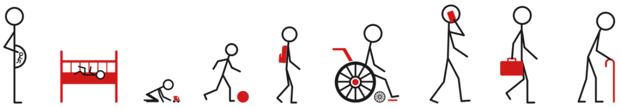
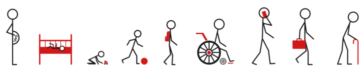
Congenital
HEART NETWORK
NORTH WEST | NORTH WALES | ISLE OF MAN

2024/25
Annual Report



North West, North Wales and Isle of Man
Congenital Heart Disease Network

Contents



Foreword from our Chair

Carolyn Cowperthwaite
Board Chair
NW CHD Network

I'm incredibly proud of the team's ***dedication to patient-centre care......***

This report highlights both the remarkable achievements and persistent challenges facing our network. I'm incredibly proud of the team's dedication to patient-centred care, evident in the progress made in the focus on patient and family's stories at Board, patient engagement, clinical governance, and staff education.

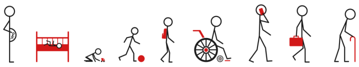
We've seen positive movement in some waiting lists, and I'm optimistic about further improvements with upcoming staff additions and new clinic opportunities. However, the critical staffing shortages, especially cardiac nurse specialists, and limited access to consultants and psychology support remain a major concern. We must address these resource gaps to truly deliver the highest quality care.

The database project continues to be a priority, though funding and timelines require close attention.

I'm pleased with the PPV group's impactful work and their commitment to amplifying the patient voice and thoroughly enjoyed and was humbled by my visit to the group. While financial pressures and risk management are ongoing, I'm confident that by working together, we can overcome these challenges and continue to improve outcomes for our patients, families, and staff. The unwavering commitment of this team is truly inspiring.

Carolyn

Carolyn Cowperthwaite
Board Chair
NW CHD Network



Clinical Directors’ Network Review

Dr Caroline Jones, Consultant Paediatric Cardiologist, Alder Hey Children’s Hospital

Dr Damien Cullington, Consultant Adult Congenital Cardiologist, Liverpool Heart & Chest Hospital

It feels a relief to exit the dark, cold winter days and step into Spring at long last. We are delighted to keep you informed of our new CHD network developments.

In this report we will highlight some of the key educational events which the network has been proud to host – namely the learning disability family day and training day for transposition of the great arteries. More planned educational activities are in the offing for the year ahead. We were delighted to welcome last year our new CHD network chair into post, Carolyn Cowperthwaite who has effortlessly taken things in her stride. The network team has been busy with addressing governance reviews across the region and have completed NHSE Standard reviews of Alder Hey and Royal Manchester Children’s Hospital.

Whilst the longer days ahead provide some welcome relief there are also some uncertainties on the horizon with significant changes in organisational top structure, namely the abolishment of NHS England and also changes to ICB funding. Whilst these matters are at large, we wish to provide reassurance as the CHD Network team, that it is very much ‘business as usual’ and we will continue to deliver the best advocacy for CHD patients and their families.

Driving Improvement and Reducing Inequality: Our 2024/25 Objectives in Action

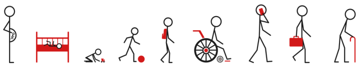
The North West Congenital Heart Disease (CHD) Network has made strong progress against its 2024/25 objectives, continuing to build a collaborative, clinically led and patient-centred system of care. Our work this year has focused on improving governance, strengthening clinical oversight, embedding robust pathways, and ensuring the voice of patients and families remains central to service development. The following summary outlines the key objectives and progress to date:

- **Strengthening Network Governance**
  Enhancing the governance structure of the Operational Delivery Network (ODN) has been a priority. We successfully recruited an independent Chair for the Network Board, bringing impartial leadership and additional scrutiny to decision-making and strategic direction.

- **Clinical Governance Oversight**
  A structured approach to clinical governance has been embedded. Regular multi-disciplinary governance meetings are now established, with case discussions, shared learning and action planning. This process ensures consistency, supports clinical quality, and helps to minimise variation in care across the region.

- **Pathways, Policies and Protocols**
  Significant work has been undertaken to review, update and develop clinical pathways, policies and protocols. A substantial number of documents are in place, providing clear guidance for clinicians and supporting equitable access to care. This remains a dynamic area of work, with ongoing updates to reflect evolving best practice and service development.

- **Improvement and Innovation: Regional Database**
  The network has made excellent progress in developing and implementing the regional all-age CHD database. The system is now capable of receiving data from providers, and we are awaiting the completion of local procedures before entering the testing phase. This initiative supports population health management, service planning and quality improvement, while also directly contributing to reducing the possibility of patients being lost to follow up, unwarranted variation and tackling health inequalities.



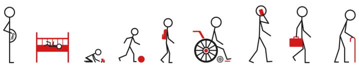
Driving Improvement and Reducing Inequality: Our 2024/25 Objectives in Action

Patient and Public Voice and Learning Disability Inclusion
Meaningful patient and public involvement remains a cornerstone of our work. Over the last year, we have developed several patient information videos, hosted regional open days and support events, and worked closely with our Learning Disability (LD) Forum. With support from the network the LD forum has undertaken provider visits to review reasonable adjustments and improve the experience of people with learning disabilities accessing CHD services. This work aligns with NHS England's drive to reduce health inequalities and ensures that all patients, regardless of background or ability, can access safe, effective, and person-centred care.

Research
In recognition of the importance of research in driving improvements in care, the Network has now published a Research Strategy. This outlines the Network's role in supporting and facilitating research activity across the region, helping to embed a research-positive culture in both specialist and local centres.

Self-Assessment and Assurance
A programme of self-assessment against national service standards is continuing. Level 1 and 2 paediatric centre assessments have been completed, with action plans in place to address identified gaps. Assessments for fetal cardiology providers are in progress. This work is key to supporting continuous improvement and ensuring compliance with national service specifications.

Equity, Access and System Partnership
Across all objectives, the Network continues to work closely with system partners, including the three North West Integrated Care Boards (ICBs), to promote equitable access to care, early diagnosis, and consistent service delivery. Our initiatives are aligned with the NHS Core20PLUS5 approach to tackling health inequalities, ensuring that children, young people, and adults with CHD receive the care they need regardless of geography, socioeconomic background or individual circumstances.



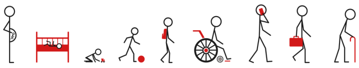
Patient Public Voice Representatives

This year has been another busy and rewarding one for patient and public involvement across the Network. Despite some challenges early in the year, the dedication and passion of our Patient and Public Voice (PPV) Group has remained strong -thank you to all our members for their continued support. While we said goodbye to four PPV members for various reasons, we've also welcomed new faces and have grown as a group. Together, we've made great progress.

We would like to extend a heartfelt thank you to the Network staff and to Alder Hey Children's NHS Foundation Trust, who host the Network, for their ongoing commitment and support during what has been a challenging year at times.

Our vision & achievements 2024-25

- To raise awareness and to recruit new members. We worked in partnership with Liverpool John Moore's University and launched a media campaign to raise awareness across the North-West of England, North Wales and the Isle of Man during World Heart Day in September 2024 and being interviewed live on local radio stations.
- PPV members have started visiting clinics to meet patients and families face-to-face.
- Hold live Zoom PPV drop-in sessions every two months to hear directly from the patients.
- We have continue to support and challenge where we feel it is important to do so especially around backlogs and waiting times for clinic appointments.
- Contacting our local MPs asking them to look into why there is a discrepancy between funding congenital heart disease services in the South of the country compared to similar sized services in the North West.
- Developed a video to share our own personal stories from antenatal diagnosis through to adult life and to weave those powerful stories into the important work of the PPV group - to be launched in May 2025.



Patient Public Voice Representatives

Our vision & achievements 2024-25

- Proud to continue representing patients and families on the North West CHD Board.

We would like to thank the new Chair of the Board, Carolyn Cowperthwaite for the support she has shown to the PPV group since starting in her new position.

Learning Disabilities (LD) Forum

An offshoot of the main PPV Group – the LD Forum has also had a very active year. Highlights of the year include:

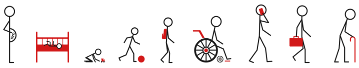
- An open day held at Liverpool Heart and Chest Hospital in June 2024. Click here the link to view what happened on the day.
- Presented 'distraction toy bags' to NW level 1 and 2 providers (both paediatric and adult congenital heart disease), to help make hospital visits a little easier for patients with learning disabilities. Thank you to the NW CHD Network, Team 1c, and The Children's Heart Association for making this possible.
- Continue to to develop their checklist to help improve experiences for patients.
- Group visited Alder Hey on 3rd October 2024, seeing the great work in place, having important discussions about fresh ideas - including the introduction of easy-read name badges.

Acknowledgements

Thank you to:

- Everyone who has been involved this year – your contributions are helping us build a kinder, more inclusive, and patient-focused Network for all
- Linda Griffiths, Nicola Marpole, Jill Moran - NW CHD Network
- Helen Chadwick NHSE Specialist Commissioner

In conclusion, the role of the PPV representatives is to support and challenge and we have had many opportunities to do both of those this year. We are grateful for the recognition of our role by the Network and remain committed to fostering an open and transparent relationship moving forward.



Training & Education

The NW CHD Network has remained committed to delivering high-quality education and training to support the professional development of staff involved in the care of paediatric cardiology and adult congenital heart disease patients. Throughout the year, the network has hosted, or supported, a range of training sessions, study days, and multidisciplinary learning events.

Events held:

- Paediatric CHD regional study day – focus single ventricle conditions- 25/04/24 for nurses and AHPs
- Paediatric ICC study day – all professionals, 13/06/24
- Transposition of the Great Arteries study day – all professionals – 27/09/24
- Pregnancy, Contraception and Heart Disease Webinar – 21/01/25

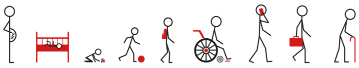
Future events:

- Neonatal and paediatric palliative care study day 29/04/25
- Learning Disability for professionals' study day 13/06/25
- Paediatric CHD regional study day – focus Tetralogy of Fallot - 25/04/24 for nurses and AHPs 08/07/25

Course & conference funding:

Once again, the Network was able to fund staff involved in the care of paediatric cardiology and ACHD patients to attend education and training events:

- British Congenital Cardiac Association Cardiology Conference – 3 staff members
- AEPC Hamburg 2025 – 1 place
- UK Maternity Cardiology Society Annual Conference 2024 – 1 place
- British Society Heart Failure annual meeting - 1 place
- International Board of Heart Rhythm Examiners (IBHRE) exam – 1 place
- British Society of Echocardiography conference 2024 – 1 place



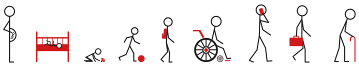
Nursing

The NW CHD Network has continued to work with nurses involved in the care of paediatric cardiac and ACHD patients through access to specialist training, peer collaboration, and shared best practices. By connecting nurses across the network, we strengthen knowledge, confidence, and care for our patients with cardiac conditions.

Future Plans

- **Nursing section of the new NW CHD Network Website will be going live soon:** This will provide a centralized platform for resources and communication.

- **Promote e-Learning for Health Module:** Continued promotion of the module which is not yet incorporated into mandatory training for CHD nurses in Level 1 and Level 2 centres. CHD Learning Hub to access the module.



Clinical Governance

Clinical Governance continues to have a major focus and has been a priority for the network over 2024–2025. It is now business as usual with a strong and well-established process in place for reporting mortalities and incidents via an online reporting form. Providers are expected to complete this report every 6 months. This also gives them an opportunity to share best practice, near misses and to discuss complaints. We have also included a section to update on any relevant audits or research projects that are being undertaken. Our Network Clinical Directors are closely involved in the clinical oversight of this process.

Network Documents

Development of a Network Mortality Reporting Form

Downloadable from
NW CHD Network Website

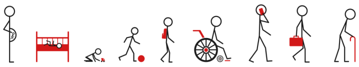
Network Incident Reporting Form

- We have updated our reporting process. We create a full report after each meeting that is available on request. However, in order to make the outcomes more accessible we have also created a one-page report that highlights themes and agreed actions. This is shared across the Network.

- Two clinical governance meetings held on 18th July 2024 and 30th January 2025, chaired by the Lead Nurse. Attendance has varied somewhat over the past year from 21-36 members of staff (from approx. 32 in the previous year). There is good representation from level one and level three paediatric cardiac centres but engagement from level 2 paediatric and ACHD services remains a challenge and is a focus for improvement in the coming year.

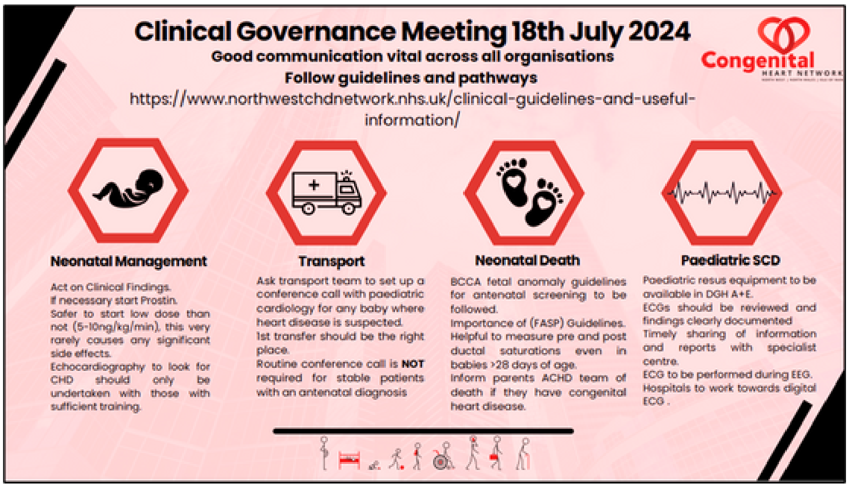
A full programme of incidents and mortalities have been discussed resulting in some common themes being identified.

Date	Number of Attendees	Incidents for discussion		Mortalities for discussion	
		Paed/Neo	ACHD	Paed/Neo	ACHD
18/07/24	21	4	0	3	1
30/01/25	36	3	0	2	1



Clinical Governance

Summary reports for meetings 2024/2025



Clinical Governance Meeting 18th July 2024

Good communication vital across all organisations

Follow guidelines and pathways

https://www.northwestchdnetwork.nhs.uk/clinical-guidelines-and-useful-information/

Neonatal Management

Act on Clinical Findings.
If necessary start Prostin.
Safer to start low dose than not (5-10ng/kg/min), this very rarely causes any significant side effects.
Echocardiography to look for CHD should only be undertaken with those with sufficient training.

Transport

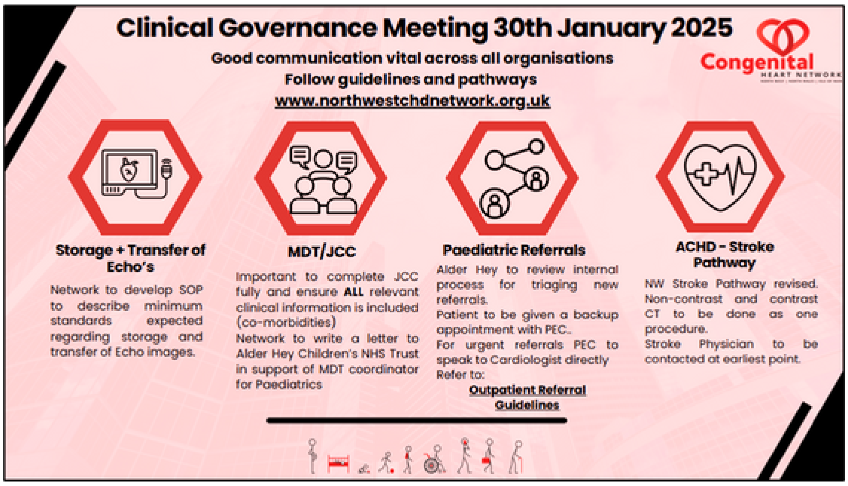
Ask transport team to set up a conference call with paediatric cardiology for any baby where heart disease is suspected.
1st transfer should be the right place.
Routine conference call is **NOT** required for stable patients with an antenatal diagnosis

Neonatal Death

BCCA fetal anomaly guidelines for antenatal screening to be followed.
Importance of (FASP) Guidelines.
Helpful to measure pre and post ductal saturations even in babies >28 days of age.
Inform parents ACHD team of death if they have congenital heart disease.

Paediatric SCD

Paediatric resus equipment to be available in DGH A+E.
ECGs should be reviewed and findings clearly documented
Timely sharing of information and reports with specialist centre.
ECG to be performed during EEG.
Hospitals to work towards digital ECG .



Clinical Governance Meeting 30th January 2025

Good communication vital across all organisations

Follow guidelines and pathways

www.northwestchdnetwork.org.uk

Storage + Transfer of Echo's

Network to develop SOP to describe minimum standards expected regarding storage and transfer of Echo images.

MDT/JCC

Important to complete JCC fully and ensure **ALL** relevant clinical information is included (co-morbidities)
Network to write a letter to Alder Hey Children's NHS Trust in support of MDT coordinator for Paediatrics

Paediatric Referrals

Alder Hey to review internal process for triaging new referrals.
Patient to be given a backup appointment with PEC..
For urgent referrals PEC to speak to Cardiologist directly
Refer to:
Outpatient Referral Guidelines

ACHD - Stroke Pathway

NW Stroke Pathway revised.
Non-contrast and contrast CT to be done as one procedure.
Stroke Physician to be contacted at earliest point.

- We are encouraged by the continuing improvement in engagement with providers particularly from Alder Hey Children's Hospital as our level 1 provider.
- We would like to especially recognise PEC involvement which has been consistent and supportive throughout the past year. Whilst there has been some engagement from the level 2 centre at Royal Manchester Children's Hospital and from our ACHD teams from across the Network we would like to see this improve.
- It is noted that there were no incidents reported to the Network during this financial year from adult services. We will be discussing the strategy for improving engagement at the Network SLT meetings, with our regular quarterly updates with providers and will also be attending the CHOG (Congenital Heart Operational Group) meetings at Liverpool Heart and Chest Hospital, to raise awareness across the ACHD clinical teams of the benefits of engagement.

Database

Significant progress has been made on the CHD North West Network Database. The Data Protection Impact Assessment (DPIA) is now signed off, and data-sharing agreements are in place. A revised timeline has been agreed upon with the vendor and provider trusts, with the first data expected to flow in May 2025.

> *“A revised timeline has been agreed upon.....”*

Initially, the system will be tested by a small pilot group before being rolled out to all Level 1 and 2 providers. Additionally, NHS England has approved the carry-over of £15,000 to support cloud storage costs for the next three years, ensuring the system’s sustainability.

In partnership
WITH

MEDIWAVE

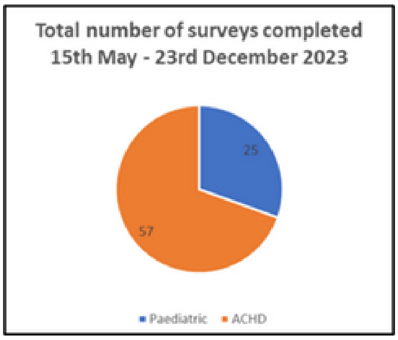
Patient and Family Experience of congenital heart services (PREMS)

- Work has continued throughout 2024-2025 to further develop the networks commitment to hearing and responding to patient experiences and feedback.
- The paediatric and ACHD surveys continue to be accessible via the online portal.
- The priority this year has been to raise awareness by providing posters for ward and clinic areas. The link is now available on the Network website.
- The clinical nurse specialists have included the QR code on the back of their business cards that they give out to patients and some providers are considering adding the QR code to the clinic letters as well.

The surveys can be found by clicking here.

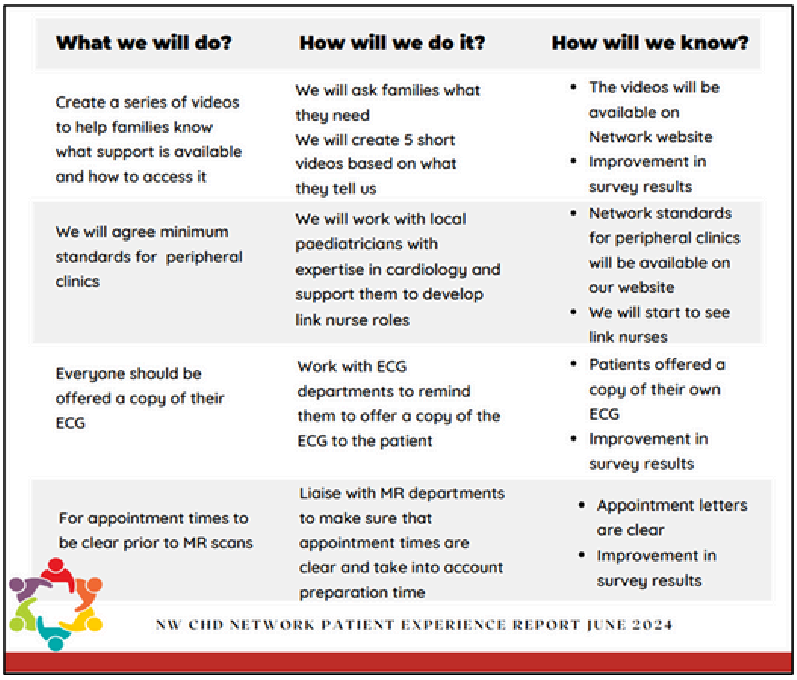
Our first Patient Experience Forum met on 6th June 2024. This had representation from Network staff, clinical staff including nursing, medical and psychological staff from provider level. Operational leads and patient and public voice was also represented. At this meeting they reviewed the outcomes of both the paediatric and adult surveys from between 15th May – 23rd December 2023.

The full report can be found here: NWCHDN PREM Report 2024



Patient and Family Experience of congenital heart services (PREMS)

Outcomes from that meeting are summarised below



What we will do?	How will we do it?	How will we know?
Create a series of videos to help families know what support is available and how to access it	We will ask families what they need We will create 5 short videos based on what they tell us	• The videos will be available on Network website • Improvement in survey results
We will agree minimum standards for peripheral clinics	We will work with local paediatricians with expertise in cardiology and support them to develop link nurse roles	• Network standards for peripheral clinics will be available on our website • We will start to see link nurses
Everyone should be offered a copy of their ECG	Work with ECG departments to remind them to offer a copy of the ECG to the patient	• Patients offered a copy of their own ECG • Improvement in survey results
For appointment times to be clear prior to MR scans	Liaise with MR departments to make sure that appointment times are clear and take into account preparation time	• Appointment letters are clear • Improvement in survey results

NW CHD NETWORK PATIENT EXPERIENCE REPORT JUNE 2024

Progress towards those outcomes

- **Video's:** Work is progressing well. We have completed a video around what support is available and how to access it and a video about how to use play at home and in hospital. We are currently working on the third video which is all about how to talk to children with a heart problem. There are two additional video's that are yet to be started.

- **Minimum Standards for Paediatric peripheral clinics:** This work is due to be started in 25/26 financial year and has been added to Network annual work plan. We have engagement from our local PECs to help with this work and will align it with the Network Self assessment process against NHS England Standards.

- **ECG's:** We have met quarterly with providers to discuss how patients can be informed about accessing a copy of their normal resting ECG. We have provided a poster for staff to display in clinic areas encouraging patients to ask and we have shared this on the NWACH Facebook page for adult patients.

- **MR Scan appointment:** We have raised this with the Lead and Operational Manager at our level one adult provider and have asked them to look into getting this letter amended so that it is clear what time patients should arrive for their MR scan.

Patient and Family Experience of congenital heart services (PREMS)

Looking to the future

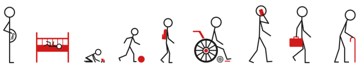
- **Patient Experience Forum:** Although the original intention was to meet every six months, this has proven challenging due to current workforce constraints and competing priorities within the Network's annual work plan. In addition, it has become evident that reviewing patient experience data on an annual basis allows for a more robust and meaningful analysis. As such, the Forum will now meet yearly to review outcomes. The next meeting is scheduled for June–July 2025 and will focus on survey responses collected between 1 January and 31 December 2024.

- **Two more surveys are ready:** We have a meeting scheduled for April 2025 to explore the financial implications and assess whether the project is feasible within the current financial envelope and constraints. If it is deemed viable, we have secured support from the digital team to assist with its delivery. If this isn't feasible we will explore alternative options.

The two surveys are aimed at:

People who are learning disabled & their families/carers

Young people going through transition



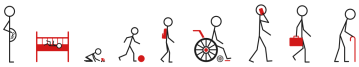
Network Risks & Challenges

For the financial year 2024-2025, the NW CHD Network has continued to adapt to the changing healthcare environment, dealing with both new and ongoing risks. In the past, there was a risk register that listed risks managed by individual providers. However, in collaboration with Alder Hey Children's NHS Foundation Trust, which acts as the host, and following regional advice on how Networks should handle and track risks, we've made changes to how risks are reported, tracked, and managed.

The Network Risk Management Standard Operating Procedure (SOP) is being updated to reflect these changes and ensure it aligns with the risk management practices used by other ODNs.

Key significant changes

- The Network has developed and implemented a dedicated risk tracker to maintain oversight of all risks reported to the CHD Network Board. This replaces previous use of the In-Phase reporting system at Alder Hey for Network-related risk monitoring.
- Provider-level risks remain the responsibility of individual organisations. Only those risks which have a direct impact on Network delivery are held under the Network category on the risk tracker.
- Individual provider risks and local actions are discussed at quarterly meetings with operational managers and lead nurses. Where appropriate, the Network offers advice and support to assist in risk mitigation.
- All paediatric cardiac and ACHD providers have been asked to report, via exception, any risks scoring 12 or above to the Network Board on a quarterly basis.
- The Network risk tracker is reviewed and updated monthly by the Network Senior Leadership Team.

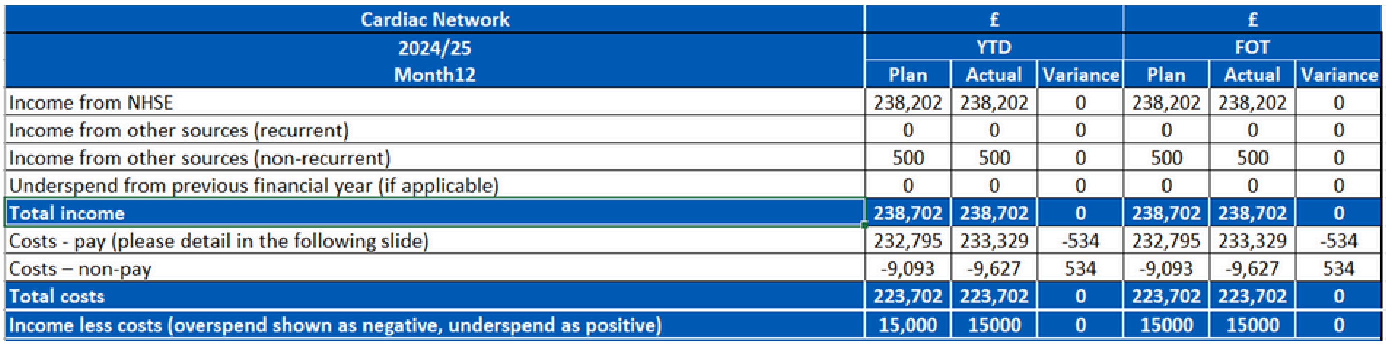


Finance Summary 24/25

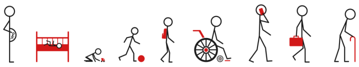
The NW CHD Network has carefully managed its financial resources to support key priorities and ensure sustainable service development.

- CHD Database Implementation – NHS England has approved the carry-over of £15,000 to cover cloud storage costs for the next three years, ensuring the system remains operational beyond the initial implementation phase.
- Workforce & Education – Investment in professional training, governance support, and clinical engagement activities has strengthened workforce development across the network.
- Operational Delivery & Network Support – Core funding has been utilised to maintain network coordination, quality improvement initiatives, and engagement with providers.

Looking ahead, securing long-term funding for database maintenance and expansion to Level 3 centres will be a priority, alongside continued investment in service improvement and workforce development to enhance care across the region.



Cardiac Network 2024/25 Month12	£ YTD Plan	£ YTD Actual	£ YTD Variance	£ FOT Plan	£ FOT Actual	£ FOT Variance
Income from NHSE	238,202	238,202	0	238,202	238,202	0
Income from other sources (recurrent)	0	0	0	0	0	0
Income from other sources (non-recurrent)	500	500	0	500	500	0
Underspend from previous financial year (if applicable)	0	0	0	0	0	0
Total income	**238,702**	**238,702**	**0**	**238,702**	**238,702**	**0**
Costs - pay (please detail in the following slide)	232,795	233,329	-534	232,795	233,329	-534
Costs – non-pay	-9,093	-9,627	534	-9,093	-9,627	534
Total costs	**223,702**	**223,702**	**0**	**223,702**	**223,702**	**0**
Income less costs (overspend shown as negative, underspend as positive)	**15,000**	**15000**	**0**	**15000**	**15000**	**0**



Looking to the future, what’s next?

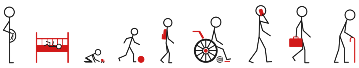
A year of progress,
a future of possibility……

As we reflect on the past year, it is clear that the North West Network has continued to make meaningful progress in strengthening services, embedding collaboration, and ensuring that the voices of patients and families remain central to all that we do.

The dedication of our clinical teams, partners and patient representatives has been instrumental in achieving the objectives set out in this report.

We are proud to support all children and young people with heart conditions, and adults living with CHD across the region. Looking ahead, we remain committed to driving further improvement, addressing health inequalities, and ensuring that every individual receives safe, high-quality and equitable care.

Our focus for the coming year will be on consolidating our achievements, deepening partnerships with ICBs and local systems, and continuing to deliver real change for our patients and their families.



We thank you for your continued support to the Network

Contact

www.northwestchdnetwork.nhs.uk

NorthwestCHDNetwork@alderhey.nhs.uk

@NwchdN

North West, North Wales and Isle of Man
Congenital Heart Disease Network
ANNUAL REPORT 2024/25