

2023/24

Annual Report



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

Contents

Foreword from our Chair

Clinical Director's Network Review

About the Network / Visions & Aims

History & Geography

Meet the Team

Governance Structure

Patient, Public Voice Representatives

Training & Education

Nursing

Clinical Governance

Database

Paediatric Partnership Group

Patient and Family Experience of congenital heart services (PREMS)

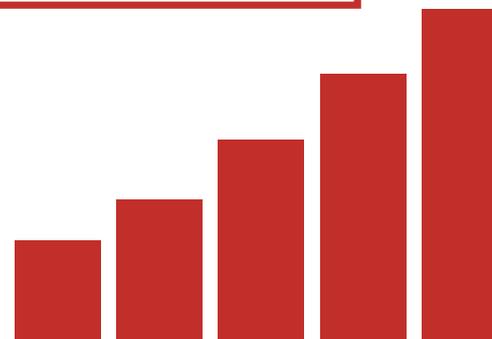
e-learning & Education Project

Network Risks & Challenges

Finance

Looking to the future, what's next?

Contact Us



Foreword from our Chair



Dr Nayyar Naqvi OBE
MBBS FRCP FRCPE FESC FACC FACP

A number of changes have taken place in the past year. Our new governance structure is embedded and working well. The Network clinical governance meetings are well established with over 30 members of the MDT engaging in discussing incidents and mortalities across the Network.

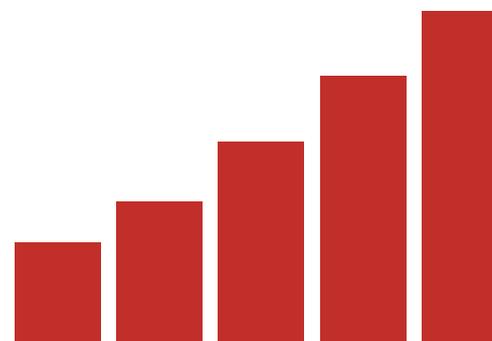
Dr Gordon Gladman has retired and his post as Clinical Director of the Network is now shared by two Co-Directors, Dr Damien Cullington, Consultant Adult Congenital Cardiologist at Liverpool Heart and Chest Hospital, and Dr Caroline Jones, Consultant Paediatric Cardiologist at Alder Hey Children's Hospital. We extend our grateful thanks to Gordon for his untiring efforts and tremendous contribution to the Network. I am convinced both Damien and Caroline will continue to work collaboratively and give an excellent service to the Network and our patients.

Our thanks also go to Dr Raphael Perry who has retired from the Board, and we welcome in his place, Mr Manoj Kuduvalli, Medical Director & Consultant Cardiac & Aortic Surgeon at Liverpool Heart and Chest Hospital.

We welcome Dr Sameer Misra, Director of Medical Education and Consultant Paediatrician & Lead for Cardiology at Bolton NHS FT, and Dr Elizabeth Shackley, Consultant Paediatrician, Stockport NHS FT as Board members, representing Paediatricians with Expertise in Cardiology across the Northwest.

We extend our sincerest wishes for success and happiness to Helen Sanderson, outgoing Network Manager. From February 2024 Nicola Marpole joined the team permanently as Network Manager and has taken up the role seamlessly and enthusiastically and hit the ground running. Michelle McLaren is Lead Nurse for Education, Training and Research. The database project has moved at pace this year making significant progress under the guidance of Project Manager Gail Maguire and Data Analyst Elizabeth Devonport. Linda Griffiths continues as the Network Lead Nurse for Quality, leading from the front as is customary for her, and Jill Moran as Network Support Officer, both providing an invaluable service to the Network.

In training and education, the ACHD nurse study day took place on 30 June 2023 and the ACHD master's programme is now moving into its sixth successful year.



Foreword from our Chair Cont/d...

Our Patient and Public Voice Group (PPV), expertly chaired by Janet Rathburn, continues to support, and advise the Network. Since COVID, the first “face to face” meeting of the PPV took place at the Marriott Hotel in Liverpool on 9 September 2023. PPV Patient Information Day, organised by Linda Griffiths, was held on 14 October 2023 and ran very smoothly. The PPV representatives have extended their thanks to Linda. The Young Persons Outdoor Event, sponsored by Somerville Heart Foundation, was on 10 September 2023. Janet says, “It was an excellent opportunity for the young patients to meet people of their own age and to chat ‘one to one’ with our Link Nurses”.

It has been an honour for me to have been Chairman of the Board of the Congenital Heart Disease Network for four years and a privilege to work with a team of highly motivated, hardworking members, all experts in their field, selflessly dedicated to serving the Network and the patients to the best of their ability. They have taught me so much over the years. I extend my grateful thanks to every single one of them. I have no doubt at all they will continue to provide the best clinical care to the patients and serve the Network faithfully and loyally. The time has come for me to give up the reigns and hand over the Chairmanship of the Network to new blood. I do this with confidence in the belief that the Network will continue to grow from strength to strength.

As my journey with the Network comes to an end, I am reminded of what Robert Frost says in *Reluctance*:

*“Out through the fields and the woods
And over the walls I have wended;
I have climbed the hills of view
And looked at the world, and descended;
I have come by the highway home,
And lo, it is ended.”*

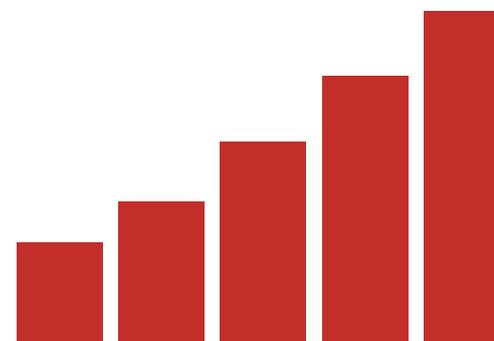
Dr Nayyar Naqvi OBE
Emeritus Consultant Cardiologist and
outgoing chair of NWCHD ODN Board

Thank you from the network

On behalf of the NW CHD ODN, I would like to extend our heartfelt gratitude to Nayyar for his dedicated service. His leadership and unwavering commitment have been invaluable, guiding us with wisdom and vision. We are deeply grateful for Nayyar’s tireless efforts in advancing our purpose and enhancing the care we provide to our patients.

Nayyar, we wish you all the very best in your future endeavours.

Nicola Marpole, Network Manager, NW CHD ODN



Clinical Directors' Network Review



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



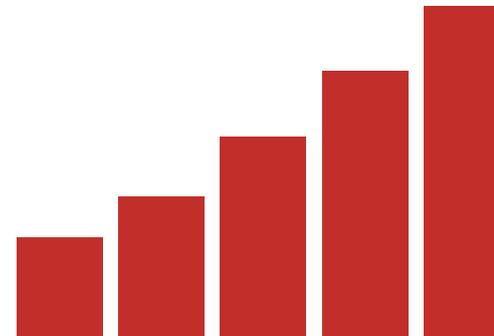
Dr Damien Cullington, Consultant Adult
Congenital Cardiologist, Liverpool Heart &
Chest Hospital

Welcome to the annual report of the North West, North Wales and Isle of Man Congenital Heart Disease network. As we reflect on the past year's accomplishments and challenges, we are reminded of the unwavering dedication and passion of our community in advancing care and support for individuals affected by congenital heart disease (CHD) and children with inherited cardiac conditions (ICC).

This year we would particularly like to thank Helen Sanderson our previous network manager for her hard work over the years and firmly congratulate Nicola Marpole on her permanent appointment to the role. We waved goodbye to Dr Nayyar Naqvi who has admirably chaired our network board meetings with positivity and enthusiasm. Many thanks from us all to Dr Gordon Gladman who has been ever present as clinical director since the development of NW network and whose contribution and leadership has laid strong foundations for all our future endeavours, we wish him all the best for a long and happy retirement!

All services within the NHS face significant challenges and congenital heart services are no different. Despite significant backlogs of clinical work still remaining, it is inspiring to see services continue to grow and thrive in spite of the challenges faced by our clinical teams around the region.

Within the Network, across the spectrum of ages, there are numerous examples of insightful audit, ground-breaking research and world leading innovation to impactful advocacy and educational efforts, each initiative outlined in this report embodies our collective commitment to improving the lives of those living with CHD. We feel honored to join the network as clinical directors this year and look forward to working with the leadership team, PPV group and all members from around the region to continue to build a network of hope, resilience, and progress.

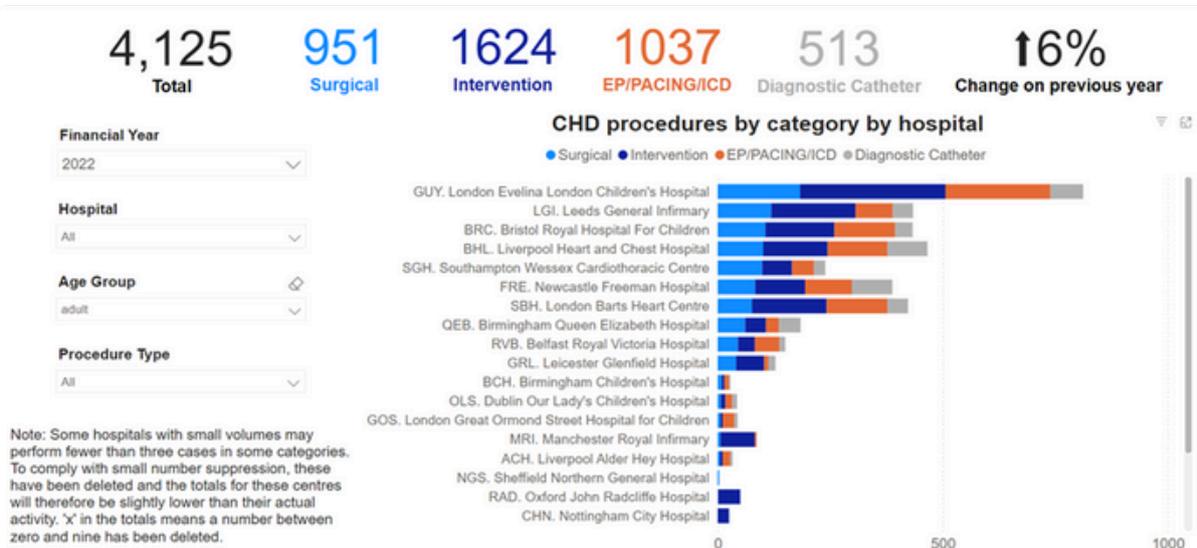


Clinical Directors' Network

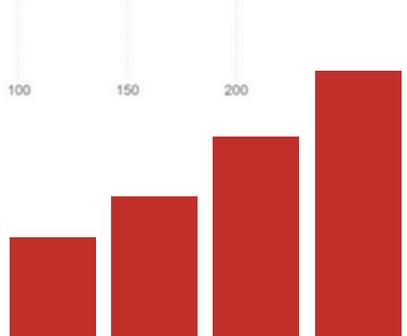
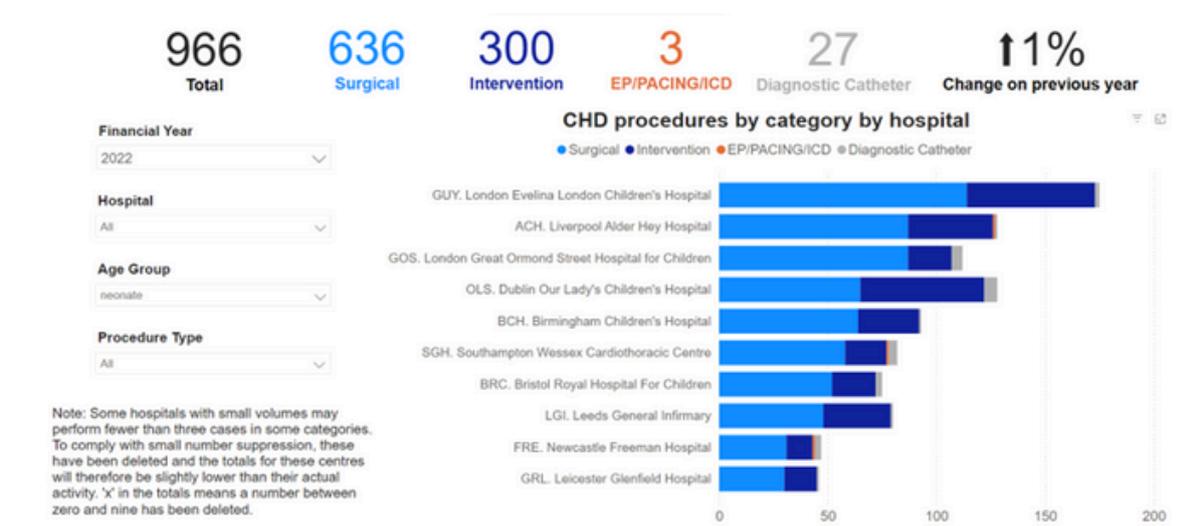
Review

The recently published NCHDA audit data 2024 summary report which covers the period 2020/21-2022/23 shows that Liverpool Heart and Chest Hospital has now firmly established itself as the largest ACHD centre outside of London in terms of its procedural numbers. Alder Hey is the largest neonatal surgical centre outside of London. We would like to personally thank the clinical and support teams across the Network for all their hard work to deliver this care.

One hospital performed over 2,000 procedures in 2022/23 while nine undertook fewer than 100



One hospital performed over 2,000 procedures in 2022/23 while nine undertook fewer than 100



About the Network



The Congenital Heart Disease Network for the North West, North Wales, and Isle of Man functions as an encompassing network, providing oversight for patients of all ages, including fetal diagnosis, paediatric cardiology and adult congenital heart disease. Hosted by Alder Hey Children's Hospital, the network receives funding from Specialised Commissioning and operates as an Operational Delivery Network (ODN), facilitating the supervision of congenital heart disease care.

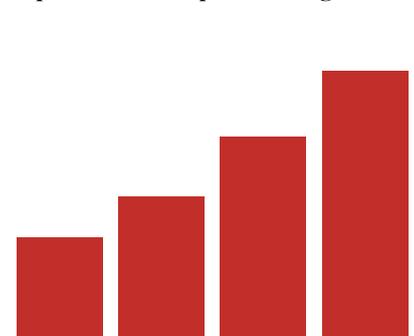
Geography



The North West, North Wales, and Isle of Man Congenital Heart Disease (CHD) network was established in 2012, formally transitioning into an Operational Delivery Network (ODN) in September 2019. Its purpose is to unite clinicians, nurses, allied health professionals, managers, commissioners, and patients with the aim of enhancing the Congenital Heart Disease service in the region. Encompassing a vast geographical area, including the North West region, North Wales, and the Isle of Man, the network serves a population of around 7.5 million individuals. Notably, the North West faces significant socioeconomic challenges, with 19.6% of its urban areas ranking among the top 10% most deprived areas in England.

Vision And Mission

"Together, we envision a seamless, patient-centred approach to delivering world-class congenital heart disease services across the North West of England, North Wales, and the Isle of Man. Through collaboration, education, and continuous improvement, we strive to create a high-quality, responsive network that places patients and families at its core. Our commitment to clinical governance and adherence to national standards ensures safety and quality across the region. Leveraging digital innovation and data-driven insights, we aim to optimise care pathways and enhance communication between providers. In the face of unforeseen challenges, we remain agile and professional, prioritising the safety and well-being of both patients and professionals."



Meet Our Team

NICOLA MARPOLE
NETWORK MANAGER



LINDA GRIFFITHS
LEAD NURSE



MICHELLE MCLAREN
LEAD NURSE



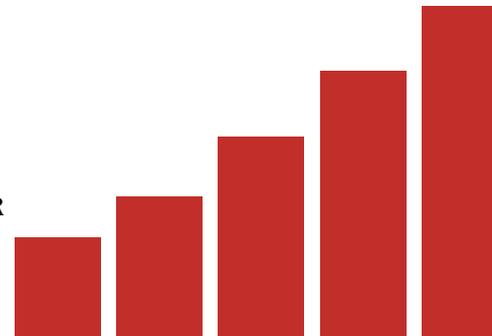
GAIL MAGUIRE
PROJECT MANAGER



LIZ DEVONPORT
DATA ANALYST



JILL MORAN
NETWORK SUPPORT OFFICER



Governance Structure

The governance structure for the North West, North Wales, and the Isle of Man Congenital Heart Disease Operational Delivery Network is organised into several interconnected layers and groups:

1. Senior Leadership Team (SLT): At the top, the NW Health & Justice and Specialised Commissioning Senior Leadership Team (blue box) oversees all Operational Delivery Networks from a regional specialised commissioning perspective. This team interacts with various oversight and delivery groups.

2. Oversight and Delivery Groups: Women's & Children's Oversight / Acute Operational Delivery (ODG) / Strategic Delivery (SDG).

These groups support decision-making and escalation to the SLT, and work alongside specialised commissioning programs of care and assurance groups.

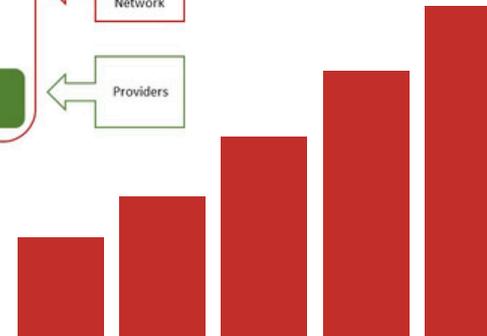
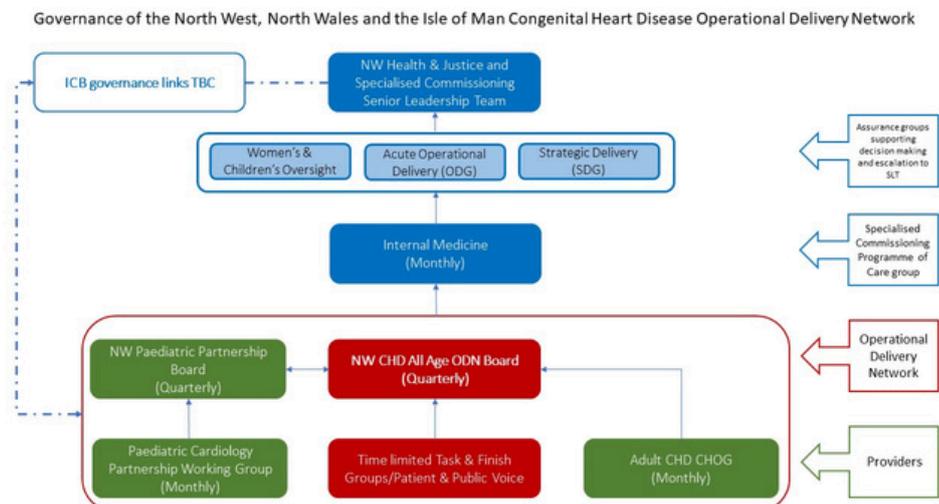
3. Internal Medicine Programme of Care (PoC) Group: This group meets monthly and serves as a bridge between the oversight/delivery groups and the NW CHD All Age ODN Board.

4. Operational Delivery Network (ODN) Board: The NW CHD All Age ODN Board, meeting quarterly, forms the core of the operational delivery network. It coordinates activities and connects with other groups within the network.

5. Providers and Support Groups:

- NW Paediatric Partnership Board / Paediatric Cardiology Partnership Working Group / Adult CHD Congenital Heart Operation Group (CHOG).

Time-Limited Task & Finish Groups/Patient & Public Voice: These groups provide targeted, temporary support and incorporate patient and public feedback.



Patient Engagement

The PPV Group has had a dynamic and productive year. With the introduction of a new Network Board structure, alongside the appointment of new Clinical Directors and a Network Manager, it has been a period of transition and growth.

Acknowledgments

We extend our heartfelt gratitude to Dr. Gordon Gladman and Helen Sanderson for their unwavering dedication, support, and commitment, as they embark on their new journeys. Enjoy your retirement and fresh challenges.

We also wish to express our appreciation to Linda Griffiths, Lead Nurse, and Nicola Marpole, Network Manager, for their continuous support and guidance. Special thanks also to Jill Moran, Network Admin Support Officer, for her invaluable assistance. Additionally, we welcome new team members Michelle McLaren, Gail Maguire, and Liz Devonport.

Meetings and Events

During the year we have continued to meet regularly, each month on the 1st Wednesday. We have also had additional meetings to look at particular aspects of our work. PPV reps continue to be very generous with their time and their commitment to the group.

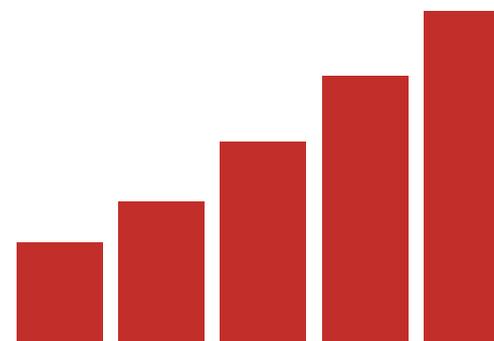
A significant highlight was our inaugural face-to-face meeting in Liverpool on September 9th, offering valuable opportunities for direct interaction and featuring an informative session led by Helen Chadwick, our NHS Commissioner.

Our second Patient Information Day on October 14th was highly successful, fostering insightful discussions and emotional responses among attendees, highlighting the importance of such events for our community.

Key Topics

During the year we have looked at a wide range of issues including;

- Access to the Patient Helpline at LHCH
- The role of PALS
- Supporting families facing financial hardship
- The role of charities at Alder Hey
- Volunteering in hospitals
- Data updates and management / Addressing backlogs and waiting times
- Transferring from Paediatric to Adult Services
- Recruitment and sustainability of the PPV Group
- Patient applications and technological advancements
- National perspectives on CHD from charities and networking initiatives



Patient Engagement

Membership and Development

Efforts to expand and diversify our membership have been ongoing, with a focus on ensuring representation from various community groups. Publicity materials have been developed with support from the Network, while updates to paperwork and role descriptions have been implemented to streamline operations and enhance effectiveness.

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.

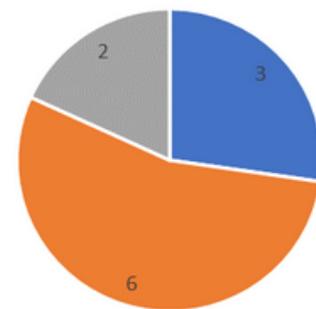
Learning Disability Forum

The learning disability forum has continued to meet most months during 23-24. They continue to meet online via zoom and currently have 11 regular members.

Achievements this year

- **LD Forum Checklist:** on 12th October 2023 the Forum visited both Manchester Royal Infirmary and Royal Manchester Children's Hospital to assess compliance against their check list of reasonable adjustments and support available for patients with a learning disability. Reports are available and have been fed back to providers.
- **Presentation at BCCA:** 3 Forum members presented the work of the Forum to the BACCNA Study Day on 14th November 2023.
- **Distraction Bags:** The forum has identified through their visits to providers that not all areas have access to distraction equipment or toys etc. They have therefore advised the Network on what should be provided. The Network has used this information to purchase what was recommended and we hope to be able to deliver these to our level 1 and 2 providers in the next few months.

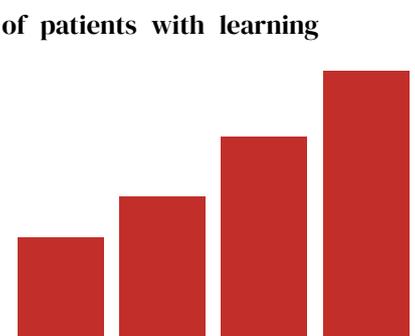
LD Forum Members



■ Patients ■ Family/Carers ■ 3rd Sector

Future work

- Over the next year the LD forum is coproducing an open day at Liverpool Heart and Chest Hospital for people with learning disabilities.
- Develop a video to support people with additional needs who need an MRI Scan of the heart.
- Further developing the checklist and will be visiting a further two providers
- Creating an emergency LD passport to support urgent admission of patients with learning disabilities.



Patient Engagement

Patient Reported Experience Measure (PREMS)

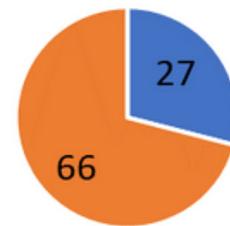
Work has continued throughout 2023-2024 to further develop the networks commitment to hearing and responding to patient experiences and feedback.

The paediatric and ACHD surveys went live on 15th May 2023 via the on line portal IQVIA.

The surveys have been designed using information from patients and family focus groups to help ensure that the questions appropriately reflect real life for patients under our care.

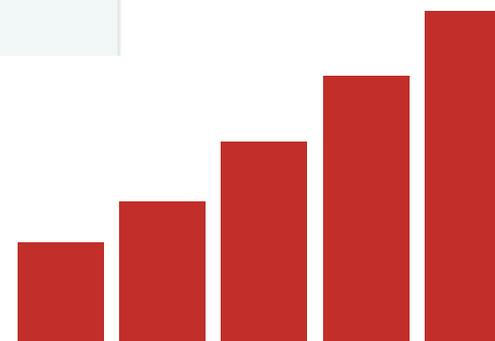
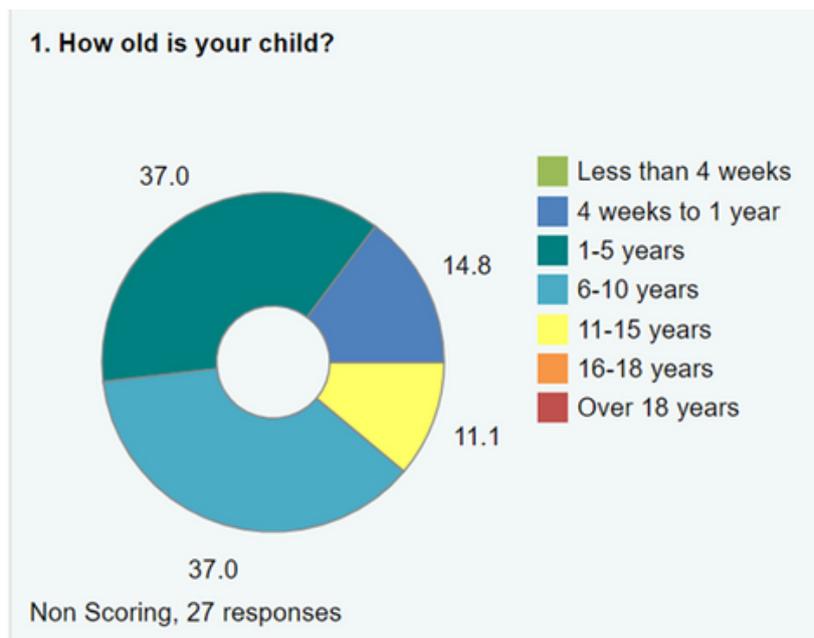
The paediatric survey underwent review by a multidisciplinary team. Notable findings emerged, such as the significant value attributed to the role of specialist nurses, with all respondents expressing satisfaction with the support provided by fetal cardiac nurse specialists.

PREMS Response 23-24 Number



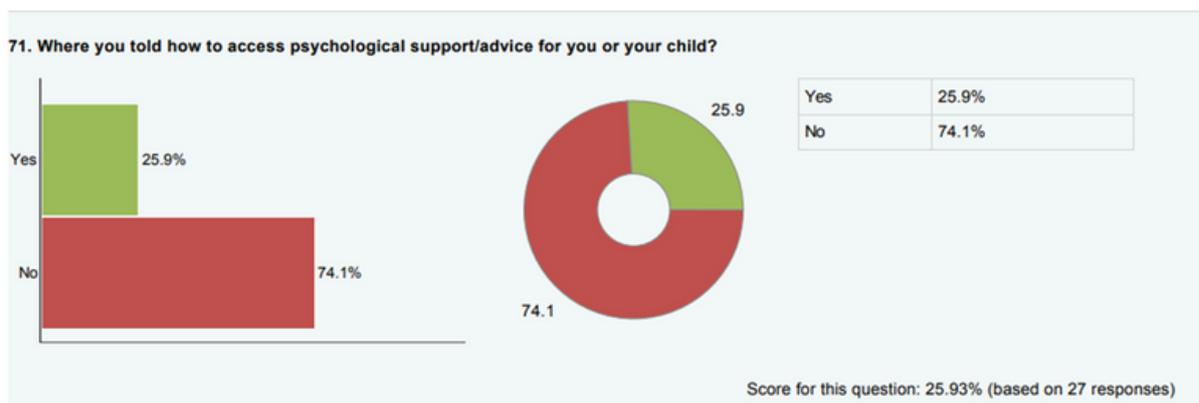
■ Paediatric ■ Adult

Below, we present specific outcomes from the survey that prompted actionable steps by the network.



Patient Engagement

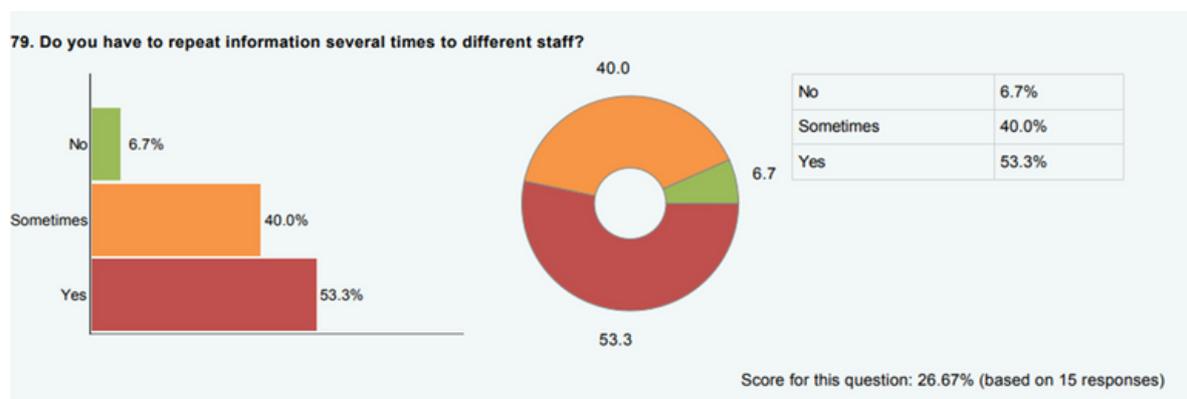
Patient Reported Experience Measure (PREMS) cont/d



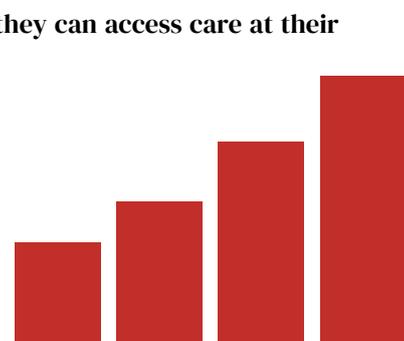
The survey has resulted in several actions being taken by the Network including:

There is limited access to psychological support across the Network. The value of peer-to-peer support provided by third sector charities is important in offering low level support to a large number of parents and families. The Network is therefore working on the following two actions.

1. Working in partnership with our patient and public voice group to improve access to smaller charities to offer peer to peer support at our provider hospitals.
2. We are working to develop a video to equip parents with the skills and knowledge to be able to prepare their children to come into hospital. This a joint project working with a local digital videographer drawing on the expertise of our clinical nurse specialist, play specialist and psychologists.



3. The development of an open access policy for named patients so that they can access care at their local DGH with the approval of their local PEC.



Patient Engagement

Patient Reported Experience Measure (PREMS) (cont/d)

Looking to the future

Patient Experience Forum

- We are planning to meet every 6 months with representation from management, clinicians, psychologists (were available) and patient and public voice representation from across the network. This will be to jointly review the outcomes from the surveys and to prioritise actions that need to be taken. We anticipate this starting in June 2024.

We are developing two more surveys over the next 12 months

- One for people who are learning disabled
- Young people going through transition

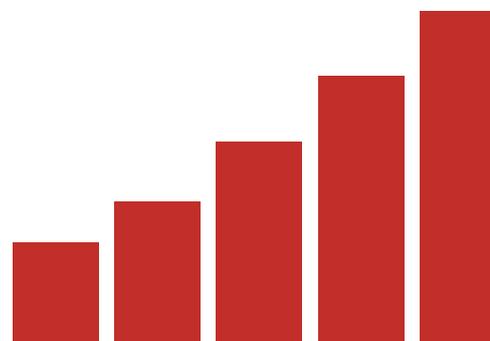
Patient Information Days

Patient Information Day (all age) 14th October 2023 - Face-to-face event held at The Marriott, Liverpool

The event was co-produced with our patient and public voice group and with support from clinicians across the NW Network. A wide variety of talks were provided from healthy lifestyle, health related anxiety, how to exercise safely and a talk about endocarditis plus much more. The day was supported by a wide range of local and national 3rd sector charities.

41 people registered to attend, and we were pleased to welcome 25 participants on the day. The event was free, which might have contributed to some no-shows. However, the feedback we received was very positive. Attendees particularly enjoyed meeting other families, patients, staff, and volunteers from various charities. Suggestions included starting the event later to increase attendance and recording the talks for later viewing. These insights will help us make future events even better.

The day provided an opportunity to advertise the role of the patients and public voice (PPV) group and resulted in 3 people showing an interest in joining.



Patient Engagement

Patient Information Days (cont/d)

Feedback from Face-to-face event

“The event was so beneficial - the opportunity to network with other like-minded people was wonderful too. I think it would be of interest to so many people. Perhaps it could somehow be promoted more widely - not sure of the answer to how as I saw it promoted on social media. Perhaps people could access the presentations virtually afterwards? Receiving the slides afterwards would be useful too.”

“I was aware of endocarditis but had never had it fully explained before, so it was great to have a clear and detailed overview from a medical professional.”

“A great reminder to be our own advocates and ask if Endocarditis might be a cause.”

Young People’s event 10th September 2023

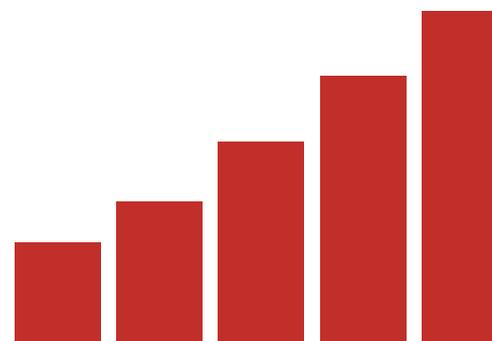
The Network hosted a young people’s event in collaboration with the Somerville Heart Foundation.

This was held at Home - Outdoor Elements Outdoor Activity and Team Building Centre

Specialist nurses involved in the transition journey were in attendance and represented the following providers:

- Alder Hey NHS Foundation Trust
- Royal Manchester Children’s Hospital – Manchester University Foundation NHS Trust
- Manchester Royal Infirmary – Manchester University Foundation NHS Trust
- Liverpool Heart and Chest Hospital NHS Foundation Trust

Due to the nature of the outdoor activity event places were limited to eighteen. We were delighted to have ten enthusiastic participants join us on the day. Although two people had to cancel and a few others couldn't make it, the event was a huge success. Families and siblings actively participated, and the feedback was overwhelmingly positive.



Patient Engagement

Congenital Heart Awareness Week 7th-14th February 2024

Catch up with the ACHD Team Q&A's

A series of events took place during congenital heart disease awareness week including an on line catch up with our adult patients via Zoom. The tea and chat approach allowed patients to talk about issues that are important to them. The ACHD Team consisted of the clinical lead for ACHD and Network Clinical Director, The Lead Nurse for ACHD and the Lead Nurse for the Network. Issues raised were:

- How to exercise safely – especially of the person has learning disabilities
- Waiting for information and decisions and how hard this can be
- Backlogs and how to contact the ACHD team

The ACHD Nurse Specialist team at Liverpool Heart and Chest Hospital also raised awareness each day of the week with various activities and displays in clinic. Finishing with a focus on healthy living.

Network Communication

Social Media continues to be one of the main platforms used by the Network to engage with patients' staff and members of the public. It is used to promote events, introduce new staff and inform about important public health communications and things specifically related to congenital heart disease.

X (formerly known as Twitter)

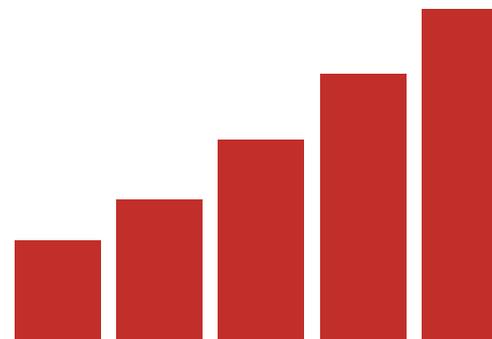
@NwchdN now has 889 followers with a steady increase each month.

NWACH Facebook Page

The Lead Nurse for the Network helps to moderate a private Facebook page for adults with congenital heart disease in the North West, North Wales and the Isle of Man. This provides a safe place for patients to contact each other for peer-to-peer support. It is also a platform to communicate with patients about events etc.

Engagement/Insights/Membership - NWACH Facebook Page

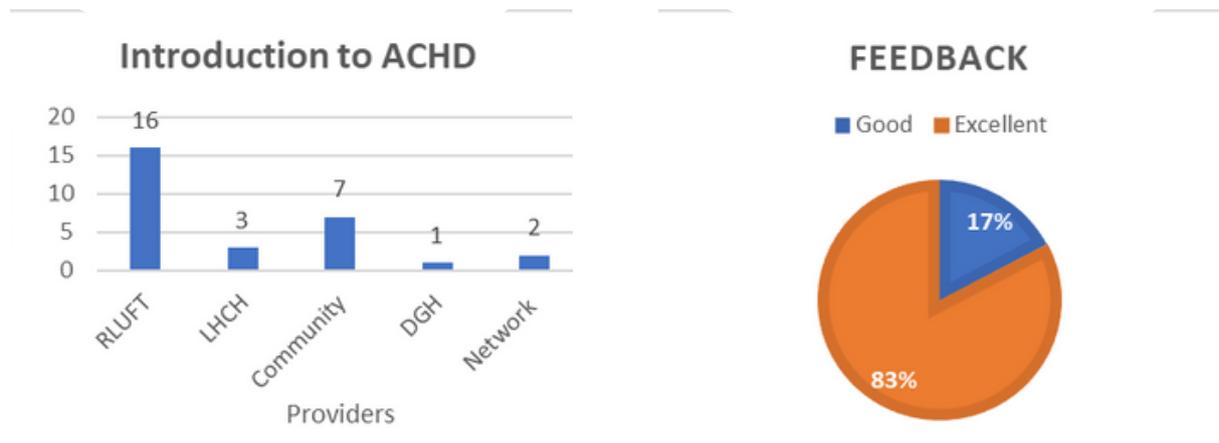
Gender	Women 66.4%	Men 32.9%	Undisclosed 0.7%
Insights summary	Posts 22 ↑ 16%	Comments 109 ↑ 54%	Reactions 120 ↑ 46%
Membership numbers	830 → 836 (Feb 2024-Apr 2024)		
Membership age range	From 13-65+ - average age 35 years old		



Training and Education

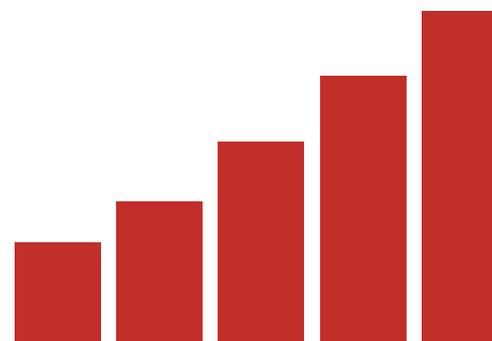
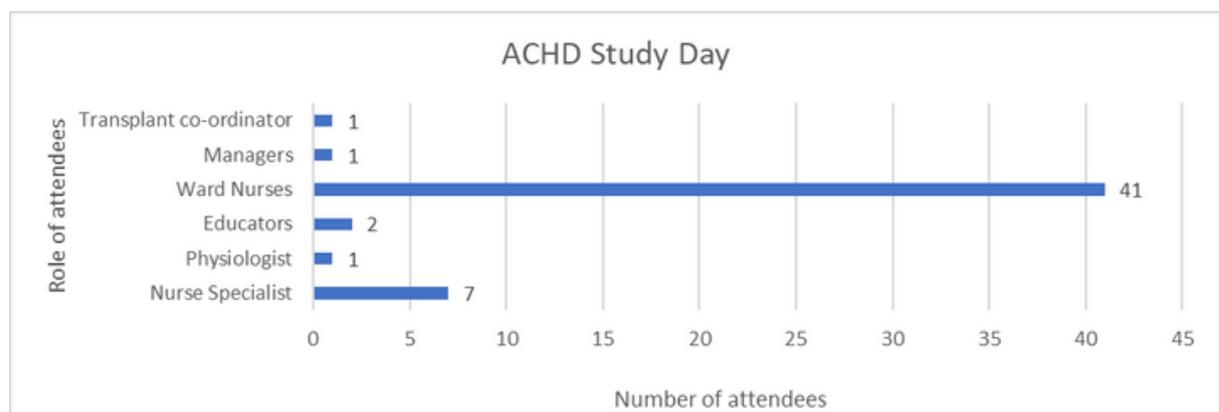
Introduction to ACHD

Our online teaching sessions, led by the Network Lead Nurse every 8 weeks, aim to raise awareness of ACHD patients across the NHS. Since inception two years ago, 111 individuals have attended. In the current year, we've hosted 5 sessions with 27 attendees from various network providers, all of whom found the teaching valuable.



ACHD Study Day

On June 30, 2023, the network hosted an ACHD Study Day for adult nurses and allied health professionals from the region. The in-person event was attended by 56 delegates and received extremely positive feedback, with attendees praising both the content and the quality of the training provided.

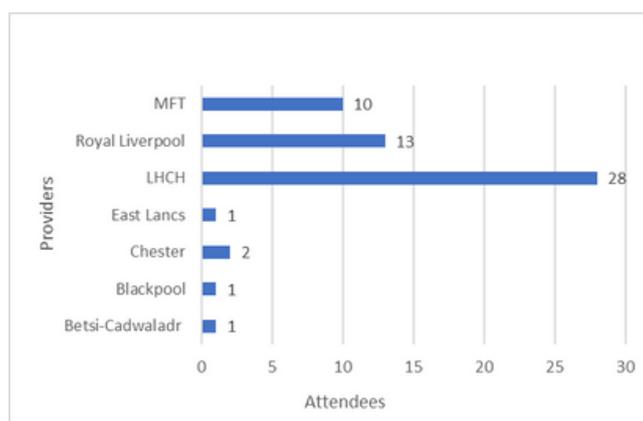


Training and Education (cont/d)

ACHD Study Day (Cont/d)

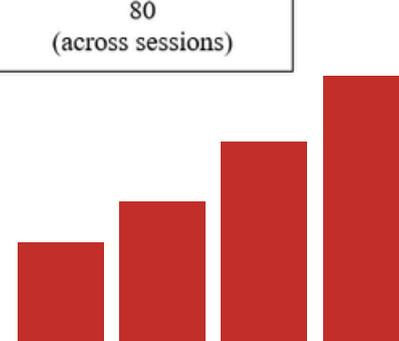
Feedback

- “A fantastic day. I had some knowledge, but this was an eye opener. Very complex. Thankyou.”
- ” It helped me to appreciate what life is like living with CHD and has enhanced my awareness of what is achievable”



Training & Education events

Training/Education Event	Description	Frequency	Participants
Cardiac Care Study Day	Introductory training on ACHD for AMUs and A+E departments.	Ad hoc	23 (over multiple sessions)
HEA324 Cardiac Module	Annual introduction to ACHD for nurses undergoing advanced cardiac training.	Annual	Not specified
Congenital Heart Hour	Weekly Zoom sessions focused on cardiac catheterisation and congenital cardiac surgery.	Weekly	Pre-registered staff
Heart Talks	Themed weekly sessions by Alder Hey cardiac surgical team.	Weekly	15-20 (increased from 5-10)
Raising awareness of ACHD sessions	Online awareness sessions for non-CHD clinicians.	Every 8 weeks	79 (over multiple sessions)
ACHD Wednesday Meetings	Interactive discussions via Teams and face-to-face.	Weekly	Varies by week
ACHD Master's Module	Standalone CPD and part of Cardiac PGCert for advanced study among healthcare professionals.	Annual	High attendance
Education task and finish group	Group working on an education strategy for the network.	Ad hoc	17 members
QAQI meetings	Monthly review and discussion of congenital cardiac care aspects.	Monthly	Departmental staff
Fetal cardiology for sonographers	Training for sonographers supported by Tiny Tickers across various hospitals.	Various dates	80 (across sessions)



Training and Education (cont/d)

Network Funding Call

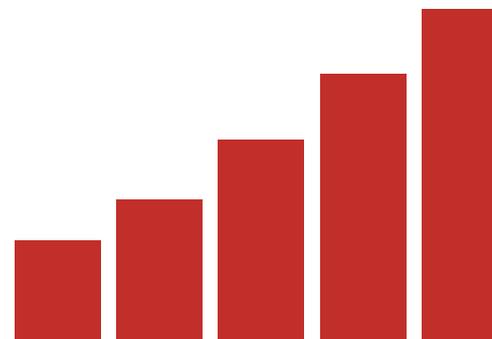
This year, the network had extra funds available due to a previous underspend caused by staff shortages. This allowed the network to invite applications from all staff groups for funding to support additional education and training for ACHD and paediatric cardiology conferences and courses. The network received many high-quality applications, making the selection process challenging.

Ultimately the network was pleased to support the following:

- 1 x Echocardiography in CHD (TTE/TOE)
- 2 x Association for European Paediatric and Congenital Cardiology Conference
- 1 x Ultrasound in the Fetal Cardiovascular Examination
- 5 x British Congenital Cardiac Association Conference

Future Events

- Paediatric CHD regional study day – focus single ventricle conditions- 25/04/24
- ICC study day – 13/06/24
- TGA themed study day – 27/09/24



Nursing

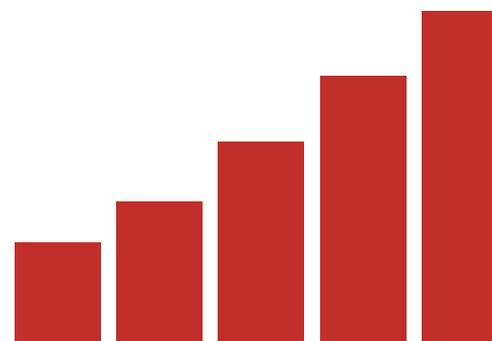
August 2023 saw the expansion of Lead Nurse hours from 0.6 WTE to 1.0 WTE in the form of a job share to work alongside the existing Lead Nurse; these increased hours are focussed on training, education and research.

Key Activities and Meetings

Activity	Description	Frequency	Participants	Current Challenges
Paediatric CHD Link Nurse Meetings	Establish role description and competencies for nurses. Promotes sharing of CHD knowledge through formal talks and case study discussions. Involves 58 members from children's community nurses and paediatric nurses in Level 1, 2, and 3 centres.	Bi-monthly	58	Low engagement and attendance. Efforts are underway to improve participation.
ACHD Link Nurse Meetings	Similar structure to Paediatric CHD meetings, with 64 members from L1, L2, and L3 centres. Promotes sharing of ACHD knowledge through talks and case studies.	Bi-monthly	64	Low engagement and attendance. Measures being implemented to boost participation.
Paediatric CHD Level 1 and Level 2 Specialist Centres' Meetings	Discuss clinical concerns and share educational resources.	Bi-monthly	Ward managers, clinical educators, and cardiac nurse specialists	None specified
NW CHD/ACHD Specialist Centres' Communication Meetings	Regular meetings of lead nurses with representation from major hospitals.	Bi-monthly	Lead nurses from Liverpool Heart and Chest Hospital, Alder Hey Children's Hospital, Royal Manchester Children's Hospital, and Manchester Royal Infirmary	None specified

Plans for the future

- Create a link nurse section on the NW CHD Network website
- Continuing promotion of the eLearning for health module and consider incorporating into mandatory training for CHD nurses in Level 1 and 2 centres: [Congenital Heart Disease - elearning for healthcare \(e-lfh.org.uk\)](https://www.e-lfh.org.uk)

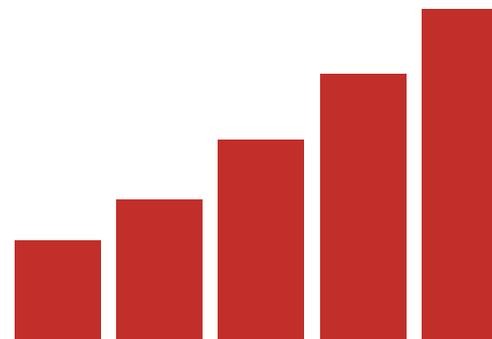
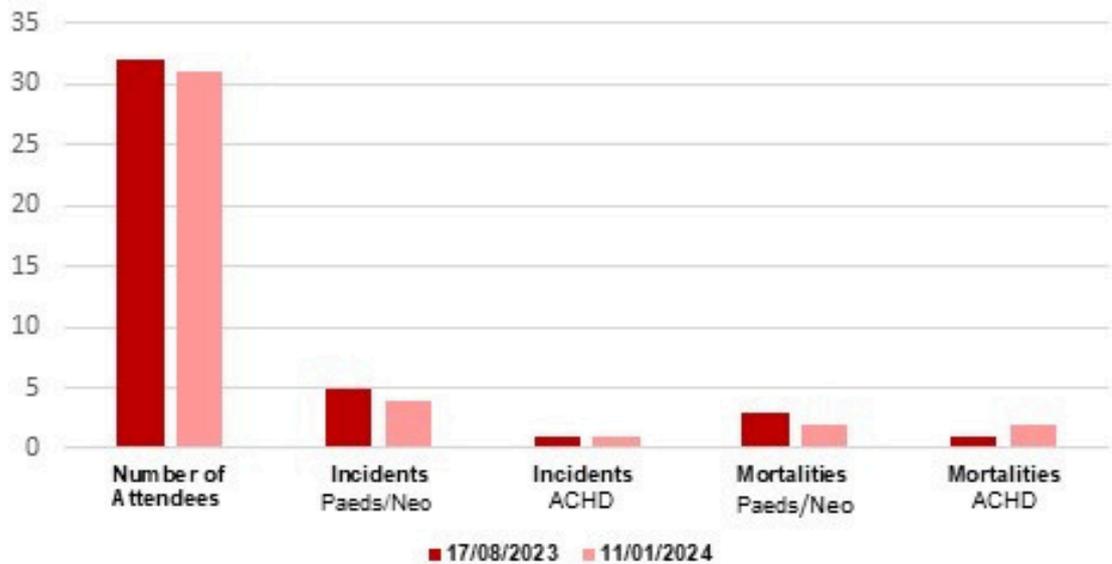


Clinical Governance

Clinical Governance has remained a major focus for the network over 2023 – 2024. There have been some significant changes to the workforce during this time. This has resulted in the leads for clinical governance stepping down from their roles in January 2024. They played a significant role in helping to develop the strong framework that now exists, and we would like to formally thank them for their contribution over this time. The clinical directors of the network have now taken over this role moving forward.

We have had two clinical governance meetings on 17th August 2023 and the 11th January 2024. Meetings continue to be chaired by the Lead Nurse. Attendance has increased to 31-32 members of staff (from approx. 28 in the previous year). There is representation from level one, two and three centres and from both paediatric and adult services.

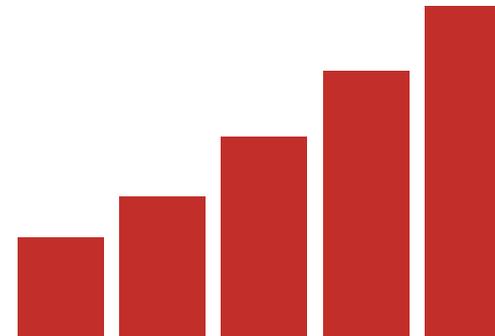
Clinical Governance Meetings



Clinical Governance (cont/d)

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

Themes	Actions
<p>Importance of Network documents and guidelines.</p>	<p>Network has a document management strategy for implementing and updating network documents.</p> <p>Relevant documents shared across the Network and available via the Network website.</p>
<p>Guidance around urgent and non-urgent paediatric referrals noted</p>	<p>Network has the following documents:</p> <ol style="list-style-type: none"> 1. Outpatient referral guidelines. 2. Non-cardiac surgery guidelines – in development. 3. Urgent referral proforma.
<p>Antenatal Management Plans – not always known about or followed at the time of delivery</p>	<p>Network is working with Neonatal Network to develop:</p> <ol style="list-style-type: none"> 1. Prenatal Diagnosis of CHD and perinatal Management plans 2. Standardised Perinatal Management Plan for babies with a cardiac diagnosis. 3. Standardised referral process.
<p>Endocarditis – need to increase awareness across primary care, A+E and also with CHD population</p>	<p>Clinical Director wrote a letter to all primary care and A+E staff reminding them to consider endocarditis in a patient with CHD and a pyrexia of unknown origin.</p> <p>Network held a patient information day on 15th October 2023 – with endocarditis as a theme</p>

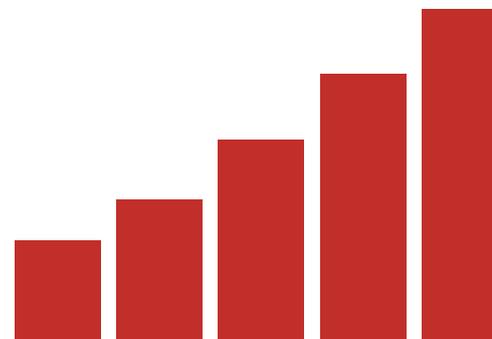


Database

In the last 12 months the network has made significant progress in designing and developing a regional all-age database, with support from our level 1 & 2 providers who have now committed resources for the project. The network data analyst, in collaboration with Mindwave, is constructing the database's architecture to provide comprehensive reports for the network and providers. These reports will include crucial information such as appointment status and transition progress, giving assurance that no patients are lost to follow-up. Once live, the database will streamline data collection and reporting processes, relieving operational burdens on providers. Beyond tracking patient status, the database will offer insights into service demand, patient flow, and equity of access, revolutionising our understanding of paediatric cardiology and adult congenital heart disease care regionally. While a complex endeavour, the network is committed to delivering on the successful implementation and realisation of the database's benefits.



Proceeding with the database implementation is crucial for bridging critical gaps in patient care and operational efficiency. Without it, we will lack insight into patient transition and continuity of care, struggle to monitor capacity and demand, and burden clinicians with inefficient access to vital information. Securing ongoing funding from NHS England for database hosting and storage costs is now imperative. A proposal detailing these costs has been submitted to regional commissioners, and we eagerly await their decision. While the initial three-year technical support from Mindwave is secured, the long-term sustainability of the project hinges on securing ongoing funding. We advocate for a three-year commitment to maximize benefits and data collection. However, if immediate financial constraints exist, funding for the first 12 months is proposed as a demonstration of the database's value and potential for future investment.



Paediatric Partnership Group



The North West Children's Cardiology Business Case is a joint initiative between Royal Manchester Children's Hospital (RMCH) and Alder Hey Children's NHS Foundation Trust (Alder Hey), with support from the NW Congenital Heart Disease Operational Delivery Network (CHD ODN). The initial business case, submitted on July 29, 2022, was rejected. Subsequently, the collaborative has submitted an updated case that elaborates further on the urgent needs and necessary changes to ensure equitable access to paediatric cardiology services across the North West region. The case highlights significant capacity shortfalls at RMCH, especially considering the higher incidence of Congenital Heart Disease (CHD) among children from Black or Asian ethnicities. Additionally, regional variations in patient waiting lists underscore the urgent need for action. The group recognise the imperative for collaborative innovation to address these challenges and propose a shift towards a unified service model to enhance access, outcomes, and long-term sustainability. Failure to enact change could jeopardise patient safety, service stability, and staff retention, with far-reaching implications for the region's paediatric cardiology services.

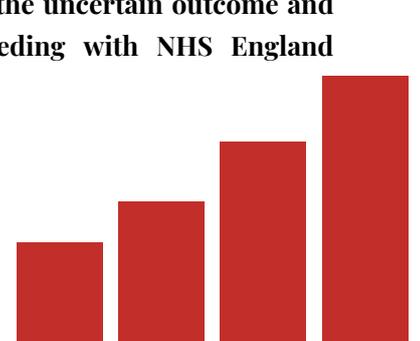
The group urged NHS England to endorse the proposed investment and commit to supporting the transition to a joint service model, but unfortunately NHS England were unable to confirm support, saying that:

"Due to limited resources and financial pressures, it's unlikely that the request for investment into this service will be supported in the current fiscal year, necessitating consideration by the NW Specialized Services Committee.

Moving forward, we require more detailed information on various aspects of the business case, including historical establishment and vacancies, inpatient and outpatient activity data for the entire NW region, and forecasted demand for the service. Additionally, a clearer assessment of health inequalities within the patient cohort and consideration of future demographic shifts are essential for informing sustainable planning.

It's important to note that our request for further information does not guarantee a favourable decision for investment at this stage. We recommend a further discussion, with ICB representatives present, to refine and shape the work moving forward".

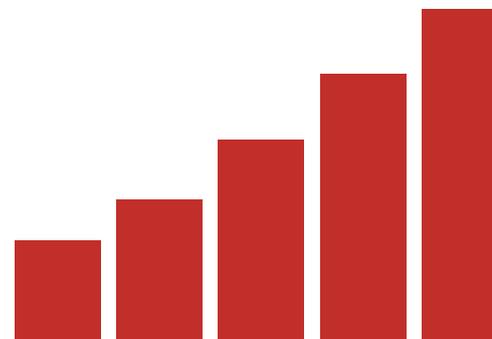
The group expressed disappointment with the outcome and deemed the extensive additional information requested by NHS England disproportionate. There is a sense of caution about allocating resources to gather the requested information considering the uncertain outcome and the group are carefully considering their response before proceeding with NHS England regarding next steps.



Maturity Matrix

The maturity matrix assesses various factors like leadership, governance, processes, resources, and performance levels. It offers a structured framework to gauge the current state and pinpoint strengths and weaknesses. This tool aids in crafting focused improvement strategies.

	Targets		
Purpose & Direction	2021 2-3	2023 2-3	2024 3
Governance & Structure	2021 2-3	2023 2-3	2024 4
Leadership & Facilitation	2021 3	2023 3	2024 4
Knowledge Capture & Reuse	2021 3	2023 3	2024 4
Integrity & Vitality	2021 2	2023 3	2024 4
Learning & Improvement	2021 3	2023 4	2024 5
Impact & Value	2021 2-3	2023 3	2024 4
Sustainability & Renewal	2021 2	2023 2	2024 4

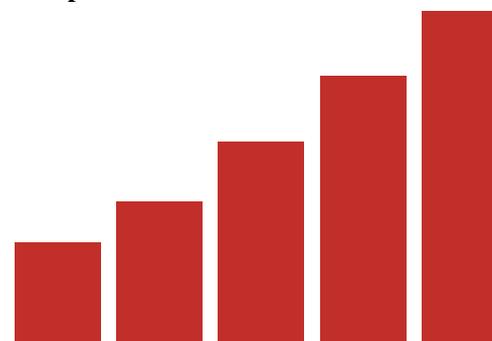


Network Risks and Challenges

The Network continues to monitor risks, controls, actions, and risk scores monthly. The risks around paediatric cardiology were discussed separately in a meeting on 30th May 2023. Senior management from both Alder Hey Children's Hospital NHS Foundation Trust, Manchester Children's Hospital, Commissioner, and the Network SLT were in attendance. Each individual risk across the Network was identified, scored, controls identified, and actions agreed. Each individual risk score, which organisation is responsible for the risk and which risk register's they should sit on were all agreed. The risks pertaining to nursing were added on 7th June and a further amendment agreed at CHD Network Board on 8th February to increase the ICC risk to 15.

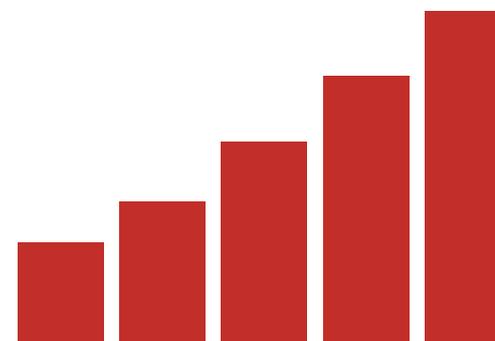
For the purposes of this report only those risks with scores 12 or above are included:

RISK	SCORE + TREND	RISK REGISTER	COMMENTS
Lack of funding to progress towards a single paediatric cardiology service	20 ➤	Network RMCH Alder Hey	Business case submitted to commissioners – response received
Backlogs across Paediatric Cardiology Level 1 + 2 centres	12 ↗ 16	Network Commissioner RMCH Alder Hey	Backlog figures continue to rise despite mitigations and controls being in place – agreed at CHD Network Board to increase risk to 16
Inadequate provision of ICC Services	10 ↗ 15	Network Commissioner RMCH Alder Hey	Due to catastrophic nature of risk – agreed at CHD Network Board to increase risk to 15
Network Database	12 ➤	Network	Network continuing to make progress on development of database



Network Risks and Challenges

RISK	SCORE + TREND	RISK REGISTER	COMMENTS
Psychology Provision	12 ➤	Network RMCH Alder Hey LHCH	Both paediatric and ACHD services are not currently meeting standards across level 1 + 2 centres
ACHD Backlogs at Manchester Heart Centre (MFT)	12 ➤	Network MRI - MFT	Backlogs are slowly improving but remain significant despite maximum controls being in place
NW CHD Network Funding	12 ➤	Network	Unable to meet service specification requirements under current funding arrangements
Paediatric Cardiac Physiology	12 ➤	Network RMCH	Staffing issues at RMCH in particular – but challenging to recruit and retain physiologists
Cardiac Nurse Specialist Staffing	12 ➤	Network RMCH	Inequity across the Network in numbers of grading of CNS Lack of fetal and transition nurse at RMCH



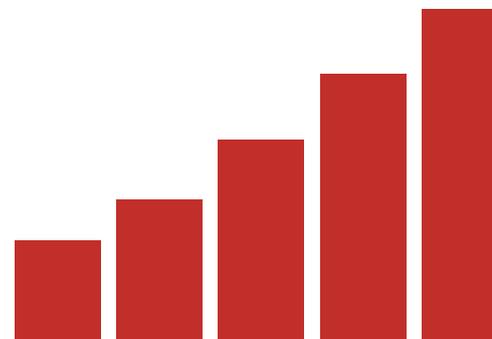
Network Risks and Challenges

Risks closed during 2023-2024

RISK	DATE OPENED	DATE CLOSED	COMMENTS
Adult (ACHD) cardiac physiologist staffing	31/01/23	01/02/24	Cardiac physiologist recruited and sickness withing the team resolved
Challenges to finding a solution to a paediatric cardiac single service	07/01/21	31/07/23	As above – risks identified separately, and this risk closed
Inability to store and share images across Paediatric cardiac level 1 + 2 centre	30/09/20	10/08/23	Integration of ISCV systems at both RMCH and Alder completed

Challenges

The Network currently has oversight of risks that are the responsibility of individual providers. The Network is therefore not responsible for many of the risks on the risk register. The Network Risk Management SOP requires updating and we will take this opportunity to review the current process and agree any necessary changes so the Network falls in line with other ODN's risk management processes.



Finance

The network experienced a notable underspend leading into the 2023-24 financial year. These funds were strategically utilised to supplement the funding provided by NHS England for the regional all-age database and to appoint a temporary part-time data analyst and a temporary full-time project manager. As a result, the network achieved a break-even position by the end of the financial year, with all funds either expended or allocated to future commitments.

Moving into the new financial year, the network has allocated funds to sustain the data analyst and project manager roles until the end of their 12-month terms. Additionally, £20,000 has been ringfenced to cover 12 months of cloud storage for the regional all-age database, ensuring continuity and support for ongoing operations.

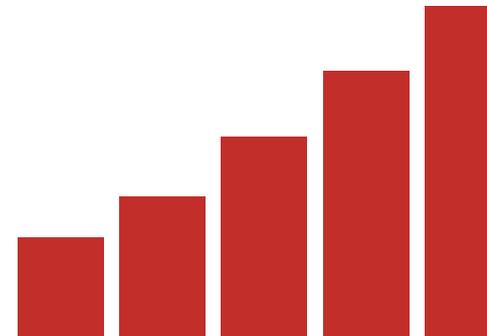
CARDIAC NETWORK 2023/24 Month 12	£ YTD			£ FOT		
	Plan	Actual	Variance	Plan	Actual	Variance
	Income from NHSE	230,704	230,704	0	230,704	230,704
Income from other sources (recurrent)			0			0
Income from other sources (nonrecurrent)			0			0
Underspend from previous financial year (if applicable)	72,593	72,593	0	72,593	72,593	0
Total income	303,297	303,297	0	303,297	303,297	0
Costs- pay (please detail in the following slide)	290,894	290,894	0	290,894	290,894	0
Costs- non-pay	12,403	12,403	0	12,403	12,403	0
Total costs	303,297	303,297	0	303,297	303,297	0
Income less costs (overspend shown as negative, underspend as positive)	0	0	0	0	0	0
Narrative - Income						

No income from other sources

Narrative - Costs

Non-pay costs were allocated against hosting patient and public voice meetings, patient information and staff training equipment to support network team members, website hosting and security fees and expenses for travel to regional providers and national CHD meeting and conferences

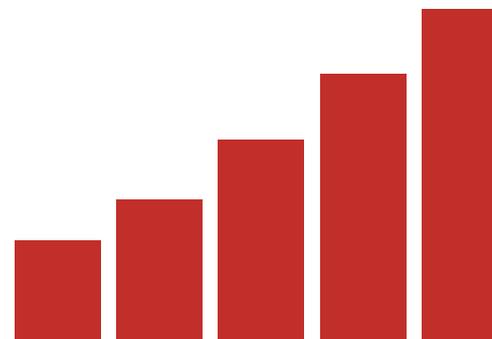
Alder Hey Children's NHS Foundation Trust has requested the network to allocate a 3% hosting fee from the 2024/25 budget. The added financial burden will place a significant strain on our budget, potentially hampering our capacity to achieve key objectives outlined in our workplan, provide necessary resources for our team, and organise events for both patients and staff. It's imperative that we find a resolution to mitigate these impacts and safeguard our ability to deliver on our commitments and maintain the quality of care and services we provide to our patients and staff.



Finance (cont/d)

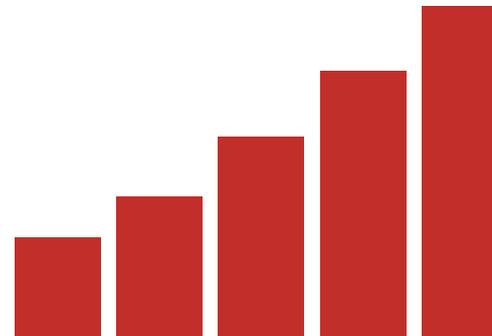
Alder Hey has formally approached NHS England, suggesting that commissioners support this fee, thus alleviating the strain on the already constrained network budget. However, Alder Hey has made it clear that if NHS England declines, the fee will be deducted directly from the network's budget. NHS England has indicated a lack of available funding for this purpose but has signalled disapproval of top slicing from network budgets. The Memorandum of Understanding (MoU) explicitly states that the entirety of the funding allocated to the host from NHS England must be accessible to the Operational Delivery Network (ODN). By signing the MoU, the host provider agrees to ring-fence this funding for the exclusive use of the network.

Networks hosted by Alder Hey are eagerly awaiting responses from NHS England and Alder Hey regarding the hosting fee issue. If NHS England advises against covering the fee and asserts that network budgets should remain untouched, Alder Hey's response will be pivotal. The outcome of these communications will greatly influence the financial landscape and operational capabilities of the hosted networks.



Looking to the future, what's next?

Exciting times lie ahead for the network as we embark on numerous impactful initiatives in the coming year. Our focus remains steadfast on enhancing patient care and experience while advancing clinical governance and collaboration. Key highlights from our upcoming workplan include establishing vital links with our three regional Integrated Care Boards (ICB), implementing innovative data collection systems, and championing patient representation through diverse engagement strategies. Additionally, we're committed to bolstering education, training, and research efforts to continuously elevate standards of care. Through close collaboration and tireless dedication, we are poised to support the delivery of exceptional healthcare services across the region.



We thank you for your continued support to the Network

Contact

www.northwestchdnetwork.nhs.uk



NorthwestCHDNetwork@alderhey.nhs.uk



@NwchdN



North West, Isle of Man and North Wales
Congenital Heart Disease
Operational Delivery Network
ANNUAL REPORT 2023/24

