network. The meeting was very well attended and generated useful discussion. Our strategy was presented at the Network board meeting in June 2023 which included a revision of our six key objectives are:

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.

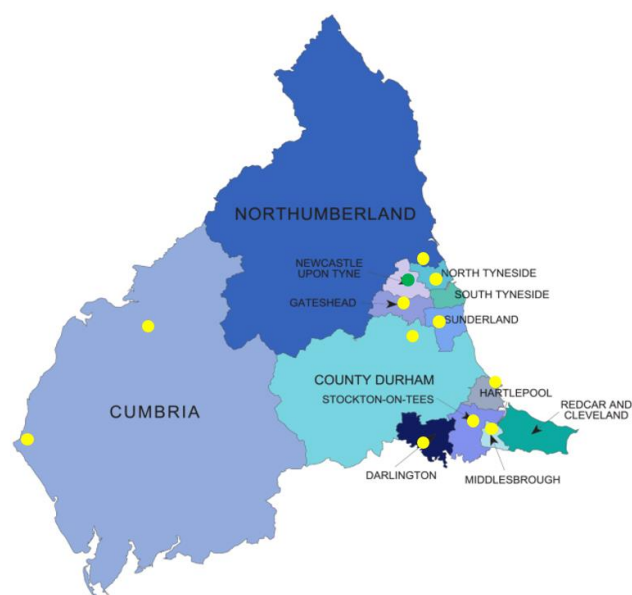
The key theme for the strategy is greater collaboration and integration between stakeholders across the geography of this CHD network. Together with a drive for skills development, training, and a focus on innovative research, it will steer us towards a more sustainable, high-quality service for congenital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

objective	fetal	neonatal	children	adults
<b>1.</b> 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
<b>2.</b> 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).
<b>3.</b> 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)
<b>4.</b> 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.
<b>5.</b> 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.
<b>6.</b> 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.
 <div>Improving patient outcomes</div> <div>Inequalities</div> <div>Population Health</div> <div>Prevention</div>				

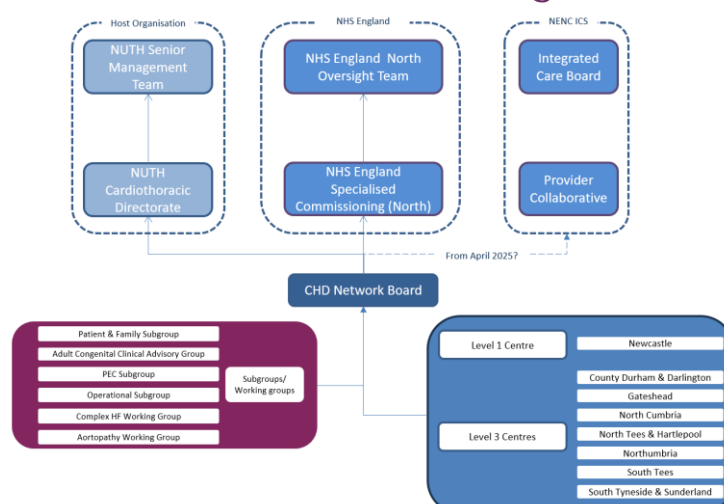
## Congenital Cardiac Services North East and North Cumbria



## Centres across the 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 and have been moved to Teams to improve attendance. Board meetings were held on the following dates;

- 17/07/2024
- 18/11/2024
- 20/01/2025
- 27/03/2025

The board meetings were preceded by a PEC (paediatrician with expertise in cardiology) subgroup meeting where regional paediatric cardiology pathways and guidelines are discussed.

### Board meeting attendance

Attendance at board meetings remains challenging and meetings have moved online. Over the last year, all providers attended at least one board meeting with three providers attending all 4 board meetings. Gateshead Healthcare do not have a paediatrician with expertise in cardiology and their patients attend Newcastle for both children and adults. CDDFT have only recently appointed a PEC and have had limited opportunity to attend.

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

Trust	# meetings
CDDFT	1
Gateshead Healthcare	0
Newcastle	4
North Cumbria	4
North Tees & Hartlepool	3
Northumbria	2
South Tees Hospitals	2
South Tyneside & Sunderland	4

## Summary of work 2024/25

### ➤ 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. During 2024/25 we developed our education strategy and programme which will continue to evolve as we gather feedback from attendees and healthcare professionals across the region.

#### Training events

During 2024/25 we hosted or presented at over 22 training events including events hosted by the network, presentations at external education events and SIM sessions at local Trusts.

#### Bespoke education

We continue to support bespoke CHD education sessions across the region as a part of our ongoing education and training commitment. This often involves a classroom-based CHD education session embedded into a wider curriculum. We believe this work is essential to maintain and develop relationships with regional teams, ensuring CHD awareness is embedded across the services in the network. Learners report feeling empowered and prepared to manage the care of a patient presenting with CHD.

#### Simulation

SimBaby continues to enhance the network education programme. An adult manikin (Dave) has been developed to complement the paediatric manikin. Dave enables the simulation team to deliver in-situ endocarditis scenarios. In-situ education empowers staff to work confidently in their own clinical environment whilst practicing evidence-based care of 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.

Feedback to date has been mostly positive, with teams reporting a greater understanding of endocarditis and risk associated with CHD. The simulation in-situ has enabled improved relationships with regional emergency departments, streamlining communication with specialist services to enhance the care pathway for CHD patients. The programme will run throughout 2025 with the aim to deliver this essential education into all emergency departments across our region.

#### Congenital course

The Newcastle Clinical Skills Academy continues to support delivery of the Certificate of Achievement in Improving Clinical Practice in Congenital Heart Disease, with dates currently advertised for the June 2025 cohort. The development of this course was led by Kaye Walsh, the network lead nurse, and is the culmination of several years of dedication and hard work. The programme offers nurses, ODPs and allied health professional colleagues the opportunity to advance knowledge and skills in the care of patients living with congenital heart disease.

As we prepare to deliver cohort five of the course it is important to recognise the contribution of the specialist healthcare team who contribute to the in-depth programme. Holistic, lifelong approach to managing care is the fundamental basis of this programme, with experts delivering sessions throughout the programme ensuring learners receive high quality, evidence based, up to date insight into the pathway of care from cradle to grave for those living with CHD. The programme this year will be delivered both in person and virtual to offer colleagues from further afield the option to participate.

#### 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. To date 133 cases have been discussed. The network team are aiming to undertake an impact analysis in the coming year to understand the effect these meetings have had on referral to the Level 1 centre and timely access to advice.



### Paediatric echo monthly meetings

Similarly to the ECG meetings, we have set up monthly virtual meetings for paediatricians from across the region to discuss echocardiograms with a congenital consultant from the Level 1 centre. Again, these meetings are an opportunity to discuss specific cases and provide an opportunity for shared learning and identify themes to inform our network education and training programme. To date 14 cases have been discussed.

## ➤ Patient and family engagement

### Family Skills (CPR) Days

Following the success of our family days in 2023/24, and after feedback from our patient and family group, we hosted a family first aids skills and CPR training day in January 2025. The day included some physical activities as well as basic CPR and first aid training provided by First Aid North East. The events were supported and attended by Chuf.

We are hoping to continue with these events and have a second event scheduled for 18<sup>th</sup> May 2025.

### Patient & Parent Participation Group (PPPG)

The PPPG is currently attended by 8-15 representatives when we meet every four months, other who cannot attend often communicate via email. We have 33 members who regularly maintain contact responding to emails. Agenda items for meeting often reflect the priorities areas for many who attend the meetings, including topics such as transition, data sharing and support for CHD patients and families. PPPG voice has been embedded in the recent psychology and wellbeing project, at the National networks meeting and fundamental to network peer support resource development project. Next steps for further development of this group will include a rotational post onto the network board and offering appropriate training for PPPG members in collaboration with Children's Heart UK.

## ➤ Clinical work programme and service improvement

### Adult CHD psychology support

NENC CHD network submitted a business case to the NUTH clinical board to establish a robust psychology service to support adult CHD patients. This included 1.0WTE clinical psychologist, psychology assistant and service administrator. As an interim the network have applied for 2-year funding to Newcastle Hospital Charities for 1.0WTE clinical psychologist to set-up the service.

### Service reviews

We continued with service reviews during 2024/25 with the aim of understanding local services and developing action plans to help teams with service development opportunities. These are informal meetings and while the national standards are reviewed the primary focus is on discussing local challenges and opportunities for improvement and development.

### Newcastle Hospitals – Level 1 surgical centre

Initial service reviews were conducted in September 2021 and much of the discussion focused on the colocation of paediatric cardiology service with other paediatric services at the Great North Children's Hospital. While colocation of services has been put on hold the service reviews have focussed on the provision of outreach clinics and supporting the education and training programme for the network.

A follow-up review of the Level 1 surgical centre was carried out in 2024 in preparation for the peer review planned for June/July 2025. The network are working with the Trust in preparation for the peer review which has a specific scope other than the national standards and will focus on outcomes, pathways, productivity, and improvements to existing service models within current resources.

### South Tyneside and Sunderland – Level 3 centre

Service reviews have been carried out at South Tyneside and Sunderland for both adult congenital and paediatric cardiology teams. The main areas of focus for the Trust action plans include;

- Adult congenital nurse specialist – business case submitted. This role forms part of the wider development of the adult congenital service at the Trust.

- Outreach clinics – these are being reviewed together with the outreach needs of neighbouring Trusts.
- Cardiac physiologists – regional training programme
- Transition – develop a transition pathway within the Trust
- Service development – identify patients that can be discharged/transferred from the Freeman, for both paediatrics and adults

#### *South Tees Hospitals – Level 3 centre*

An initial service review was carried out for paediatric cardiology in October 2022. The main focus of the discussion was regarding the provision of a paediatric cardiology nurse specialist for Teesside, identifying patients to contribute to the regional database and ensuring the local paediatrician with expertise in cardiology is able to spend a minimum 20% of their total job plan (including Supporting Professional Activities) in paediatric cardiology (in accordance with the British Congenital Cardiac Association definitions).

The next paediatric review is scheduled for Monday 9<sup>th</sup> June 2025 and the adult congenital review to be arranged before September 2025.

#### *North Cumbria – Level 3 centre*

Review meetings were held for both paediatrics and adult services at North Cumbria in May 2024. Actions from the meetings focussed on the provision of outreach clinics for adult patients (planned for Workington Diagnostic centre from July 2025) and support to establish a link nurse role. In paediatrics the focus was on establishing an honorary contract at Newcastle Hospitals for Dr Yee Mon Aung and clinical sessions at the Freeman Hospital and support to establish a link nurse role for paediatrics.

#### *County Durham and Darlington – Level 3 centre*

Service review meetings are to be arranged with the teams at CDDFT later in the autumn 2025.

#### *Northumbria Healthcare and Gateshead Health – Level 3 centres*

With the proximity of both Trusts to the level 1 centre service reviews have been deemed unnecessary. However, the network engages with the clinical teams on guideline and pathway development and education and training needs of local staff through the clinical advisory groups.

#### *Common themes from service reviews*

Overall across all Trusts actions have centred around the following;

- Outreach clinics
- Clinical sessions at Freeman Hospital
- Support for education and training for clinical physiology workforce
- Support in establishing nurse roles to improve service provision
- Transition pathways within local centres and out from the level 1 centre
- Discharge/transfer of patients to local services
- Lack of and age of echocardiography machines

The Network are addressing these by;

- Outlining a regional strategy for CHD services across the North East and North Cumbria
- Creating clinical subgroups to develop local guidelines and pathways
- Reviewing the outreach provision across the region with the aim of maximising resources by possibly combining outreach services across multiple level 3 centres
- Progressing with charity applications for echo machines

#### Working groups

During 2024/25 we revised our approach to how we engage with local teams. It was felt that although the board meetings are an effective way of feeding back on progress on the workplan and national priorities, there often wasn't opportunity to address more detailed objectives.

We therefore set up a quarterly paediatric clinical advisory group to discuss clinical priorities and work on regional guidelines and pathways. Quarterly operational meeting were set up to share information and best practice, discuss operational pressures and opportunities for mutual aid.

### Regional waiting list and activity dashboard

We are at the very early stages of designing a waiting list and activity dashboard for NENC CHD services. Due to the lack of centrally accessible data we have established a process whereby each unit submits data to the network team on a quarterly basis (see [Appendix 1](#)). While this information is accessible within each unit for paediatric patients as the clinics are coded as 'paediatric cardiology' the same is not true for adult patients who are seen in mixed cardiology clinics and are therefore not easy to identify.

## **National/Regional collaborations**

### ➤ National collaborations

#### Children's Hearts UK (formerly Children's Hearts Federation)

NENC network sit on the Children's Heart UK Professionals steering group and contribute to the activities of the CHF board. NENC CHD network are working with CHF to implement a patient and parent representative training programme to support patients and families to engage with network boards and facilitate the codesign of local services.

#### British Heart Foundation

We co-hosted an Under 18s Peer Support event in November 2024 with the British Heart Foundation. 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 invited us to collaborate to launch an innovative pilot that supports young people in the area.

Fully funded by BHF we hosted two "One-day connection events" for individuals aged 12-18 years. Our focus on 12-18-year-olds stems from recognising that this is a key age range for social development. The events featured fun activities with skills-based components such as cooking workshops and team-building challenges and were designed to offer opportunities for young people of similar age to connect and build meaningful friendships.

The events provided 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.

An outline report can be found in [Appendix 2 – BHF Under 18s peer support outcome report](#) but some highlights include;

#### Insights from Young People

- Appreciated the opportunity to connect with others who have similar experiences.
- They spoke of several benefits such as building friendships and enhancing self-esteem.
- Attending consecutive events helps give them confidence to make friends and exchange contact details.

#### Insights from Parents

- Agreed that the format helped their children form friendships.
- Observed that their children have continued to stay in touch via WhatsApp, gaming, and Zoom.
- Making connections with other parents outside of hospital settings is highly valued

The young people described the following benefits from attending these types of events:

- Meeting new people and making friends, developing social skills
- Meeting people who have the same condition, so they don't feel alone
- Creating a community, teamwork
- Having fun and "do different things than normal"
- Feeling positive

#### National CHD Networks

The national CHD networks meet monthly with the national commissioner. Last year, NENC network lead on the National CHD workforce census and activity workstreams and led the nursing workforce review on behalf of the CHD Clinical Reference Group (see [Appendix 3](#)).

We attended and presented at the National CHD Networks meeting in Dublin in November 2024 and presented at the national CHD workforce summit in November 2024.

The workforce workstream involved analysis from several separate pieces of work including fetal cardiology survey, nurse survey, clinical scientist review and patient flow survey, together with the workforce census.

The activity workstream reviewed surgical, catheter intervention and outpatient activity from all Level 1 CHD centres across England for 2023/24.

A national CHD workforce strategy was drafted on the outputs from these workstreams which were presented at a steering group involving a range of stakeholders including NHSE, CRG, and national charities. Several defined projects have emerged from this work which will be initiated in 2025/26 to further develop services nationally.

## ➤ Regional collaborations

### Children's Heart Unit Fund (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. See Appendix 4 for recent quarterly report.

### Paediatric cardiology support for CDDFT

The network facilitated the movement of clinical staff from Trusts across the region to run clinics at University Hospital of North Durham to address the waiting list for paediatric cardiology referrals and improving capacity at the Level 1 surgical centre.

Following the success of this initiative, we are including this in our regional strategy to deliver CHD services and working towards establishing a regional waiting list and MDT.

### Level 1 centre cardiothoracic clinical board

In June 2024 we had an initial meeting with the cardiology team to discuss the development of Newcastle (and NENC) as a centre for advanced heart failure for adult CHD patients. Following initial discussions, it became evident that this would be best achieved by reviewing HF services for both congenital and non-congenital patients at Newcastle. This will be a large and ongoing piece of work, and we will feedback on progress in this annual report.

### Clinical Networks

We sit on the board for the Paediatric Critical Care/Surgery in Children network and attend the Paediatric Regional Update meetings. We work collaboratively on bespoke projects where there is crossover between the networks.

We contribute to 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 such as imaging and aortopathy.

### Provider collaborative

We have attended several meetings hosted by the NENC Provider Collaborative (PvCO) and recently attended the clinical strategy meeting. We have contributed to discussions regarding clinical priorities in the region including identifying vulnerable services, to help inform the PvC strategic approach to clinical services.

Together with the children's services management team at County Durham and Darlington NHS Foundation Trust, we recorded a podcast to showcase the use of the portability agreement in use across the region. This enabled the network to facilitate the movement of clinical staff from neighbouring trusts to run clinics at University Hospital of North Durham addressing the growing waiting list for paediatric cardiology referrals and improving capacity at the Level 1 surgical centre.

## Challenges

### ➤ Access to regional data

#### Regional CHD data

Access to CHD patient identifiable data has stalled completely from providers across NENC. The main barriers are the lack of region-wide data sharing agreements to support the network roles and cost of accessing data from NHSE regional team or NECSU.

This is making it difficult to deliver some of the network specification including;

- managing capacity and demand across NENC ensuring effective patient pathways and use of resources
- managing waiting lists and monitoring waiting times
- identify where in the region CHD patients reside to establish best location of outreach services, and
- identify transition age patients and where they reside to ensure effective transition to adult services.

The lack of access to data is also preventing delivering several quality improvement projects including lost to follow up review, aortopathy audit and adult CHD A&E attendance.

#### NCARDS data

The Network have successfully submitted an NCARDS data request application and have recently received historical data submitted to NCARDS 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 NCARDS, 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 have impacted the level of support available for outreach clinics, however the network team are in discussions with the clinical board to design a more sustainable offer. One such opportunity is better utilisation of current workforce and delivering physiologist-led and nurse-led clinics.

This is being incorporated into our regional CHD strategy which will be published in 2025.

## Work carried over to 2025/26

### ➤ Clinical work programme and service improvement

Several projects will be carried over to 2025/26 and beyond due to their complexity and the challenges with access to data, and some are longer-term projects that will span across a number of years. These projects will feature in the annual workplans, and progress will be monitored by the network manager in the network delivery plan and the NHSE quarterly review updates.

#### 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 several 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.

### Service Reviews

Work on developing the paediatric cardiology pathway in the south of the region will continue in 2025/26 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.

### Regional Guidelines and Pathways

While we have made progress in developing several regional guidelines the process has been slow while clinical teams recover from the pandemic. However, 2024/25 seen momentum with this work improve which we expect to continue on 2025/26, particular with the development of fetal cardiology and adult CHD guidelines.

### 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 mutual aid for outreach clinics); 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.

### National Heart Failure data

During 2024/25 the network commissioned the NECSU to deliver data to support a project identifying heart failure patients seen at the Freeman Hospital, which included patients who had contact with acute services elsewhere in the country immediately prior to their admission or transfer to the Freeman Hospital. This year we will analyse the data to support the development of Newcastle as the first-point of contact for complex ACHD patients with heart failure.

### Regional CHD data

During 2024/25 the network commissioned the NECSU to deliver data to support a project to identify where CHD patients reside in NENC. The aims of the project are to;

- Identify CHD patients within the region who have a diagnosis or procedure codes including analysis of coding differences and identification issues within providers across the network's remit.
- Geographical mapping of identified CHD patients in comparison to regional hospital sites

During 2025/26 we will be able to have a clearer understanding of how many patients there are in NENC with CHD and where they reside which will help inform service delivery, patient pathways and outreach clinics.

### ACHD outreach clinics

We are working with the adult cardiology team at Cumberland Infirmary to set-up monthly adult congenital outreach clinics at [Workington diagnostic centre](#). We are aiming to establish these from July 2025 and will feedback to the network board on progress.

During 2025/26 we are also aiming to set-up monthly outreach clinics at [Bishop Auckland Hospital](#) and expand the provision across [Teesside Hospitals](#).

## ➤ National collaborations

### CHD national workforce strategy

The NENC CHD network are leading the next phase of the national CHD workforce programme by conducting a second workforce census to understand differences in recruitment and retention in CHD workforce since the first census in 2023. Together with the outputs from fetal cardiology, nursing, and patient flow review projects, the 2025 census data will outline a national CHD workforce strategy which is expected to be published in the last quarter of 2025/26.



## ➤ 2025/26 workplan

The workplan for 2025/26 aligns with the 3-year network strategy and is outlined below.

Table 2. CHD Network work plan for 2025/26

Priority	Objective <i>What change are you seeking to bring about?</i>	Expected Benefit <i>What benefit do you expect to realise from achieving the objective?</i>	Financial / Workforce / Estates	Potential Implications <i>What resources are needed to deliver the objective?</i>
Workforce	Targeted training programme for sonographers. Establish a PEC training programme. Physiologist subgroup and training programme. Business case model for L3 specialist nurses.	Identify workforce gaps across the region. Identify staff development opportunities. Create innovative ways for working including nurse- and physiologist-led clinics.	Workforce	Support from Trusts, NHSE, ICB and Health Education England National CHD networks
Governance	Formalise network clinical governance process. Embed clinical guideline development process.	Clarity around network clinical governance. Clear pathway and guideline review programme.	Financial, workforce	Support from clinical teams, input from network clinical leads
Service development / Improving value	Regional CHD strategy – gap analysis of services and commissioning. Regional waiting list and activity dashboard and regular reporting. Service reviews for L3 centres. Newcastle ACHD-HF service development. Develop Teesside CHD service alongside cardiology. Regional transition services – initial scoping.	Improve patient access/experience. Maximise resources by improving access to services and better use of the regional workforce, including non-medical workforce. Monitor capacity and demand across the region. Highlight pressure points across the system. Develop mitigation and escalation protocols.	Workforce, financial	Provider organisations, information governance, IT, NHSE PPV group, access to patient data
Health Inequalities	Monitor DNA/WNB appointments and waiting times across NENC. Identify barriers to access to services. Chuf psychology scoping and awareness project.	Identify which areas would benefit from outreach services. Improve patient experience and efficiency by reducing DNAs/WNB and LTFU. Provide solutions to address inequalities in access.	Financial	Provider organisations, IT, primary care organisations, access to patient data
Reducing Variation	Improve outreach support. Review existing and develop new pathways. Understand the barriers to accessing healthcare for adult patients.	Harmonisation of pathways across the network. Improving access to services by better use of the regional workforce, including non-medical workforce.	Workforce, financial	Provider organisations Q exchange application submitted to support understanding barriers for ACHD project, access to patient data
Patient voice / Patient experience	PPV representation on network board. PPV group – feedback into network board. Training opportunity (Children's Hearts UK). Develop patient experience videos.	Ensure board membership has broad representation. Ensure PPV representatives feedback on network workplans and objectives. Ensure the PPV members feel equipped to contribute fully. Ensure our work and service development is codesigned and lead by service users.		PPV group Board members

## 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 the expenditure for 2025/26 is outlined in **Table 4**.

Table 3. NENC CHD Network budget 2023/24

2024-25					
Outgoings					
post	grade	Salary rate	Gross cost	WTE	Gross cost
Clinical Lead	Consultant	£ 126,281.00	£ 160,611.00	0.1	£ 16,141.00
Clinical Lead	Consultant	£ 102,466.00	£ 130,085.00	0.1	£ 13,074.00
Lead Nurse	Band 8a	£ 50,952.00	£ 64,375.00	0.8	£ 48,281.25
Lead Nurse	Band 8a	£ 57,349.00	£ 72,615.00	0.2	£ 14,523.00
Network Manager	Band 8a	£ 57,349.00	£ 72,615.00	1.0	£ 72,615.00
Admin & Clerical	Band 3	£ 22,816.00	£ 27,990.00	0.6	£ 16,878.00
<b>Network staff expenditure</b>					<b>£ 181,512.25</b>
Clinical psychologist	Band 8b (Apr-Jun)	£ 68,525.00	£ 86,580.00	0.2	£ 4,351.00
Clinical psychologist	Band 8b (Apr-Jun)	£ 58,972.00	£ 74,335.00	0.2	£ 3,735.00
<b>Network supported staff expense</b>					<b>£ 8,086.00</b>
<b>Total staff expenditure</b>					<b>£ 189,598.25</b>
non-staff expense (see separate table)					£ 15,900.16
<b>Total outgoings</b>					<b>£ 205,498.41</b>
<b>Income</b>					
Network Budget 2024/25					£ 207,826.00
<b>Funding applications</b>					
NuTH Charity - PPG					£ 3,300.00
NuTH Charity - transition animation project					£ 1,800.00
<b>Total income</b>					<b>£ 212,926.00</b>
2024/25 balance					<b>£ 7,427.59</b>

Table 4. General expenses for 2024/25

Category	Cost
Catering	£ 238.50
Clothing	£ 544.58
Conference	£ 437.20
course fees	£ 530.00
Data analytics	£ 2,547.00
Equipment	£ 2,388.01
Marketing	£ 208.32
Patient engagement	£ 1,697.33
stationery	£ 94.16
Training	£ 948.00
Travel	£ 2,267.06
Venue	£ 911.00
SIM baby Warranty	£ 3,089.00
<b>Total</b>	<b>£ 15,900.16</b>



## ➤ Funding applications

This year we were successful in obtaining funding from Newcastle Hospitals Charity to support patient engagement events and provide holistic support for inpatients at the Freeman Hospital. Additional funding from Newcastle hospital charities has supported the creation of a young person transition animation film. This creative piece has been coproduced by young people with lived experience of transitional care from paediatric to adult services while living with a long-term health condition. The final film will be circulated in the Autumn.

## New for 2025/26

## ➤ Clinical work programme and service improvement

### New network clinical lead for adult congenital

From May 2025, Dr Helen Oxenham will be taking over as clinical lead for the CHD network. We would like to take the opportunity to thank Dr Louise Coats for her valuable contribution in establishing the network in the North East and North Cumbria and welcome a different perspective from Helen in 2025.

### ACHD Clinical Advisory Group (CAG)

Following the success of the paediatric CAG and operational subgroup, we have set up a monthly meeting for regional cardiologist. This will take a slightly different format to the paediatric CAG in that it will include case discussions as well as guideline and pathway development discussion. We will be encouraging attendance from trainees in the region at both the paediatric and ACHD CAG meetings.

### CHD peer review

A national peer review of CHD services is planned for 2025/26 which will take the form of an online assessment overseen by the local CHD network and site visits from the NHS England national team. Each CHD network will support the NHSE national team in conducting the peer review at each level 1 surgical centre.

### National CHD waiting list dashboard – surgery, intervention and outpatients

NENC CHD network are working with the national commissioner to design a national waiting list dashboard to monitor waiting lists across the country, identify services under particular pressure and have early sight of mutual aid opportunities. The dashboard includes data submitted monthly from all 9 CHD networks across England and Wales

## ➤ Patient and family work programme

### Youth Worker project

The network team are submitting a charity application to support the placement of a 1.0 WTE Band 4 youth worker within the existing team at the Great North Children's Hospital. The role will support young people age 14-24 years living with heart disease with the aim to:

- Develop and implement a youth strategy for young people living with heart disease, ensuring that their voice is heard
- Engage with clinical teams to understand service needs, developing a robust referral criteria
- Support the network in developing young person group engagement activities
- Support young people living with heart disease, including inpatient and outpatient access for young people living in the North East and North Cumbria region
- Develop peer support opportunities for young people in the region

### 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 2025.

### CHD Lived Experience Peer Support Videos

The project aims to capture the lived experiences of patients and families living with CHD. It will focus on creating a suite of short films that can be accessed by patients and families as and when they feel the need to reach out for support. The films will offer insight across the lifespan of the disease to ensure those who are looking find resources relevant to them and their experiences at that time.

This project is supported by the NENC Provider Collaborative.

### Oral hygiene and oral health campaign – Friday 13th June 2025

In collaboration with the Newcastle oral health team and the British Society of Dental Hygiene and Therapy, the network is supporting a one-day oral hygiene campaign to spotlight the importance of oral hygiene relating to CHD. Team members will actively engage health promotion activities across the inpatient and outpatient services at the specialist centre.

### 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.

## ➤ Education and training

### Cardiac physiology subgroup and training programme

We will be establishing a cardiac physiologist subgroup for the network who will develop regional guidelines and patient pathway for echo teams, run quarterly meetings to share best practice and learning, develop a PEC echo training programme and develop a physiologist-led outreach and training programme across NENC.

### Fetal sonographer training programme

The Network are working with fetal medicine colleagues across NENC and simulation teams at NUTH and Teesside University (Darlington campus) to outline a training support offer for sonographers across the region. The programme will include the development of regional guidelines and pathways to ensure equity of care across NENC and will inform a national review of the FASP screening programme.

### Regional study half-day event – paediatrics

We will be hosting a half-day learning event in September 2025 for the network board clinical members and their colleagues. The event will encompass structured teaching, case discussion and feedback from patients and families.

### ECG and arrhythmia teaching 2 half day events (paediatrics and adults)

Following the success of the monthly ECG meetings and the one-day ECG and arrhythmia course, we will be holding 2 half-day events to deliver some structured teaching and have a broader discussion around common themes identified in the monthly meetings.

## Appendices

### Appendix 1 – Regional waiting list and activity dashboard



NENC CHD Activity  
and Waiting List Quar

### Appendix 2 – BHF Under 18s peer support outcome report



U18 Peer Support  
Pilot 2024 Insights\_(Ex

### Appendix 3 – NHSE CHD workforce review summary



CHD workforce and  
activity review on a p:

### Appendix 4 – Chuf Psychological Care Scoping and Awareness/ Education Project



CHUF Funded Project  
Quarterly Report Jan-