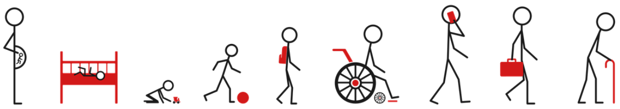
Congenital
HEART NETWORK
NORTH WEST | NORTH WALES | ISLE OF MAN

2025/26
Annual Report



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

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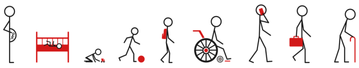


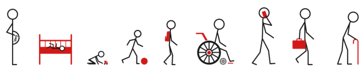
Foreword from our Chair

Carolyn Cowperthwaite
Board Chair
NW CHD Network

As I reflect on the past year, I am struck by the incredible resilience and dedication of our network team. Our commitment to patient-centred care remains paramount, guided by the invaluable insights of our Patient and Public Voice (PPV) group. Their "critical friend" approach ensures that lived experience continues to shape our most important initiatives, including our work to ensure patients receive high quality care closer to home in our local cardiology centres and strengthening transition pathways for young people and their families.

Celebrating Major Milestones

A standout milestone this year is the significant progress of our Regional CHD Database. We are now moving into the live data testing phase, which is a major step forward in how we will use technology in the future to enhance patient safety, service planning, and equitable care. As we move into the next phase, we look forward to supporting all centres to participate fully, cementing this database as a vital, collective tool for the future of our network.



Excellence in Education

Our education programme continues to be a jewel in our crown—ranging from our network-led congenital heart disease sessions to our groundbreaking learning disability study days. Education remains a core function of our network and is essential to our clinical growth. We are fully committed to championing these sessions, ensuring our staff have the resources and learning opportunities they need to thrive.

Leading the National Conversation

The North West hosted the CHD National Networks Annual Meeting in Liverpool in March. This was a prestigious opportunity for our region to lead the national review of clinical standards and to showcase the excellence, innovation, and collaborative spirit of our Network on a national stage.

Thank you for your unwavering dedication to our patients across the North West, North Wales, and the Isle of Man. Together, we are building a stronger, more connected future for CHD care.

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

This year has been marked by significant progress across the North West, North Wales and Isle of Man Congenital Heart Disease Network, reflecting the dedication of our multidisciplinary teams and the strength of our regional collaboration. As the largest Level 1 congenital heart services outside London, our centres have continued to deliver high-quality, patient-centred care at scale, with outstanding procedural activity across both adult and paediatric services, and sustained commitment to improving equity of access throughout our Level 2 and Level 3 network.

The maturing of our clinical governance framework has been a particular highlight, with strengthened processes for shared learning, clearer oversight of risk, and increasing participation across providers. Our ongoing work to standardise transition pathways, improve communication, and deepen engagement with children, young people, adults and families ensures that lived experience remains central to our service development.

A major achievement this year has been the development of our Regional CHD Database, which has successfully entered the live testing phase. This represents a transformative step towards consistent, high-quality data collection that will underpin future service planning, quality improvement and more equitable care. Alongside this, our education and training programmes have continued to grow, supporting workforce development and celebrating excellence across the Network.

Despite financial and operational challenges, our collective resilience and focus have enabled meaningful progress in digital transformation, governance, patient information, and pathway redesign. As we look ahead to 2026/27, we do so with confidence—building on a strong foundation, renewed partnerships, and a shared commitment to delivering exceptional CHD care for every patient across our region.

Activity Overview & Key Metrics (Jan -Dec 25)

Level 1 Adult Service

Activity at Liverpool Heart and Chest Hospital (LHCH) remained strong throughout 2025, reflecting both the complexity of the regional CHD population and the continued demand for specialist care. A total of 265 cardiac catheter procedures were undertaken, comprising 145 interventional procedures and 120 diagnostic catheterisations. In addition, the service delivered 138 ACHD electrophysiology and device procedures, reflecting the growing role of pacing and EP interventions in adult congenital care. This sustained level of activity demonstrates the centre's ongoing role in delivering timely, specialist interventions for adults with congenital heart disease.

Outpatient demand also remained high, with 5,378 clinic attendances recorded across the year. This volume highlights the scale of ongoing surveillance, long-term follow-up, and multidisciplinary support required to manage the growing adult CHD population. It also reinforces the importance of continued investment in outpatient capacity, digital pathways, and workforce resilience to ensure timely access to specialist review.

At surgical level, the centre delivered 143 congenital cardiac surgical procedures in 2025, supported by 347 clinic attendances. These figures reflect a stable surgical programme and the continued delivery of complex, highly specialised care for adults requiring operative intervention. The balance between surgical activity and outpatient review demonstrates the centre's commitment to comprehensive pre-operative assessment, post-operative follow-up, and continuity of care.

Together, these metrics illustrate a service operating at significant scale, with strong procedural throughput and high levels of patient engagement across outpatient and surgical pathways. They also provide a clear foundation for future planning, particularly in relation to workforce, capacity, and the development of digital tools to support efficient, patient-centred care.

LIVERPOOL HEART & CHEST HOSPITAL NHS FOUNDATION	TOTAL NUMBERS
Total cardiac catheter procedures	265 (145 interventions + 120 diagnostics)
Electrophysiology and Device procedures	138 (92 electrophysiology + 46 device)
Total clinic attendances (including helpline calls)	5,378
Total surgical clinic attendances	347
Total surgical procedures	143

Level 1 Paediatric Service

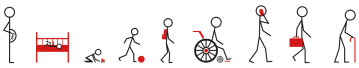
Activity across the paediatric Level 1 centre at Alder Hey Children's Hospital remained consistently high throughout 2025, reflecting the complexity and volume of cardiology care delivered to children and young people across the region. The surgical programme undertook 329 cardiac operations, demonstrating both the scale and specialist nature of the centre's work in managing complex conditions from infancy through adolescence.

Interventional and diagnostic cardiology activity was also high, with 200 catheter-based procedures completed over the year. This included a broad range of diagnostic assessments and therapeutic interventions, supporting timely decision-making and reducing the need for more invasive surgical approaches where appropriate. In addition, the electrophysiology service delivered 70 EP catheter procedures, highlighting the centre's growing expertise in managing arrhythmias in children and young people.

Outpatient activity continued to rise, with 1,922 new patient attendances and 7,531 follow-up appointments across cardiology and cardiac surgery. This significant volume reflects the long-term, multidisciplinary nature of paediatric cardiology care, where ongoing surveillance, transition planning, and family support are essential components of high-quality service delivery. The sustained demand also underscores the importance of continued investment in outpatient capacity, digital tools, and workforce resilience to ensure timely access to specialist review.

ALDER HEY CHILDREN'S HOSPITAL NHS FOUNDATION TRUST	TOTAL NUMBERS
Cardiac surgery	329
Cardiology interventions/diagnostics	200
EP catheter procedures	70
Clinic attendances (Cardiology & Cardiac Surgery)	New patients: 1,922 Follow-up patients: 7,531

Taken together, these figures illustrate a paediatric service operating at substantial scale, delivering complex interventions while maintaining strong continuity of care for children, young people, and their families. They also provide a clear foundation for future planning as the Network continues to strengthen pathways, support transition into adult services, and ensure equitable access to specialist care across the North West.



Patient Public Voice Representatives

PPV Reps around the region

PPV representation at Network Board remains well established, ensuring the patient voice informs strategic discussions and decision-making.

The Patient and Public Voice (PPV) Group

Representing the views and experiences of patients and families across the Network

17 Active Members from Across the Region

PPV Representatives by Region	
Greater Manchester	2 Reps.
Isle of Man	1 Rep.
North Wales	2 Reps.
Merseyside & Cheshire	8 Reps.
Lancashire & South Cumbria	4 Reps.

In summary, the PPV group continues to provide effective support and constructive challenge to the Network, ensuring that patient perspectives remain integral to service development.

Key Focuses for the PPV Group

Geographical Inequalities

- Members have actively pursued this issue, including engagement with local MPs
- Met with the NHSE Lead Commissioner for Specialised CHD Services (November 2025) which provided assurance that funding allocation is equitable at a national level, however, variation in how resources are deployed locally remains unclear and is an ongoing concern

Engagement & Advocacy

- created a video called a "Journey of Hope" to highlight and promote the role of PPV members
- Virtual PPV drop-in sessions

Patient Information Day - 7th March 2026

- expert speakers from across the region
- PPV members sharing their lived experiences

The Learning Disability (LD) Forum

The Learning Disability (LD) Forum

An Important and Active Subgroup

Key Achievement:

Co-produced MRI Heart Scan Video

In partnership with:

- The Makaton Charity
- The Somerville Heart Foundation
- Clinical Teams

Site Visits & Reasonable Adjustments

- Visits to Preston Royal Infirmary & Barrow-in-Furness
- Highlighting Good Practice & Areas for Improvement

Training & Education

New section for T&E now available on the NW CHD website

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 promoted, a range of training sessions, study days, and multidisciplinary learning events.

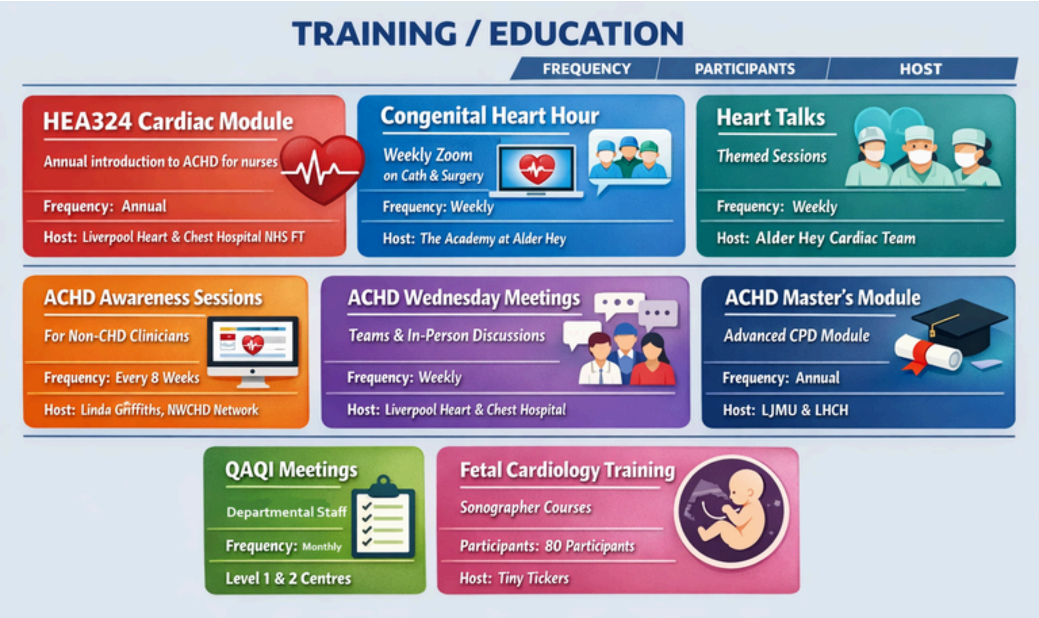
Events held:

- **Neonatal and paediatric palliative care study day 29/04/25**
- **Little Hearts at Home Platform Webinar 14/05/25**
- **Learning Disability for professionals' study day 13/06/25**
- **CHD/ACHD regional study day – focus Tetralogy of Fallot - for nurses and AHPs 08/07/25**

Michelle McLaren, Network Lead Nurse, delivered a monthly Introduction to CHD session throughout 2025 as part of the in-house continuing education programme for paediatric nurses at University Hospitals of Morecambe Bay NHS Foundation Trust.

The Network funded a member of the ACHD nurse specialist team to undertake the Liverpool John Moores University Master's module, Adult Congenital Heart Disease: Care of the Patient Through Their Lifespan.

Meetings & Training Sessions



TRAINING / EDUCATION

FREQUENCY | PARTICIPANTS | HOST

HEA324 Cardiac Module
Annual introduction to ACHD for nurses
Frequency: Annual
Host: Liverpool Heart & Chest Hospital NHS FT

Congenital Heart Hour
Weekly Zoom on Cath & Surgery
Frequency: Weekly
Host: The Academy at Alder Hey

Heart Talks
Themed Sessions
Frequency: Weekly
Host: Alder Hey Cardiac Team

ACHD Awareness Sessions
For Non-CHD Clinicians
Frequency: Every 8 Weeks
Host: Linda Griffiths, NWCHD Network

ACHD Wednesday Meetings
Teams & In-Person Discussions
Frequency: Weekly
Host: Liverpool Heart & Chest Hospital

ACHD Master's Module
Advanced CPD Module
Frequency: Annual
Host: LJMU & LHCH

QAQI Meetings
Departmental Staff
Frequency: Monthly
Level 1 & 2 Centres

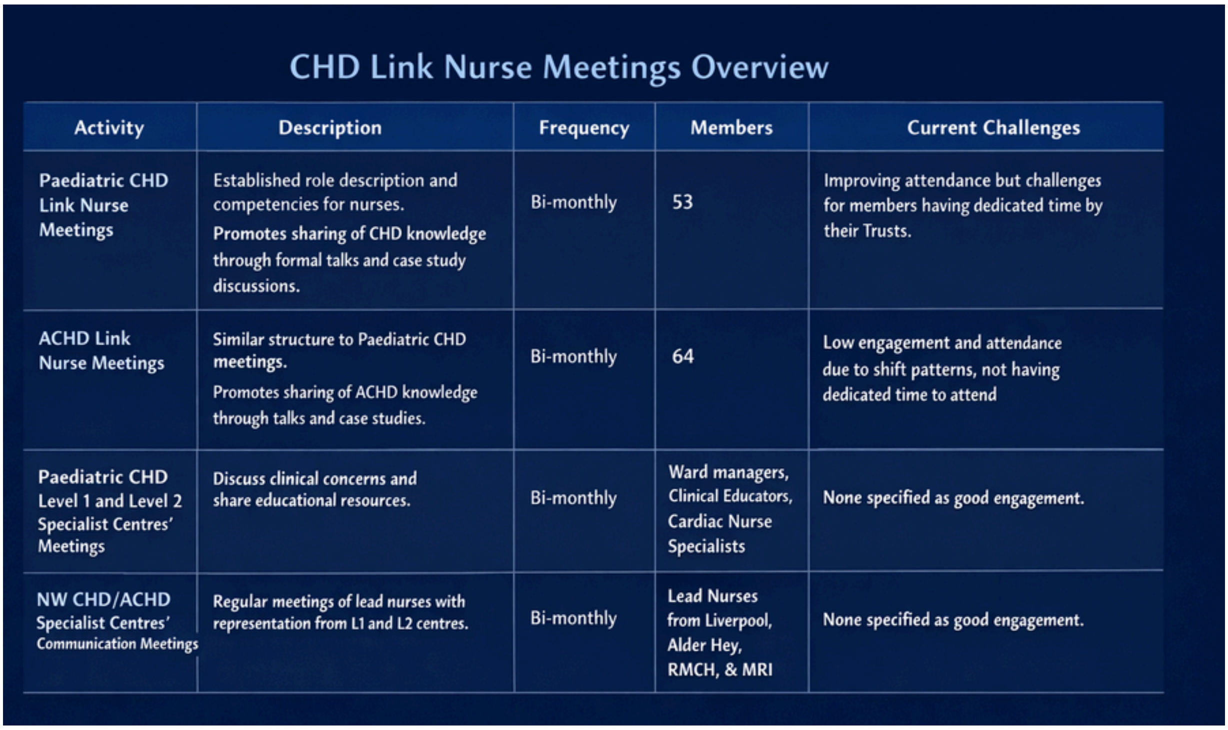
Fetal Cardiology Training
Sonographer Courses
Participants: 80 Participants
Host: Tiny Tickers

Nursing

New section for Nursing now available on the NW CHD website

The NWCHD Network continues to support the nursing workforce involved in paediatric cardiac and ACHD care by facilitating access to specialist training, encouraging professional collaboration, and enabling the dissemination of best practice. This networked approach strengthens clinical knowledge, supports professional confidence, and aims to contribute to improved patient outcomes.

Key Activities and Meetings



CHD Link Nurse Meetings Overview

Activity	Description	Frequency	Members	Current Challenges
Paediatric CHD Link Nurse Meetings	Established role description and competencies for nurses. Promotes sharing of CHD knowledge through formal talks and case study discussions.	Bi-monthly	53	Improving attendance but challenges for members having dedicated time by their Trusts.
ACHD Link Nurse Meetings	Similar structure to Paediatric CHD meetings. Promotes sharing of ACHD knowledge through talks and case studies.	Bi-monthly	64	Low engagement and attendance due to shift patterns, not having dedicated time to attend
Paediatric CHD Level 1 and Level 2 Specialist Centres' Meetings	Discuss clinical concerns and share educational resources.	Bi-monthly	Ward managers, Clinical Educators, Cardiac Nurse Specialists	None specified as good engagement.
NW CHD/ACHD Specialist Centres' Communication Meetings	Regular meetings of lead nurses with representation from L1 and L2 centres.	Bi-monthly	Lead Nurses from Liverpool, Alder Hey, RMCH, & MRI	None specified as good engagement.

Clinical Governance

Clinical Governance has remained a central priority for the Network throughout 2025–2026, with a well-established and robust process now fully embedded across all provider organisations. This maturing framework continues to support transparency, shared learning, and coordinated improvement across the region.

Network reporting and oversight

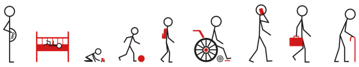
All providers are now required to submit a high-level incident and mortality overview every six months via the Network's online reporting tool. This structured process supports shared learning by enabling teams to report best practice, identify near misses, raise complaints for discussion, and update the Network on audit and research activity. Network Clinical Directors continue to oversee this work closely to ensure strong clinical governance and clear accountability.

Engagement with the reporting process, however, remains a challenge. While the July 2025 cycle saw the highest number of submissions to date at 11, this reduced to 9 completed reports in January 2026. To help improve consistency and compliance, the Network has asked each provider to nominate a named individual who will take responsibility for coordinating and submitting the six-monthly return moving forward.

In addition to these organisational reports, clinicians continue to submit individual incidents and mortalities through a standardised process. Guidance and downloadable templates are now easily accessible on the Network website, further supporting timely reporting and encouraging ongoing engagement across provider teams.

Enhancements to reporting

Over the past year, the Network has strengthened how learning is communicated. A full report is produced after each Clinical Governance meeting and is available on request. To make outputs easier for busy clinical teams to access, the Network now circulates a concise one-page summary outlining the key themes, actions and learning from each meeting. These summaries are shared widely across the Network to support rapid dissemination and promote shared ownership of improvement actions.



Meeting Activity and Attendance

Clinical Governance Meetings

Date	Number of Attendees	Incidents for discussion		Mortalities for discussion	
		Paed/Neo	ACHD	Paed/Neo	ACHD
Jul 2025	28	0	1	4	1
Jan 2026	24	1	0	2	0

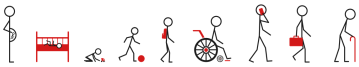
Participation from paediatric cardiac centres has remained strong and consistent. However, engagement from Adult Congenital Heart Disease (ACHD) services continues to be a challenge. Despite repeated discussion at CHOG (Congenital Heart Operational Group) about the importance of ACHD representation, this remains an area requiring focused attention in 2026–2027.

Themes, learning and positive outcomes

The Network continues to create valuable opportunities for multi-provider case discussion, resulting in tangible improvements, collaborative projects, and shared learning. Across the two meetings, several key themes emerged:

Key learning from July 2025

- Transition and Young People’s Experience: Agreement to audit current transition processes and develop a young people’s feedback survey. The Network will lead a quality improvement project to strengthen transition pathways.
- Non-Invasive Ventilation (NIV): Reinforcement that any child on NIV with significant changes in respiratory needs should be discussed with NWTS to ensure optimal management.

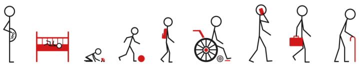


Key learning from July 2025 (Cont/d)

- Antenatal Screening: Clarification that insulin-dependent mothers have a 3–5% CHD risk. Capacity limitations prevent benchmarking against other centres. A Neonatal–Cardiac Study Day will be arranged for 2026.
- Post-Mortem Processes: Recognition of backlog in complex pathology cases. The Network will work with Alder Hey pathologists to clarify pathways and improve reporting.
- Communication: Strong emphasis on maintaining clear cross-organisational communication and adherence to established network guidelines.

Key learning from January 2026

- **Fetal Coarctation:** A dedicated session will be added to the Summer 2026 Cardiac Neonatal Study Day to support pathway development with neonatal teams.
- **Level 3 Cardiac Physiology Pilot:** The pilot demonstrated clear benefits, but future progress is limited by lack of NHSE funding. The Network will seek Board support and formally approach NHSE.
- **Digital Access to Clinical Information:** Reminder to encourage families to check NHS App / MyMFT for up-to-date information.
- **Red Flag Learning:** PAH with syncope or haemoptysis identified as a critical red flag requiring immediate specialist involvement.
- **Child Death Review:** Local cardiac input has been provided, and the Network will continue to ensure learning from local reviews is shared.
- **Regional Education:** The Network will host webinars for A&E and primary care staff in 2026.
- **Risk Oversight:** The Network Board will continue to maintain oversight of ICC risks across the region.
- **Communication & Guidelines:** Continued emphasis on consistent communication and use of Network pathways.



Conclusion

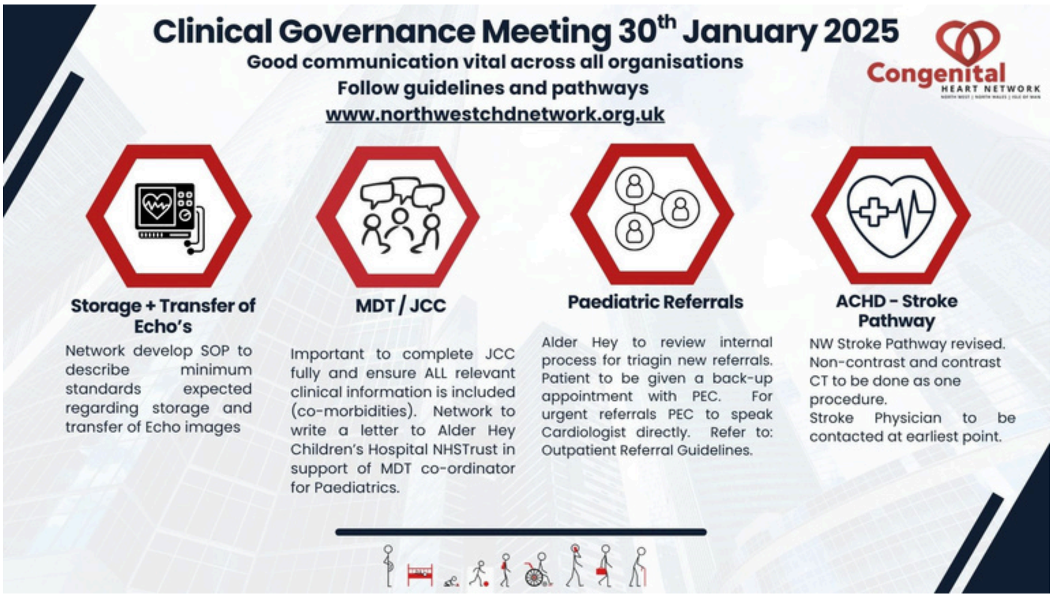
The Network has made strong progress in embedding a culture of consistent reporting, shared learning, and collaborative governance. While attendance from ACHD services remains an area for improvement, the Network continues to be successful in bringing multiple providers together to review cases, identify trends, and develop meaningful improvement initiatives. The learning and actions identified during 2025–2026 will support ongoing enhancement of patient safety and quality of care across the regional congenital heart disease pathway.

> ***'learning and actions identified during 2025-26 will support ongoing enhancement of patient safety and quality of care across the region'***

Meeting Summary Metrics

Date	Number of Attendees	Incidents for discussion		Mortalities for discussion	
		Paed/Neo	ACHD	Paed/Neo	ACHD
Jul 2025	28	0	1	4	1
Jan 2026	24	1	0	2	0

Clinical Governance Meeting Summaries



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

MDT / JCC

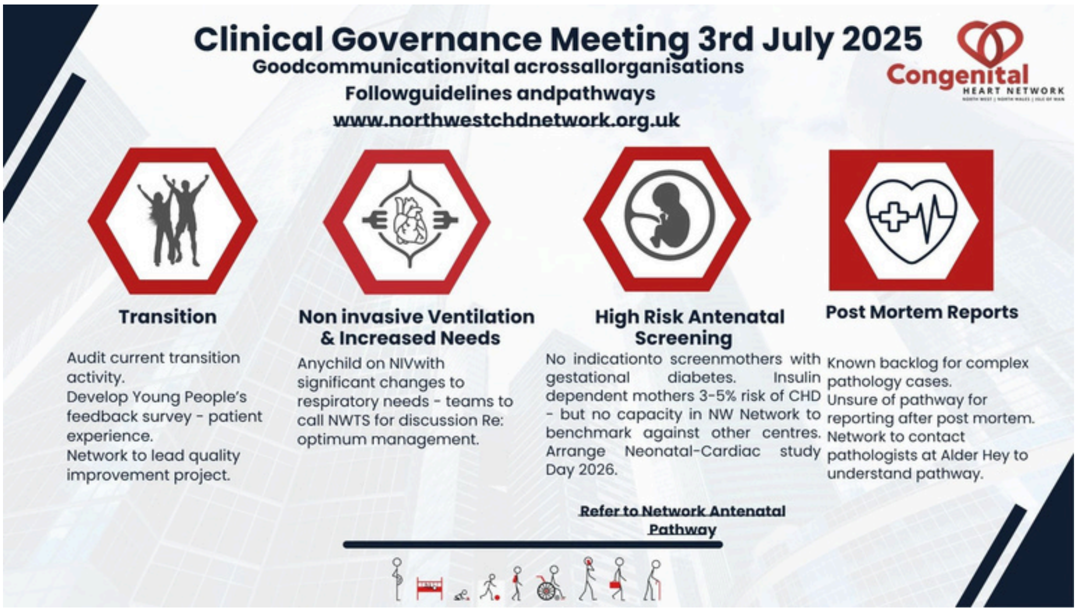
Important to complete JCC fully and ensure ALL relevant clinical information is included (co-morbidities). Network to write a letter to Alder Hey Children's Hospital NHSTrust in support of MDT co-ordinator for Paediatrics.

Paediatric Referrals

Alder Hey to review internal process for triagin new referrals. Patient to be given a back-up appointment with PEC. For urgent referrals PEC to speak 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.



Clinical Governance Meeting 3rd July 2025

Goodcommunicationvital acrossallorganisations
Followguidelines andpathways
www.northwestchdnetwork.org.uk

Transition

Audit current transition activity.
Develop Young People's feedback survey - patient experience.
Network to lead quality improvement project.

Non invasive Ventilation & Increased Needs

Anychild on NIVwith significant changes to respiratory needs - teams to call NWTS for discussion Re: optimum management.

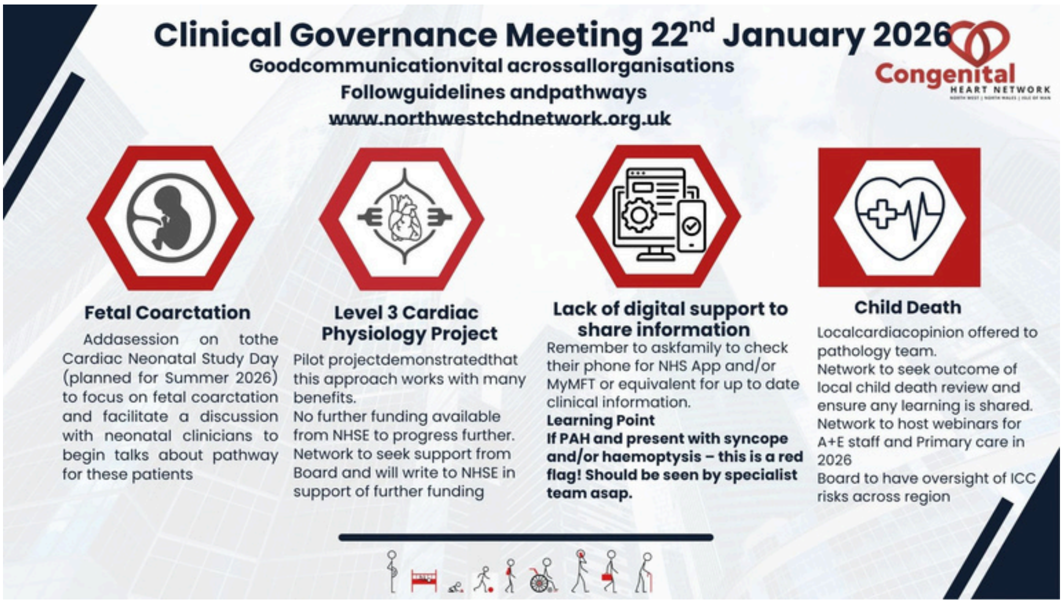
High Risk Antenatal Screening

No indicationto screenmothers with gestational diabetes. Insulin dependent mothers 3-5% risk of CHD - but no capacity in NW Network to benchmark against other centres. Arrange Neonatal-Cardiac study Day 2026.

Refer to Network Antenatal Pathway

Post Mortem Reports

Known backlog for complex pathology cases.
Unsure of pathway for reporting after post mortem.
Network to contact pathologists at Alder Hey to understand pathway.



Clinical Governance Meeting 22nd January 2026

Goodcommunicationvital acrossallorganisations
Followguidelines andpathways
www.northwestchdnetwork.org.uk

Fetal Coarctation

Addasession on tothe Cardiac Neonatal Study Day (planned for Summer 2026) to focus on fetal coarctation and facilitate a discussion with neonatal clinicians to begin talks about pathway for these patients

Level 3 Cardiac Physiology Project

Pilot projectdemonstratedthat this approach works with many benefits.
No further funding available from NHSE to progress further.
Network to seek support from Board and will write to NHSE in support of further funding

Lack of digital support to share information

Remember to askfamily to check their phone for NHS App and/or MyMFT or equivalent for up to date clinical information.
Learning Point
If PAH and present with syncope and/or haemoptysis – this is a red flag! Should be seen by specialist team asap.

Child Death

Localcardiacopinion offered to pathology team.
Network to seek outcome of local child death review and ensure any learning is shared.
Network to host webinars for A+E staff and Primary care in 2026
Board to have oversight of ICC risks across region

Future Challenges

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 Project

The Network has made meaningful progress this year on the development of a unified CHD database designed to support consistent data collection, improved reporting, and a clearer understanding of activity and outcomes across the region. This work is central to strengthening our quality framework and enabling more robust, comparable data to inform service improvement.

Key Milestones 2025/26

- The design of the database was finalised following extensive engagement with clinical and operational teams, ensuring the system reflects real-world workflows and clinical priorities.
- The project team also successfully uploaded test data from Liverpool Heart and Chest Hospital (LHCH), providing early assurance that the system can receive and process data as intended.
- In addition, Alder Hey Children's Hospital has confirmed that they will be ready to upload their data from April 2026, marking another important step towards full regional implementation.

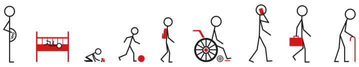
The project has not been without challenge. Engagement across organisations has varied, and late input from some stakeholders has required elements of the work to be revisited, contributing to delays. Engagement with Manchester Foundation Trust (MFT) has been particularly complex; however, we have now received confirmation that their internal approval process is complete. MFT is working towards a September 2026 deadline to finalise their development work, with data upload planned for October 2026. While this represents a significant delay, it is encouraging that the Trust has now formally committed to the project and established a clear timeline.

In partnership with

CLARYON SYSTEMS

Despite these challenges, the work undertaken this year provides a strong foundation for the next phase.

The database will remain a major priority for 2026/27 as we move into testing, phased implementation, and the establishment of a governance framework to ensure data quality, security, and long-term sustainability across the Network.

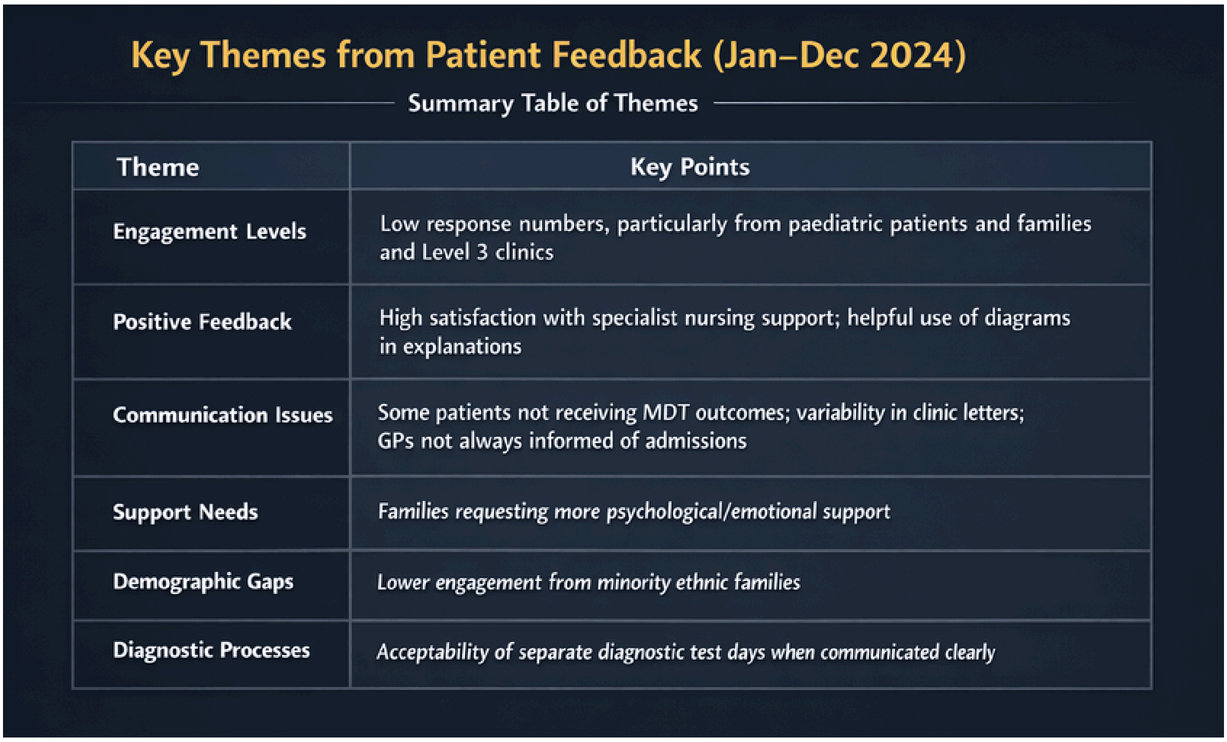


Patient and Family Experience of congenital heart services (PREMS) 2025-26

Overview

During the 2025/26 financial year, the Network further strengthened its approach to gathering and responding to patient feedback. The priority remained improving survey accessibility, enhancing engagement across age groups and provider levels, and ensuring insights directly inform service development.

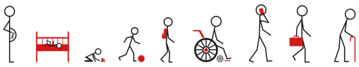
Survey access was broadened through posters in clinics, QR codes on clinical nurse specialist business cards, and publication of survey links on the Network website. Several providers have now begun adding QR codes to clinic letters, supporting a key recommendation from the Patient Experience Forum held on 8 December 2025. A major development this year was the introduction of a new transition patient experience form, creating a dedicated mechanism to capture the views of young people moving to adult services.



Key Themes from Patient Feedback (Jan–Dec 2024)

Summary Table of Themes

Theme	Key Points
Engagement Levels	Low response numbers, particularly from paediatric patients and families and Level 3 clinics
Positive Feedback	High satisfaction with specialist nursing support; helpful use of diagrams in explanations
Communication Issues	Some patients not receiving MDT outcomes; variability in clinic letters; GPs not always informed of admissions
Support Needs	*Families requesting more psychological/emotional support*
Demographic Gaps	*Lower engagement from minority ethnic families*
Diagnostic Processes	*Acceptability of separate diagnostic test days when communicated clearly*



Network Risks & Challenges

During 2025–2026, the NW CHD Network continued to strengthen its approach to risk reporting, building on the foundations established in previous years. A more consistent and standardised process is now in place, with all paediatric cardiology and ACHD providers expected to submit risks scoring 12 or above to the Network Board through exemption reporting.

Although the Network previously discontinued use of the In-Phase system at the request of Alder Hey as the host organisation, A this position changed during the year, and the Network was instructed to resume recording Network risks in In-Phase to ensure visibility for the host Trust. Alongside this requirement, the Network has continued to maintain its unified Network risk tracker, which is reviewed monthly by the Senior Leadership Team to support ongoing oversight and accountability.

> *‘expanded risk reporting requirement* ***to Level 3 providers’***

Progress Made

Over the past year, the Network has further formalised expectations by introducing a PPx template, designed to ensure that only exceptional or changing risks are escalated to the Board itself. This has significantly improved the consistency of reporting from Level 1 and Level 2 providers and has provided clearer visibility of recurrent themes—particularly around workforce, imaging capacity, bed availability, ICC service provision, and long-standing funding constraints.

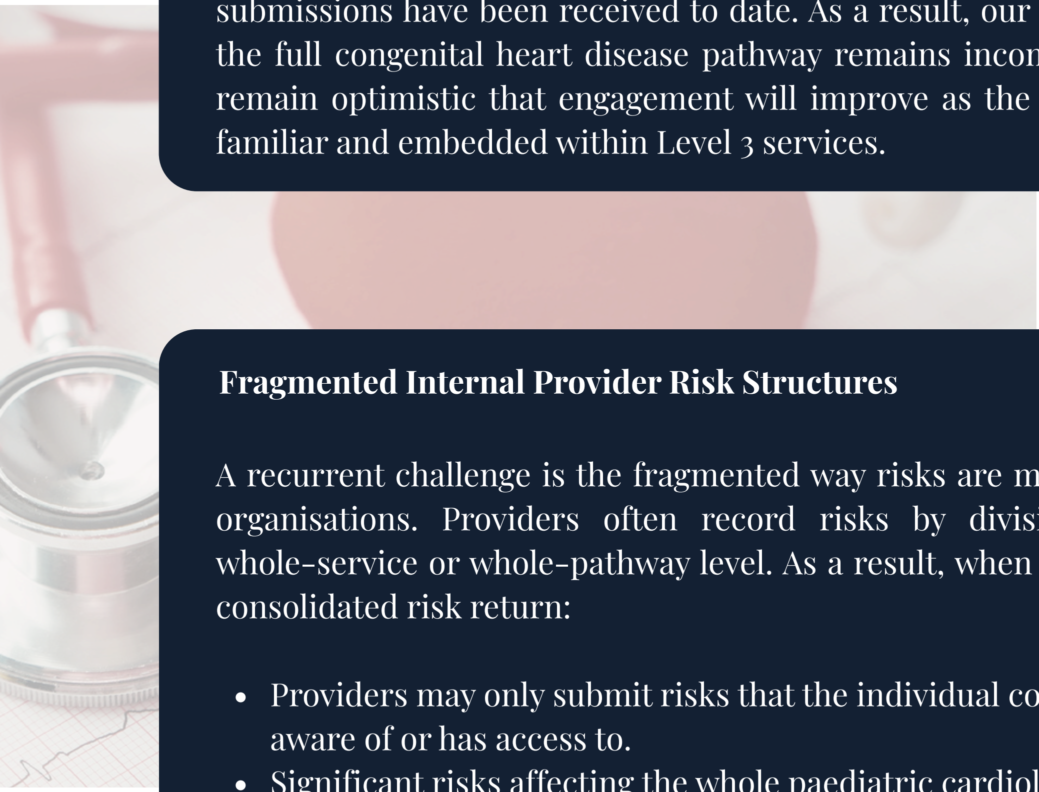
The Network also expanded the risk reporting requirement to Level 3 providers for the first time this year, ensuring that risks across the entire congenital heart disease pathway can be reviewed holistically.

Ongoing Challenges

Despite these improvements, there remain significant challenges that limit the Network's assurance around system-wide risks:

Limited Engagement and Incomplete Assurance

Most Level 1 and Level 2 centres have continued to submit their quarterly exemption reports throughout the year, demonstrating improving engagement with the Network's risk reporting process. This year also marked the first time we extended the reporting requirement to Level 3 providers; however, no submissions have been received to date. As a result, our visibility of risks across the full congenital heart disease pathway remains incomplete. Nonetheless, we remain optimistic that engagement will improve as the process becomes more familiar and embedded within Level 3 services.



Fragmented Internal Provider Risk Structures

A recurrent challenge is the fragmented way risks are managed within provider organisations. Providers often record risks by division, rather than at a whole-service or whole-pathway level. As a result, when the Network requests a consolidated risk return:

- Providers may only submit risks that the individual completing the return is aware of or has access to.
- Significant risks affecting the whole paediatric cardiology or ACHD service may remain unreported at Network level.
- Some historical or agreed pathway-wide risks are therefore not included on provider registers. This was an issue first identified in 2024–2025 and still present in 2025–2026.

Ongoing challenges ....cont/d

Inconsistent Alignment Between Local and Network Risk Registers

The previous annual report highlighted discrepancies where some providers had not incorporated agreed Network-level risks—such as ICC service provision, psychology, and physiology—into their local registers. Several of these risks were therefore removed from the Network tracker in February 2025 due to lack of local registration. Similar inconsistencies are still observed in this reporting year.

Impact on Board Assurance

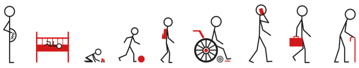
While the introduction of structured templates and clear expectations has improved the clarity of submissions, the Network cannot yet be fully assured that it has a complete, accurate overview of all paediatric cardiology and ACHD risks across the region. The variability in submissions and the fragmented nature of local risk management frameworks mean that the Board does not yet receive a full picture of system-wide risk exposure.

Examples of risks escalated to the Board 2025-26

Providers have continued to report a number of high-scoring risks (12+), including:

- Network finance and staffing pressures, with structural funding constraints and miscalculated historical budgets confirmed by the host Trust.
- Database project delays linked to limited engagement from key provider organisations.
- Workforce shortages at Level 1 centres, especially medical, physiology, and psychology staffing.
- Insufficient imaging and bed capacity to meet NHSE CHD standards.
- Inequity and gaps in transition and ICC service provision.

These risks continue to be monitored through the Network risk tracker and escalated appropriately.



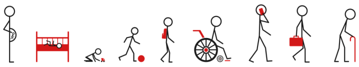
Looking Ahead

In 2026–2027, the Network will continue strengthening its risk management framework through:

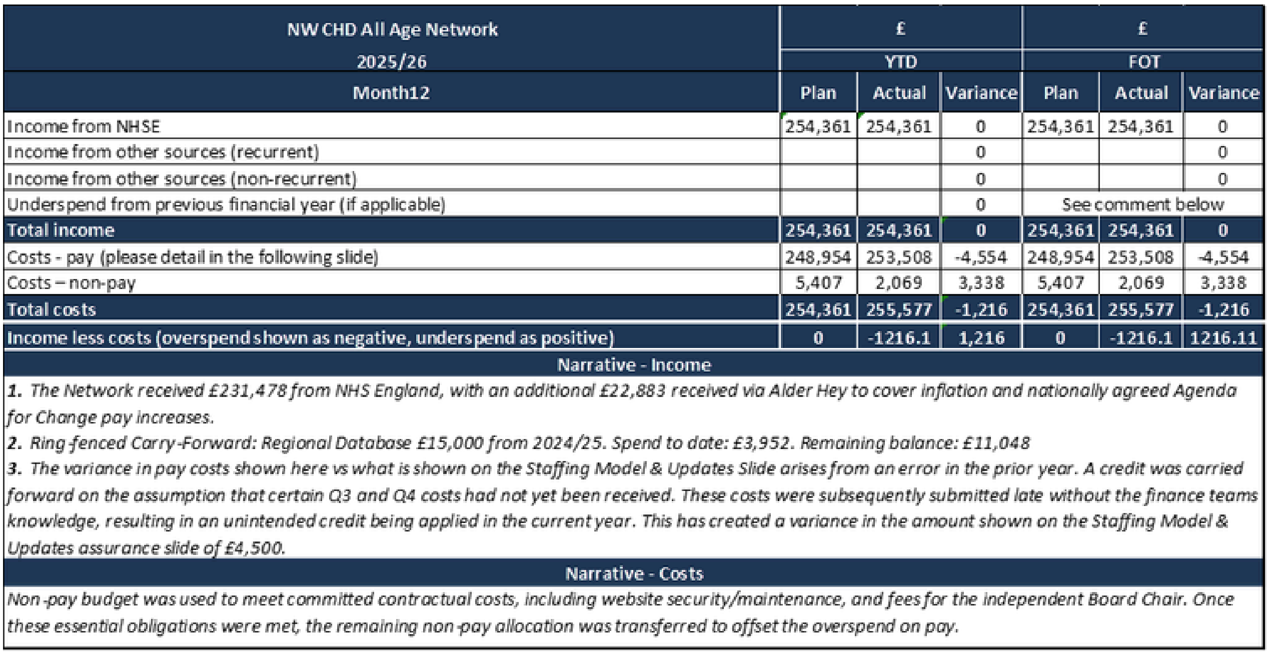
- Working with providers to ensure all relevant CHD and ACHD risks are identified, captured, and escalated appropriately.
- Supporting providers to embed service-level, not just divisional, oversight of risks.
- Continuing to review and challenge significant risks at the Board, ensuring consistent scrutiny and support for mitigation plans.

The previous system involved the Network creating a risk register that mainly included risks identified by clinical staff. However, it became clear that these risks were not always properly reflected in the provider risk registers. Specifically, the risks linked to the current model of paediatric cardiac services were agreed upon on 30/05/2023 by senior management from both Trusts, Network staff, and commissioners.

When the new risk tracking system was introduced this year in February 2025, it became clear that while Alder Hey NHS Foundation Trust had included the agreed risks in their risk register, Royal Manchester Children's Hospital had not done the same. As a result, several historical risks are no longer being tracked by the Network. This issue has been raised at NW CHD Network Board for clarification.



Finance Summary 25/26



NW CHD All Age Network 2025/26	£			£		
	YTD			FOT		
Month12	Plan	Actual	Variance	Plan	Actual	Variance
Income from NHSE	254,361	254,361	0	254,361	254,361	0
Income from other sources (recurrent)			0			0
Income from other sources (non-recurrent)			0			0
Underspend from previous financial year (if applicable)			0	See comment below		
Total income	254,361	254,361	0	254,361	254,361	0
Costs - pay (please detail in the following slide)	248,954	253,508	-4,554	248,954	253,508	-4,554
Costs – non-pay	5,407	2,069	3,338	5,407	2,069	3,338
Total costs	254,361	255,577	-1,216	254,361	255,577	-1,216
Income less costs (overspend shown as negative, underspend as positive)	0	-1216.1	1,216	0	-1216.1	1216.11

Narrative - Income

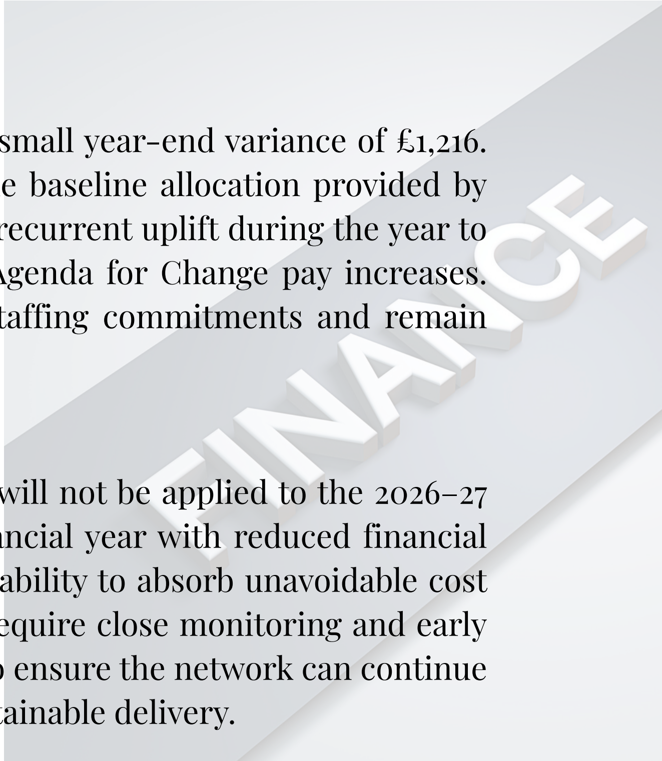
1. *The Network received £231,478 from NHS England, with an additional £22,883 received via Alder Hey to cover inflation and nationally agreed Agenda for Change pay increases.*

2. *Ring-fenced Carry-Forward: Regional Database £15,000 from 2024/25. Spend to date: £3,952. Remaining balance: £11,048*

3. *The variance in pay costs shown here vs what is shown on the Staffing Model & Updates Slide arises from an error in the prior year. A credit was carried forward on the assumption that certain Q3 and Q4 costs had not yet been received. These costs were subsequently submitted late without the finance teams knowledge, resulting in an unintended credit being applied in the current year. This has created a variance in the amount shown on the Staffing Model & Updates assurance slide of £4,500.*

Narrative - Costs

Non-pay budget was used to meet committed contractual costs, including website security/maintenance, and fees for the independent Board Chair. Once these essential obligations were met, the remaining non-pay allocation was transferred to offset the overspend on pay.



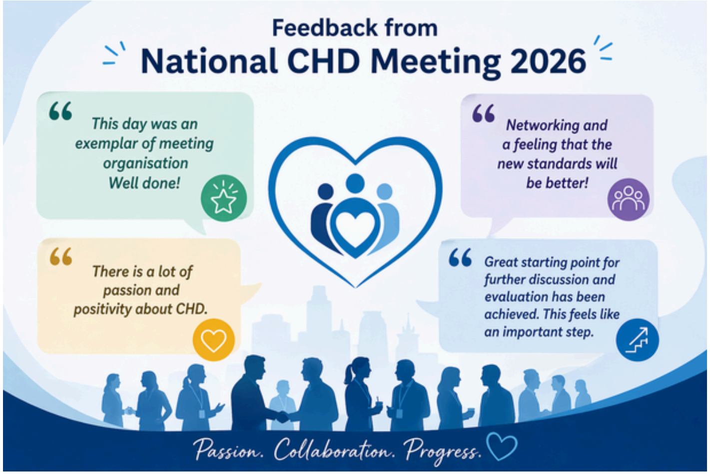
The network ended 2025–26 broadly on plan, with a small year-end variance of £1,216. This position reflects the fact that, in addition to the baseline allocation provided by NHSE, Alder Hey as host organisation applied a non-recurrent uplift during the year to cover inflationary pressures and nationally agreed Agenda for Change pay increases. This adjustment enabled the network to meet its staffing commitments and remain close to balance at year end.

NHSE and Alder Hey have confirmed that this uplift will not be applied to the 2026–27 budget. As a result, the network enters the new financial year with reduced financial headroom and a degree of uncertainty regarding its ability to absorb unavoidable cost pressures within the recurrent allocation. This will require close monitoring and early dialogue with the host provider and commissioners to ensure the network can continue to meet its statutory functions and maintain safe, sustainable delivery.

National CHD Network Meeting

In March 2026, the Network hosted a national standards meeting bringing together clinical leaders, commissioners, operational colleagues and patient representatives from across the congenital heart disease community. The purpose of the day was to take the first steps towards reviewing the existing national CHD standards, explore areas where they no longer fully reflect current practice, and begin shaping the next iteration to ensure they remain relevant, achievable, and aligned with the needs of patients and services.

Updating the standards is essential as the CHD landscape continues to evolve. Advances in technology, increasing patient complexity, workforce pressures, and the growing emphasis on transition, digital pathways, and equity of access all mean that the current standards require refinement to remain fit for purpose. The meeting provided a valuable opportunity to gather collective insight, share experiences from across the country, and identify where greater clarity, flexibility, or modernisation is needed.



Feedback from

National CHD Meeting 2026

"This day was an exemplar of meeting organisation Well done!

"Networking and a feeling that the new standards will be better!

"There is a lot of passion and positivity about CHD.

"Great starting point for further discussion and evaluation has been achieved. This feels like an important step.

Passion. Collaboration. Progress.

The day was highly successful, with strong engagement, constructive discussion, and a clear shared commitment to ensuring the standards continue to drive quality and consistency across the CHD pathway. Participants welcomed the opportunity to collaborate, compare approaches, and contribute to shaping the national direction.

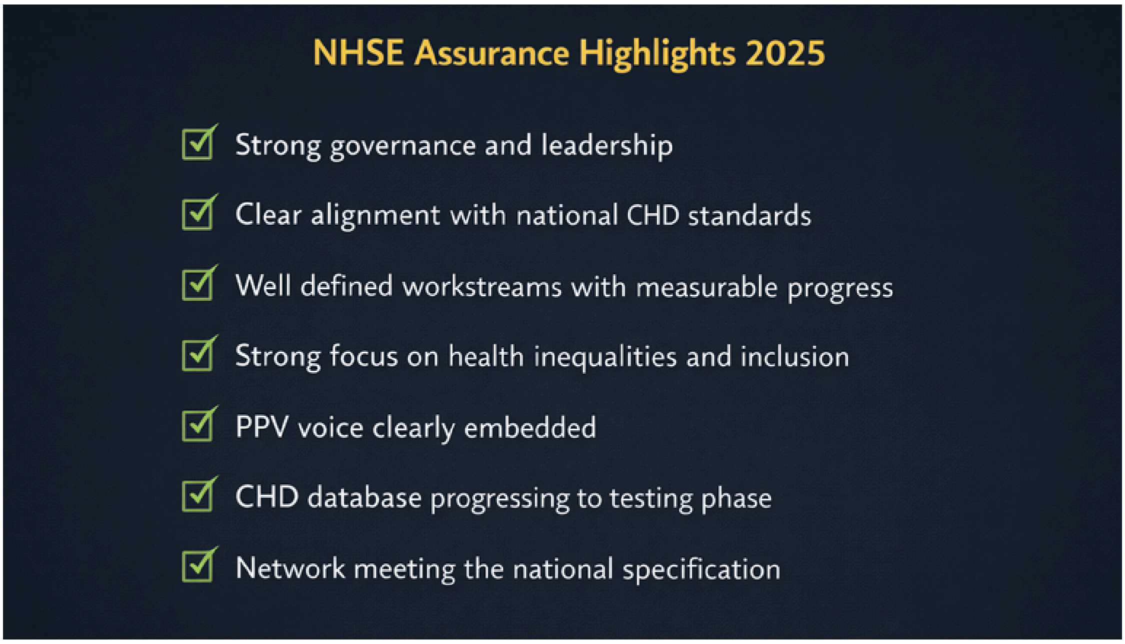
Next steps include synthesising the feedback gathered during the meeting, drafting proposed revisions, and establishing a structured process for wider consultation. The Network will continue to play an active role in this work, supporting national colleagues to refine and test updated standards ahead of formal approval and implementation.

NHSE Assurance Highlights

Our most recent assurance submission received positive feedback from NHS England, recognising the Network’s strong governance, clear strategic direction, and the meaningful progress made across all workstreams. NHSE highlighted the strength of the Network Board and the effectiveness of the PPV Group, noting that patient and public voices are clearly embedded in decision-making and continue to add real value to the programme.

The assurance review commended the alignment of our objectives and priorities with the national CHD standards and service specification, acknowledging the clear benefits this brings to improving patient care and outcomes. NHSE also recognised the quality of our workplans, the clarity of actions within each workstream, and the consistent reporting of progress into the Internal Medicine Programme of Care.

A number of specific achievements were highlighted, including the publication of the PPV video and the Network’s active involvement in the fetal self-assessment process. NHSE also praised the Network’s strong focus on health inequalities, noting the clear recognition of population health needs and the inclusive approaches embedded across the workplan. The planned development of dashboards to identify variation by geography, deprivation, sex and ethnicity was welcomed as an important future step.

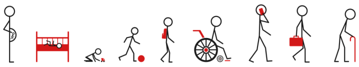


NHSE Assurance Highlights 2025

- ☑ Strong governance and leadership
- ☑ Clear alignment with national CHD standards
- ☑ Well defined workstreams with measurable progress
- ☑ Strong focus on health inequalities and inclusion
- ☑ PPV voice clearly embedded
- ☑ CHD database progressing to testing phase
- ☑ Network meeting the national specification

Feedback also acknowledged the Network’s stable staffing position and the progress made on the CHD database, with NHSE noting that the system has now entered the testing phase and has the potential to strengthen planning, reduce risk, and improve oversight of patient pathways.

Overall, NHSE concluded that the Network is meeting the requirements of the national specification and delivering its workplan methodically and effectively. This positive feedback provides a strong foundation as we move into 2026/27, reinforcing the value of the work undertaken this year and the confidence NHSE has in the Network’s leadership, priorities, and delivery approach.



Network Objectives & Achievements

Strengthening Clinical Governance Across the Network

We continued to embed a consistent and transparent approach to clinical governance. Network-wide governance meetings were held every six months, bringing together multidisciplinary teams to review cases, share learning and agree improvement actions. This structured process has strengthened shared accountability and supported a culture of continuous quality improvement across all providers.

Turning Learning into Action

A key focus this year was ensuring that learning translated into tangible change. Across the Network, teams identified priority learning points, agreed action plans and implemented improvements. This work has helped reduce variation, enhance safety and ensure that best practice is consistently applied.

Improving Transition Pathways for Young People

We began a comprehensive evaluation of transition pathways from paediatric to adult CHD services. Mapping current practice across the region has highlighted variation and opportunities for improvement. This work lays the foundation for a more standardised, patient-centred transition experience that supports young people and their families at a critical stage of their care journey.

This will remain a major focus for 2026/27 as we move from evaluation into co-design and implementation of improved pathways across the Network.

Reviewing Level 3 Peripheral Clinic Provision

To support equitable access to specialist care closer to home, we undertook an evaluation of Level 3 peripheral clinics across the region. This review has provided valuable insight into current provision, demand and variation, setting the foundation for future work to develop recommendations that will strengthen local access and ensure alignment with national standards.

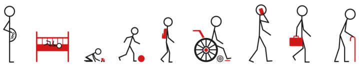
This work will continue into 2026/27 as we develop, agree, and begin to implement a refreshed and more standardised model for Level 3 provision across the North West.

Delivering Phase 1 of the Regional CHD Database

A major milestone this year was the progress towards delivery of Phase 1 of the regional all-age CHD database. Our Level 1 centres have made excellent progress in preparing for onboarding, demonstrating strong engagement and readiness to adopt the new system. This represents a significant step forward in improving data quality, supporting population health management and reducing unwarranted variation.

Progress with Level 2 centres has been slower due to internal governance processes that must be completed before they can begin the required implementation work. While this has created some unavoidable delays, the Network continues to work closely with these centres to support them through their internal approvals and ensure they are well-positioned to come on board as soon as their processes allow.

Once fully implemented across all providers, the database will underpin future service planning, quality improvement and follow-up processes, strengthening the consistency and equity of CHD care across the region.



Strengthening Patient and Public Voice, Including Learning Disability Inclusion

We progressed the development of a Network dashboard to monitor key service metrics. This tool will support governance, assurance and continuous improvement by providing clear, accessible information on service performance.

Co-Producing Accessible Patient Information Resources

Working with patients, families, providers and charities, we developed new patient information resources to support understanding, empowerment and self-management. This co-production approach ensures that materials are accessible, inclusive and reflective of real patient needs.

Redesigning the Network Website

We undertook a full redesign of the Network website to improve usability, accessibility and clarity. The refreshed site will provide a central, trusted source of information for patients, families and professionals, supporting transparency and engagement.

Developing an Education and Training Plan

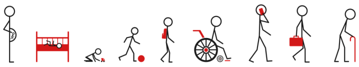
To support workforce development, we progressed work on a structured education and training plan for the regional CHD workforce. This will help ensure consistent knowledge, skills and confidence across providers, supporting high-quality care at every stage of the pathway.

Supporting Research, Innovation and Best Practice Adoption

The Network continued to champion research and innovation, supporting providers to participate in studies and adopt emerging technologies and best practice. This work strengthens the evidence base for CHD care and contributes to improved outcomes and service efficiency.

Strengthening Collaboration Across the CHD Pathway

Collaboration remained a defining feature of our work. We continued to work closely with fetal, maternity, neonatal, intensive care and surgery in children networks to ensure seamless, high-quality care across the entire CHD pathway. This whole-system approach supports early diagnosis, timely intervention and equitable access for all patients.



Recognising Linda's Outstanding Service

Lead Nurse, Linda Griffiths starting out on her nursing career

This year we also marked the retirement of our Lead Nurse, Linda Griffiths, whose impact on the North West CHD Network cannot be overstated. Linda has been a driving force behind our patient experience work, championing inclusive, compassionate care and leading initiatives that have genuinely changed how services listen to and learn from children, young people, adults and families. Her leadership of the Patient and Public Voice group, Learning Disability Forum, her commitment to improving transition pathways, and her tireless work to strengthen clinical governance have left a lasting legacy across the region.

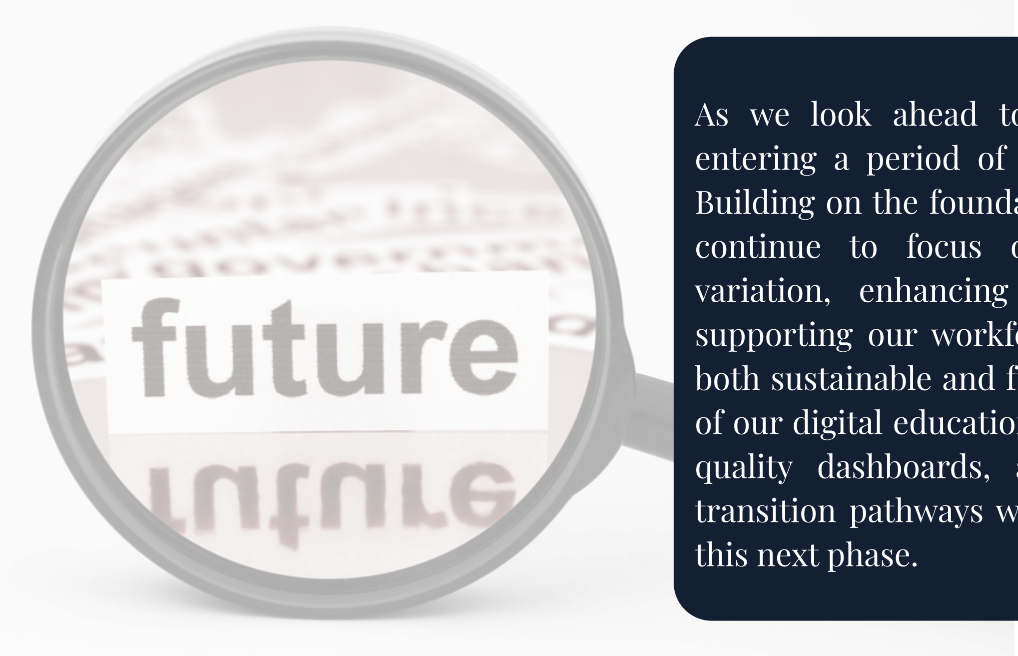
Linda retires after an extraordinary 44 years of dedicated nursing service to the NHS, and we are deeply grateful for the expertise, energy and humanity she has brought to the Network. We wish her every happiness in her well-earned retirement.

Linda (centre) with the PPV Group Patient Information Day 7th March 2026

Looking to the future, what’s next?

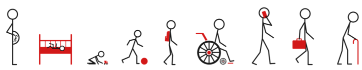
Remaining committed to listening to the voices of ***children, young people, and adults with CHD and their families……***

The past year has been one of meaningful progress for the North West Congenital Heart Disease Network. Across services, we have strengthened collaboration, improved pathways, and continued to place patients and families at the centre of everything we do. Our collective achievements reflect the dedication of clinicians, managers, commissioners, and patient representatives who work tirelessly to deliver safe, equitable, and high-quality care across the region.



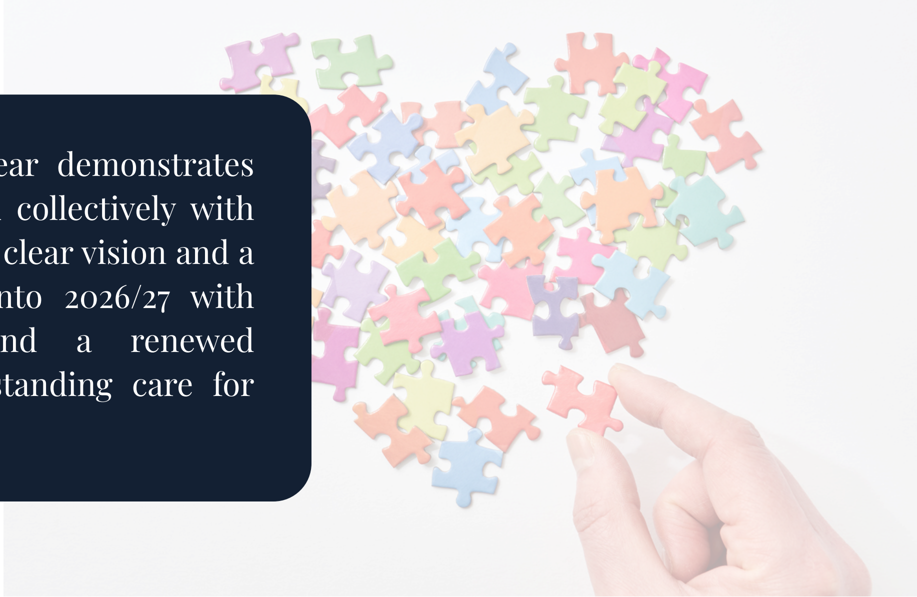
As we look ahead to 2026/27, the Network is entering a period of opportunity and ambition. Building on the foundations laid this year, we will continue to focus on reducing unwarranted variation, enhancing digital connectivity, and supporting our workforce to deliver care that is both sustainable and future-ready. The expansion of our digital education offer, the maturing of our quality dashboards, and the strengthening of transition pathways will all play a central role in this next phase.

Like many NHS services, the Network continues to operate within a challenging financial environment. While these pressures require careful prioritisation and thoughtful use of resources, they also reinforce the importance of working collaboratively, maximising value, and ensuring that our collective efforts are directed where they can have the greatest impact. Despite these constraints, the Network remains committed to innovation, partnership, and delivering improvements that are both achievable and sustainable.



We remain committed to listening to the voices of children, young people, adults with CHD, and their families. Their insights will continue to shape our priorities, from improving communication and accessibility to ensuring that services reflect the diverse needs of our population, including those with learning disabilities and additional needs.

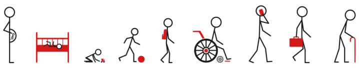
The year ahead will also see the Network deepen its partnerships with national bodies, local providers, and voluntary sector organisations. Through shared learning, transparent reporting, and a continued focus on outcomes, we will work to ensure that every child requiring cardiology support and every adult with congenital heart disease in the North West receives the right care, in the right place, at the right time.



The Network's progress this year demonstrates what is possible when we work collectively with purpose and compassion. With a clear vision and a strong foundation, we move into 2026/27 with confidence, determination, and a renewed commitment to delivering outstanding care for our region.

Nicola

Nicola Marpole
Network Manager
NW CHD Network



We thank you for your continued support to the Network

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North West, North Wales and Isle of Man
Congenital Heart Disease Network
ANNUAL REPORT 2025/26