



2022/23

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

ANNUAL REPORT



Document Control

Document Type	Annual Report 2022/23	
Document Status	COMPLETE (with single service section)	V3
Document Owner(s)	<p>CHD Network Team: Nayyar Naqvi, Chair, NW CHD Board Gordon Gladman, Clinical Director Nicola Marpole, Network Manager Linda Griffiths, Lead Nurse Jill Moran, Network Support Officer</p>	
Document Approval	Gordon Gladman	
Document Abstract	<p>This annual report for the North West CHD Network outlines the background to the network, its vision and key objectives, achievements and challenges, and key updates for the period February 2022 to January 2023. It also looks to the future, providing an overview of plans from February 2023.</p>	

Document Change Control				
Date of Version	Version Number	Lead for Revisions	Type of Revision	Description of Revision
8th June 2023	V2	Jill Moran	Editorial	
22nd June	V3	Jill Moran	Editorial	With Single Service Section)



Contents

Foreword from our Chair	1-2
Clinical Director's Network Review	3-4
About the Network	5
History & Geography	5
Meet the Team	6
Governance Structure	7
Vision & Aims	8
Patient, Public Voice Representatives	9 - 10
Self-Assessment Against National Standards	11-12
Clinical Audit	13
ICS Framework	14-16
Strategic Developments including Visions & Aims	17-21
Training & Education	22-24
Nursing	25
Clinical Governance	26
Patient and Family Experience of congenital heart services (PREMS)	27-29
e-learning & Education Project	30-32
Communications & Engagement	33-36
Network Risks & Challenges	37
Finance	38
Learning Disabilities Forum	39
Looking to the future, what's next?	40
Contact Us	41



Foreword from our Chair



Dr Nayyar Naqvi OBE
MBBS FRCP FRCPE FESC FACC FACP

It has been my privilege to serve as Chairman of the Board of the Congenital Heart Disease Network of the North-West, North Wales and the Isle of Man for the past four years. The vision of the Network is to support through collaboration, education and improvement, the delivery of world class congenital heart disease services for patients and their families, covering a population of approximately 7.5 million people. Our role has been to assist providers in the delivery of a collaborative model of care, to oversee the governance of this service model, to support operational delivery and ensure the pathways of care are meeting the national service standards. The goal is to address and reduce inequality and improve patient experience and outcomes. The Board is made up of hardworking, highly dedicated professionals and patient representatives, all endeavouring to provide the very best service to our patients.

The Network faced significant workforce challenges during 2022-23. Fortunately, an interim Manager has been appointed and the Lead Nurse has returned after a period of absence.

A project manager to oversee the all-age database project and a Lead Nurse for education, training and research have been appointed. Despite these difficulties, much has been achieved.

Clinical governance has remained a major focus for the Network. The first Network clinical governance meeting took place on 8 December 2022. Transformation is at the heart of the Network vision. The Network database project is progressing well and currently on target. The Network are supporting our paediatric cardiac teams to achieve their vision of having a single paediatric cardiology service across the Northwest. They have been busy operationalising their policy to self-assess CHD providers against the NHSE Standards to identify gaps in services and agree action plans with providers, Network and Commissioners. The website for the Network has been developed further with several new pages being developed this year including the young persons' page. The Twitter page remains active with the Network using social media to share its work, including promoting and advertising events and achievements.



Foreword from our Chair

Cont/d

Despite staffing constraints our Lead Nurse has continued to develop the Link Nurse forums and nursing strategy over the past year. I am delighted to hear that a new Lead Nurse (0.4 WTE) has been appointed to focus specifically on training, education and research across the Network.

The Network co-produced a patient information day on 15 October 2022, led by Janet Rathburn, Chair of our PPV (patient and public voice) group. This group remains active with strong representation on our Board. The Network has continued to work closely with our PPV group. It's encouraging to hear that the Network is seeking patient and family experience of congenital heart disease services (PREMS). The survey revealed many good points and a few that required improvement.



The proposal to consolidate the membership of the North West, North Wales and the Isle of Man Network Board with the NW Adult Congenital Heart Disease Partnership Board was discussed by both Boards and unanimously agreed. The aim will be to have one Board consisting of representatives from both organisations to facilitate and further improve service delivery and outcomes on behalf of all patients from both groups.

This will be my last report. I will continue as Chairman till the new Board comes into operation. It has been my honour to have been Chairman of the Network, to have served as faithfully and diligently since as I could over the past 4 years, and to have worked with a fantastic team of members to whom I express my grateful thanks.

I have greatly enjoyed my time with the Network but as Geoffrey Chaucer said, "All good things must come to an end"!

Nayyar Naqvi OBE



Clinical Director's Network Review



Dr Gordon Gladman
Network Clinical Director &
Consultant Paediatric Cardiologist

As we finally emerged from the COVID 19 pandemic (though it still hasn't left us), regional and national data revealed the significant impact the virus had inflicted on NHS waiting times for both inpatient and outpatient activities.



Pandemic Challenges

With 'standalone' Level 1 centres for Paediatric Cardiology and ACHD, the North West region coped better than many surrounding areas, where understandably at the height of the pandemic, all local provision had been turned over to supporting those critically ill with COVID at the expense of other medical conditions perceived to be 'slightly less urgent'. Nonetheless, as will be identified in this report, there remain significant challenges for those North West providers of congenital heart disease care, predominantly centred around 'catching up' with delayed outpatient assessments. Happily, it remains the case, that the Network has not identified evidence suggesting that within our region, those in need of urgent clinical care, came to any significant harm as a result of the specific pandemic challenges.



Network Team

The Network 'core team' have continued working hard to maintain communication with Network members; monitor the clinical effect of the pandemic on the provision of care across the region and provide support wherever possible. A 'positive' effect of the pandemic was that by necessity, it brought clinical members of the Network (be that clinicians, nurses or support staff) closer together with each other but also created closer relationships with commissioners, managers and most importantly families. The Network PPV group remains an active and vital component of our network, providing not only 'sensible censorship' where appropriate, but always acting as a two-way communication channel with the families and patients they represent.



Clinical Director's Network Review

Cont/d



Achievements

Despite the negative impact of Covid already outlined, the annual report always provides an opportunity to 'showcase' the many achievements of Network members and as will be highlighted throughout the report, members have remained active during 2022/23 and are to be congratulated on significant accomplishments, completed often under relatively adverse conditions.

Having now witnessed 40 years of NHS changes and contrasting (but very similar) challenges throughout those years, I feel confident that the willingness of Network members to 'step up' to and confront the latest challenge, confirms that a fundamentally 'safe and sustainable' service can be maintained, though there is always room for improvement!!



Final Report

This is likely to be my last annual report and I thank all those Network members involved in supporting me in my previous endeavours but also for providing the on-going care and essential support for those born with congenital heart disease.

I firmly believe the Network will continue to play an important role in maintaining standards and over-seeing the delivery of both paediatric cardiology and ACHD care throughout the region.

Thank you.
Gordon



About the Network

The role of the all age Congenital Heart Disease Operational Delivery Network is to support providers in the delivery of a collaborative model of care, to oversee the governance of this service model, to support operational delivery and ensure the pathways of care are meeting the national service standards. The purpose of the lifelong Congenital Heart Disease Network is to bring together a wide range of providers to work across organisational boundaries to ensure that everyone has access to high quality, evidenced-based care. The goal of the North West, North Wales and the Isle of Man CHD Network is to address and reduce inequality and improve patient experience and outcomes. We work with the principle of putting the patient at the heart of services and are committed to developing excellent CHD services through every stage of a person's journey



History & Geography



The Network covers a large geographical area including the North West region, North Wales and the Isle of Man, covering a population of approximately 7.5 million people.

The North West, North Wales and the Isle of Man Congenital Heart Disease (CHD) network has been in existence since 2012, formally becoming an ODN in September 2019.

The Network's purpose is to bring together clinicians, nurses, allied health professionals, managers, commissioners and patients to improve the Congenital Heart Disease service across the region.



Meet the Team



Network Clinical Director
Dr Gordon Gladman
Consultant Paediatric Cardiologist



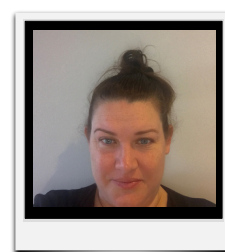
Chair Network Board
Dr Nayyar Naqvi OBE



Dr Caroline B Jones
Consultant Paediatric Cardiologist



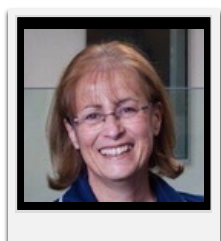
Dr Damien Cullington
Consultant Adult Cardiologist



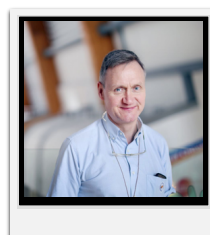
Helen Sanderson
Network Manager
(currently on maternity leave)



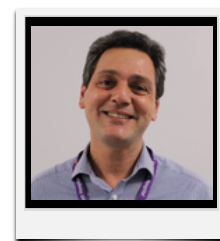
Nicola Marpole
Network Manager



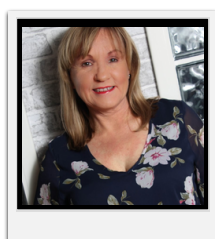
Linda Griffiths
Lead Nurse



Rob Johnson
Network Governance Lead



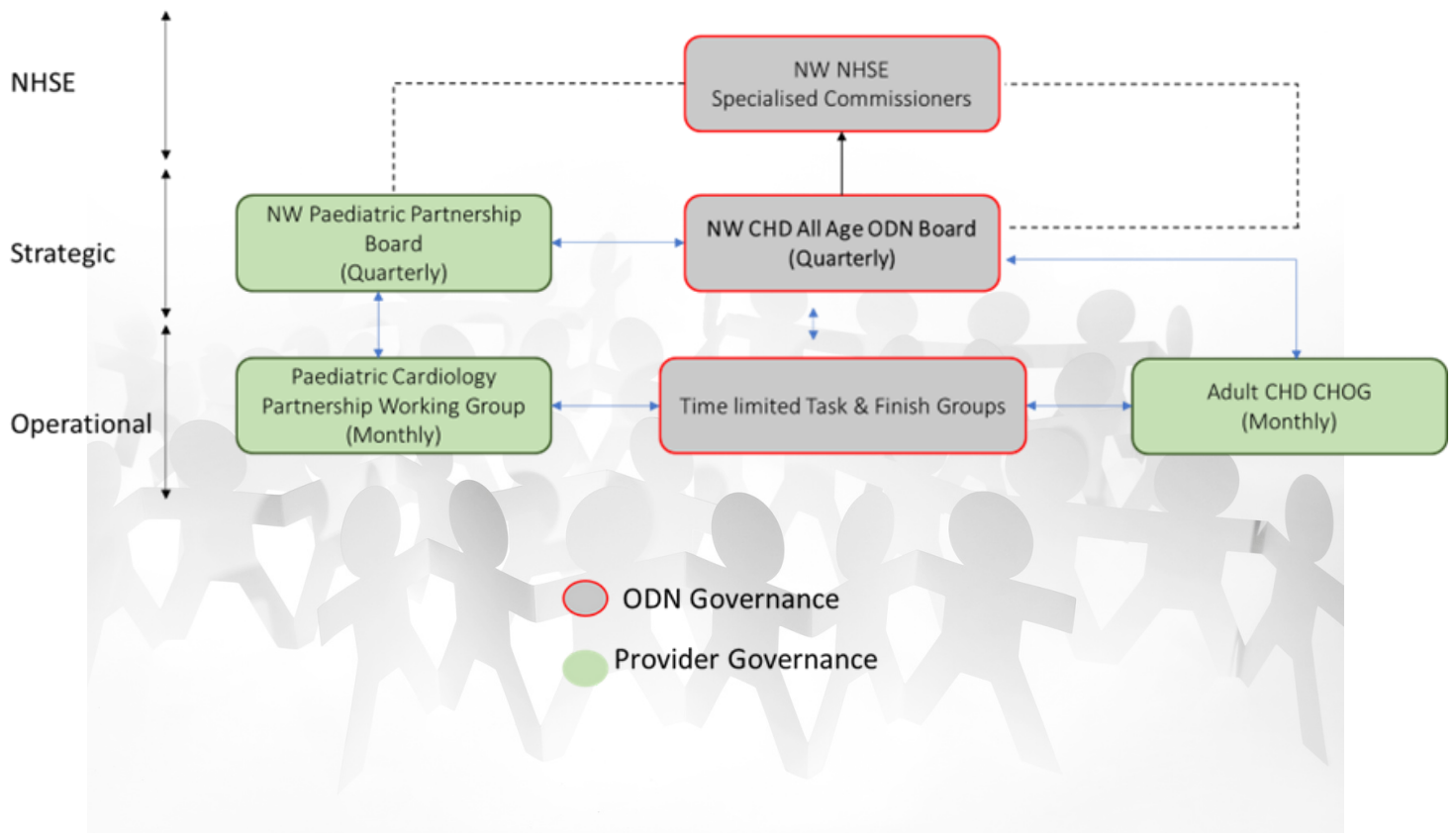
Vas Papaioannou
Network Governance Lead



Jill Moran
Network Support Officer



Governance Structure



A single paediatric cardiology service case for change is in development. If approved it is proposed that the NW Paediatric Partnership Board will be consolidated into the NW CHD All Age ODN Board to mirror the strategic oversight structure for the adult service.

The CHD PPV group meet regularly and provide independent representation to the NW CHD All Age ODN Board.

Task & Finish Groups are convened as required to support actions from the NW CHD All Age ODN Board.



Vision & Aims



Is to support through collaboration, education and improvement, the delivery of world-class congenital heart disease services for patients and families in the North West of England, North Wales and the Isle of Man.



To provide a high quality, fit for purpose network, demonstrating value & providing strategic direction

To provide seamless care across the region, ensuring equity of access to services in a timely manner, with the aim of providing high quality care as close to home as possible

To put the patient at the heart of all CHD Services

To have a robust and clear clinical governance framework to support quality improvements in care that benefit patients regionally

To provide assurance that 'national standards' are being met across the network, ensuring quality & safety and to work with providers where any 'gaps' in service provision are identified.

To develop digital systems that enables the sharing of clinical information between regional providers in a timely manner. To use digital solutions, informatics, outcome data and innovation as a tool for service improvement.



Patient & Public Representatives

The Network has a robust, mature and well-developed Patient and Public Voice Group (PPV). Established in 2020 the group has developed rapidly and become an essential part of the Network.

ACHIEVEMENTS

Over the last 12-16 months the PPV Group has successfully achieved the following:

Critical Friend

A vital part of the role of the group is to be a critical friend. The group has challenged the Network on a number of issues especially related to data. We are looking forward to the development of a new database.

Keeping going!

Due to unforeseen staffing difficulties it was hard for the group to have a link with the Network, we are grateful to those who stepped in to keep us in the loop.

Creative Links

The group decided they wanted to help to strengthen the links between hospitals and charities. This has led to more charity volunteers working in hospitals.

Patient Information Day

Providing a Patient Information Day in October 2022. It was well attended and well received.

Neonatal

Acting upon the findings of a presentation to highlight the need for improved neonatal detection rates. This led to additional training days being provided by Tiny Tickers.

BCCA

The chair of the group did a joint presentation with the Lead Nurse at the BCCA Conference.

Membership

Welcoming new members to the group.

Communications Survey

Being part of the monitoring group when the Communication Survey went live on the website.

Patient Information

Continuing to develop Patient Information leaflets.

Learning

Inviting a number of professionals to our meetings to improve our knowledge base.

Collaboration

Working with Clinical Lead Nurse to improve patient experience.

Representation

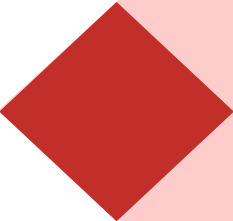
Provide a PPV voice at all Network Board Meetings.



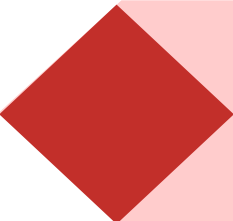
Patient & Public Representatives

Cont/d

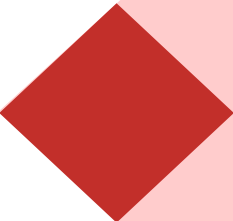
FUTURE WORK



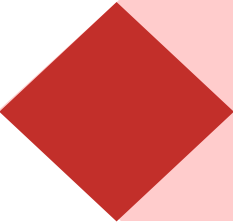
Continue to develop the role of charities in hospitals and to raise awareness of all relevant charities



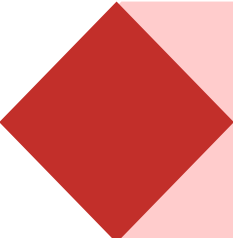
Continue to be a critical friend



Looking at how transition from Paediatric to Adult care can be improved



To support further Patient Information Days and other forms of information sharing

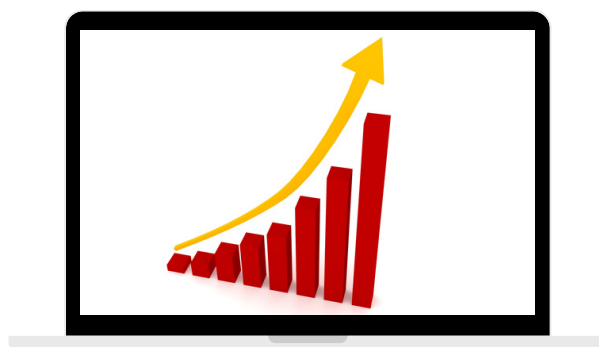


To ensure the sustainability of the PPV and to recruit new members, to ensure continuity when the terms of office of 8 current members come to an end in July 2024



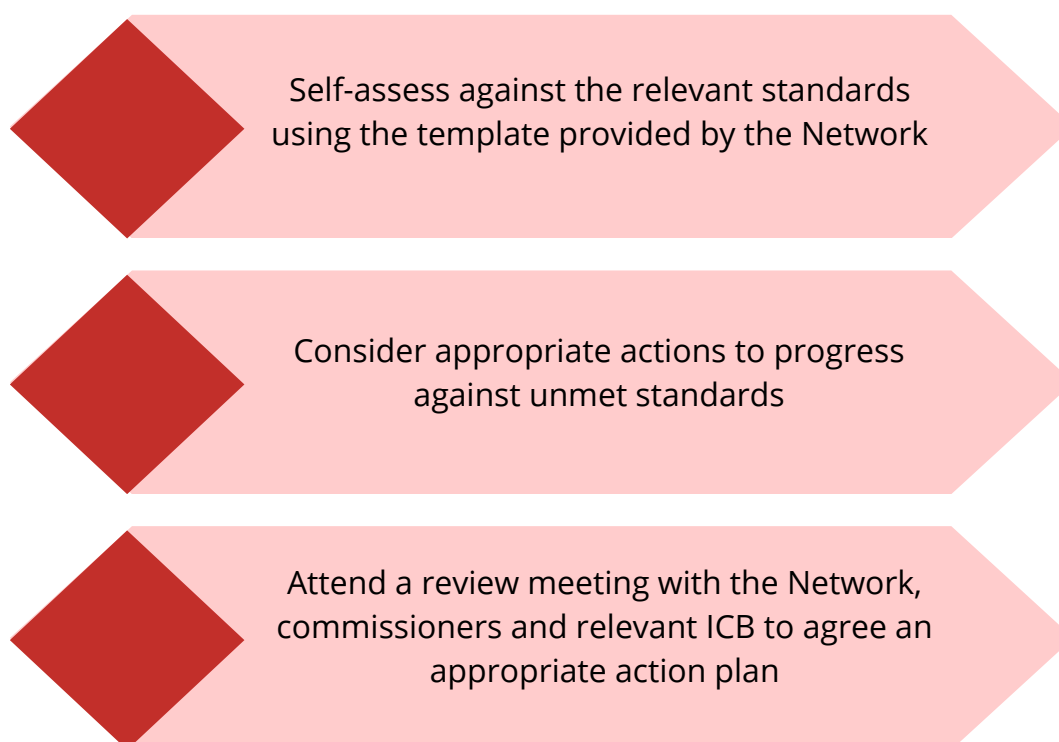
Self-Assessment Against National Standards

On behalf of NHS England, the North West Congenital Heart Disease Operational Delivery Network is facilitating a full self-assessment of all level 1, level 2 and level 3 Congenital Heart Disease services against the relevant CHD national standards, published by NHS England in 2016.



We are seeking to understand the extent to which CHD services across the region are delivering these standards currently, what gaps exist, and what actions or supportive measures may be required in order to close these gaps.

To facilitate this review, CHD services are asked to:



Individual service assessments and action plans will inform ongoing discussions between all parties to ensure a commitment to improving services.

Centres will be asked to re-assess regularly as part of a rolling programme to provide continued assurance that actions identified to address gaps in service are being achieved.



Self-Assessment Against National Standards

Cont/d

ACHIEVEMENTS

First centre in England has successfully completed the self-assessment

Outcomes of the self-assessment will form an integral part of the joint Manchester & Liverpool Single Paediatric Cardiology Services business case which if approved by NHSE will overcome some of the long term challenges in delivering equitable access to paediatric cardiology services across the region.

Final report submitted to the Welsh Specialised Services Committee (WHSSC) December 2022. A unanimous decision reach to adopt the English National CHD Standards across Wales.

The NW & SW Networks are working closely with the Welsh providers to establish the best way to implement these standards, while supporting the gaps in service identified during the self-assessment process, on a centre-by-centre basis.

THE FUTURE IS BRIGHT



The challenge is to manage the current service demands while balancing the impact of high workload and insufficient staff, resulting in high turnover and non-resilient services for a population of patients with complex needs and cardiac conditions.

All providers to have an agreed action plan which will be reviewed annually

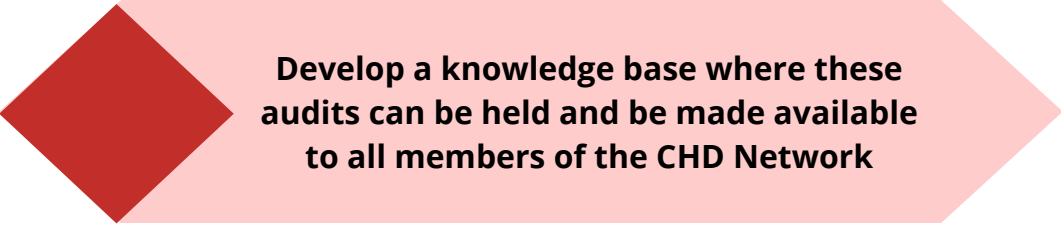
Continue to work with centres to support ongoing actions identified during the self-assessment process

Ensure all centres are self-assessed on a regular 3-5 year rolling programme



Clinical Audit

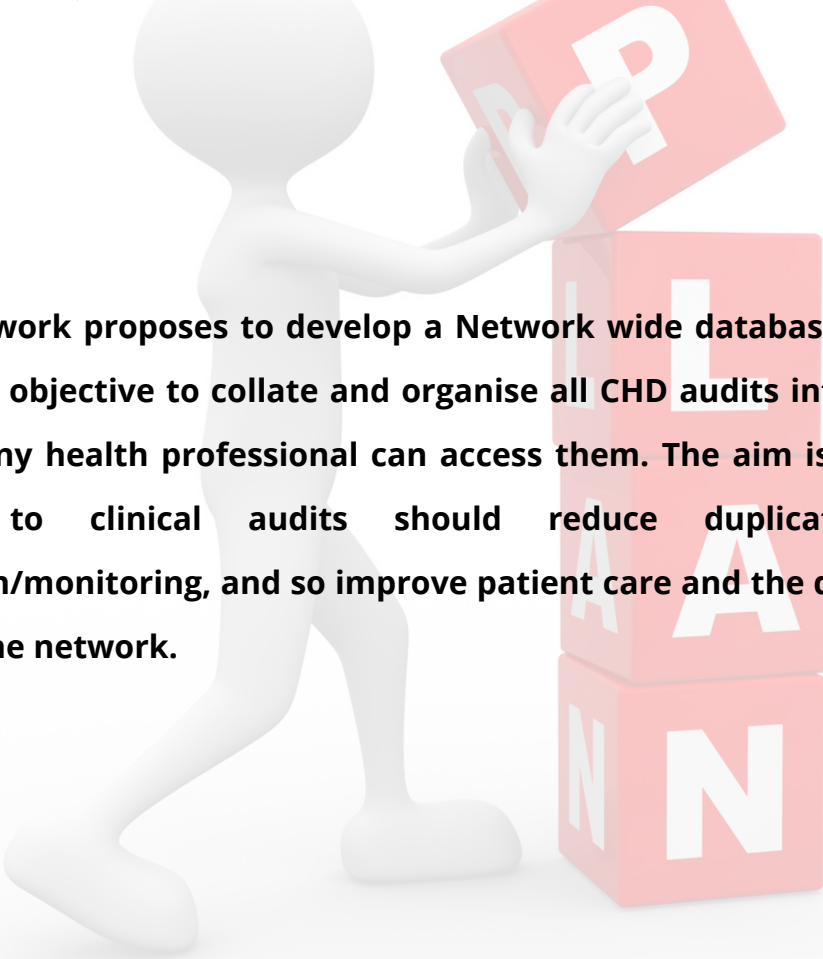
FUTURE PLANS



Develop a knowledge base where these audits can be held and be made available to all members of the CHD Network



Develop a strategy for collating all network wide audits



The Network proposes to develop a Network wide database of clinical audits with the objective to collate and organise all CHD audits into a single 'library' where any health professional can access them. The aim is that unrestricted access to clinical audits should reduce duplication of service provision/monitoring, and so improve patient care and the quality of CHD care across the network.



ICS Framework & Implications for the Network

What are integrated care systems?

Integrated care systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.

Following several years of locally led development, recommendations of NHS England and passage of the Health and Care Act (2022), 42 ICSs were established across England on a statutory basis on 1 July 2022.

What is included in a integrated care system?



Integrated care partnership (ICP)

A statutory committee jointly formed between the NHS integrated care board and all upper-tier local authorities that fall within the ICS area. The ICP will bring together a broad alliance of partners concerned with improving the care, health and wellbeing of the population, with membership determined locally. The ICP is responsible for producing an integrated care strategy on how to meet the health and wellbeing needs of the population in the ICS area.



Integrated care board (ICB)

A statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area. The establishment of ICBs resulted in clinical commissioning groups (CCGs) being closed.



Local authorities

Local authorities in the ICS area, which are responsible for social care and public health functions as well as other vital services for local people and businesses.



ICS Framework & Implications for the Network Cont/d



Place-based partnerships

Within each ICS, place-based partnerships will lead the detailed design and delivery of integrated services across their localities and neighbourhoods. The partnerships will involve the NHS, local councils, community and voluntary organisations, local residents, people who use services, their carers and representatives and other community partners with a role in supporting the health and wellbeing of the population.



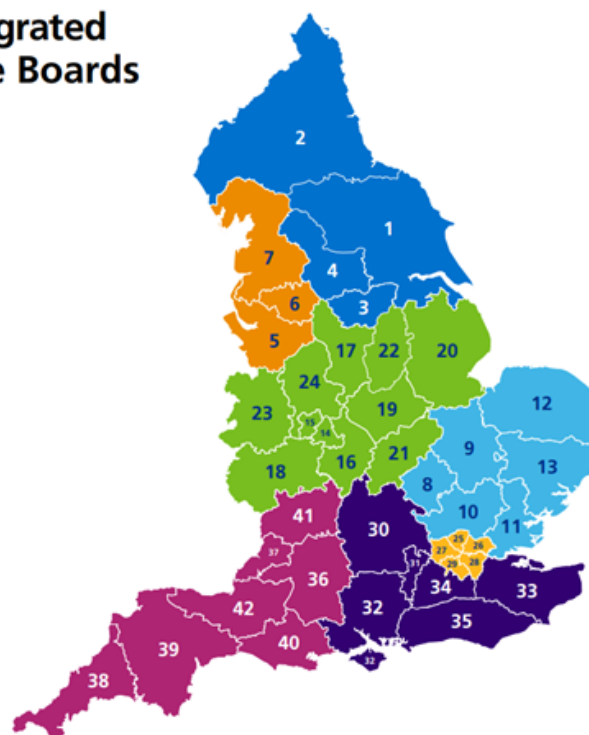
Provider collaboratives

Provider collaboratives will bring providers together to achieve the benefits of working at scale across multiple places and one or more ICSs, to improve quality, efficiency and outcomes and address unwarranted variation and inequalities in access and experience across different providers.

Networks have and continue to prove their value in co-ordinating pathways of care, ensuring equitable access to healthcare and so reducing health inequalities, assuring, and improving quality. Consequently, networks are anticipated to play a pivotal role in ICSs moving forward as this success is built upon.

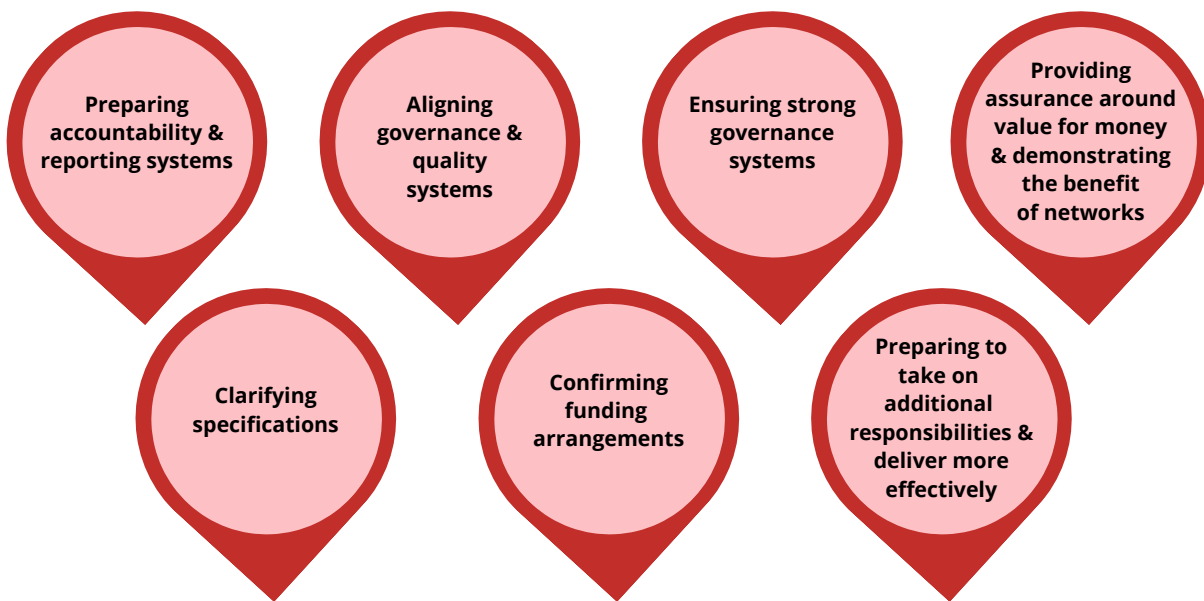
North West	
5	NHS Cheshire and Merseyside
6	NHS Greater Manchester
7	NHS Lancashire and South Cumbria

Integrated Care Boards



ICS Framework & Implications for the Network Cont/d

The coming year will see Networks continue to develop and prepare for the new ICS landscape with full integration into the three NW ICBs planned for early 2024. Work has started and will continue through 2023/24 to ensure networks are ready:



Relevant Achievements

The North West, North Wales and Isle of Man Network is working locally and nationally to ensure that we are ready for the developing ICSs proposals. Working with Commissioners, ICBs, Providers, and other Networks to ensure that we are prepared for the future changes and able to continue to develop and improve the quality of CHD care across our area and nationally.

Future Plans

The Network will continue to participate in, develop with, and adapt to the emerging ICS frameworks to ensure the best possible care for its population.



Strategic Developments

Including Visions & Aims

CHD All-Age Database



The Network has been involved in two strategic ventures (both on-going) during 2022-23. The All-age CHD regional database and the Single Paediatric Cardiology Business Case both aim to:

- **improve patient care**
- **improve equity of access**

The ODN faced significant staffing challenges during 2022 – 2023 with the loss of the Network data and project managers, the Network Manager being on maternity leave and some unexpected long-term sickness. This meant that many of the on-going projects, including the collection and sharing of data, and the development of the regional all-age CHD database had to be put on hold.

It is a key objective for the ODN to facilitate the sharing of data to enable better understanding of gaps and risks in service across the region. With the appointment of the interim Network Manager and the return of the Lead Nurse it has been a priority during the last quarter of 2023 to ensure the recommencement of locally collected data along with the prioritisation of the re-launch of the all-age database project.

Patients within CHD services are managed at provider level, with each provider utilising its own hospital-based patient administration system (PAS). These systems vary in their ability to accurately monitor backlogs, DNA rates and identify all the patients for whom the provider is responsible. It is therefore difficult to get an accurate regional picture of the number of CHD patients being cared for within the ODN footprint.

There is a recognised risk that due to the use of multiple, unlinked systems, patients could become lost to follow-up. In collaboration with NHS England and providers the CHD ODN Board made the collective decision to develop and implement an all-age regional database.



Strategic Developments

Including Visions & Aims

CHD All-Age Database



AIMS

- Ensure patient safety and reduce clinical risk
- Provide High quality accurate data
- Monitor and review CHD patient backlogs
- Permit effective and dynamic capacity and demand planning
- Facilitate the provision of a comprehensive equitable service across the region
- Provide a web-based, access anywhere dashboard



PROGRESS & ACHEIVEMENTS TO DATE

- Agreement from level 1 & 2 providers to develop and implement an all-age regional database
- Funding towards the development, implementation and maintenance of the database secured from Regional Commissioners, additional funds provided from ODN underspend
- Project manager appointed to oversee the project
- Mindwave Ventures Ltd, one of the leading NHS approved, Personal Health Record/Patient Portal developers in the UK, engaged to develop and deliver the all-age database solution
- Collection, analysis and submission of both regional and national waiting list and backlog data reinstated
- Providing quarterly data summary to the NW CHD Network Board for the L1 & L2 Providers
- Regular reports to the PPV group
- Improved working relationships with providers



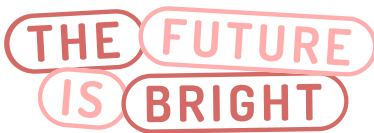
Strategic Developments

Including Visions & Aims

CHD All-Age Database



- Providing a regional solution within a limited budget and timeframe
- Integration across 30+ providers, many using different digital platforms



- Undertake a scoping exercise, leading to a 'road-map' to formulate the integration of the database across level 3 providers
- Continued review and revision where appropriate to ensure the database delivers the ODN KPIs and the needs of providers



Strategic Developments

Including Visions & Aims

Paediatric Cardiology Partnership Group



Addressing immediate patient safety concerns, national service standards and moving towards a single regional service

There have been longstanding challenges in delivering equitable access to paediatric cardiology services across the North West, which reflect the region's unique demography in hosting two of the four largest children's specialist hospitals in the UK, Royal Manchester Children's Hospital (RMCH) and Alder Hey Children's NHS Foundation Trust (Alder Hey).

The open and constructive dialogue developed, in particular over the last 4 years, has enabled both Trusts, along with the ODN, to consider options for addressing regional health inequalities, the current capacity disparity, and organisational risks borne by both. There is a strong rationale and appetite for the development of a 'single service' in which the level 1 and level 2 centres, while retaining focus on their respective duties accordingly, would move towards a single workforce, operating model and patient waiting list. The mobilisation of this model is however reliant on the receipt of sufficient funding, to provide the required staffing and infrastructure support.

There is a significant shortfall in capacity at RMCH to meet the demand for paediatric cardiology. Although non-recurrent efforts to reduce waiting lists have provided partial mitigation, the fundamental shortfall in clinical capacity has meant a drastic increase in RMCH's waiting lists for new appointments and backlogs to follow-ups.

In order to address not only the RMCH safety and capacity issues, but to also solidify joint working efforts towards the 'single service' the collaborative is in the process of writing a business case to NHS England requesting funding which if successful will allow the service to address disparity of access, improve outcomes, boost staff recruitment & retention, and contribute to the long-term sustainability of both Alder Hey and RMCH services.



Strategic Developments

Including Visions & Aims

Paediatric Cardiology Partnership Group (Cont/d)

The collaborative aims to:

- Deliver equitable and outstanding child centred cardiology care across the North West, which is resilient & capable of meeting patient led demand
- Improve patient experience through timely access to cardiology services within Alder Hey, RMCH and across the North West
- Develop a joint approach to cardiology services and specialist clinics at both sites
- Develop a joint approach to education and training
- Develop a clear common approach to Research and Innovation
- Optimise Paediatric cardiology referral and treatment pathways
- Optimise capacity and access to diagnostic imaging, scans and interventional cardiology across both sites



Collaborative progress and achievements to date:

- The first iteration of the single service business case was submitted to NHS England in 2022. Unfortunately, the case was not approved
- Following feedback from NHS England, Royal Manchester Children's Hospital, Alder Hey Children's NHS Foundation Trust and the CHD ODN are working closely with the regional commissioning team to write an amended version of the case with the aim to re-submit in July 2023

Future plans:

- Prioritise and strengthen the service provided by RMCH
- Develop organisational agreements to support cross site working
- Operational review with the aim to bring parity across sites



Training & Education

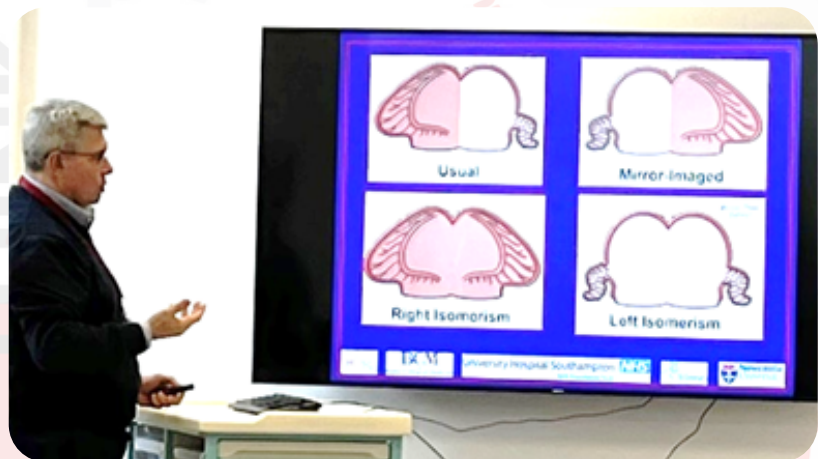
Training and education remain an essential role for the Network. This was affected by Network staffing issues over the previous year. Since June 2022 the education programme has continued to get back on track. Every effort is made to consider the training needs of all levels of staff – offering different levels of training and accessibility.

Achievements over last 12 months

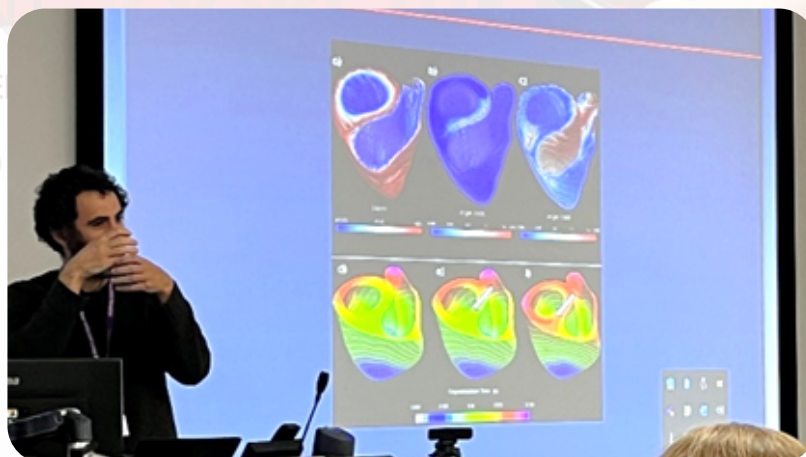
Higher education

The Network continued to support the ACHD master’s module which included a week long, face to face, in depth education on 14th November 2023 in partnership with Liverpool John Moore’s University. This was evaluated very well and had delegates from across the UK that attended.

Our CHD Experts
teaching on ACHD
Masters module



EDUCATION



Training & Education

Cont/d

Work is continuing on the development of the Paediatric CHD Masters Module. We hope this will be live next year. Both the paediatric CHD and ACHD modules will become part of a full Masters programme in Cardiology that will be available for all health care professionals, including clinicians, AHP and ANPs.

Local Network Study days

The Network was not able to support any formal study days during 22-23 due to staffing constraints. However, we are planning several face-to-face study days this year. The first being an ACHD Study for nurses and AHP's on 30th June 2023.

The Alder Hey Academy

The Alder Hey Academy based at the Institute in the Park have been providing online webinars via Zoom and are available for all clinicians throughout the Network. Topics cover a wide range of issues across paediatrics and adults with a focus on intervention. Clinicians can register to receive the zoom links by emailing: theacademy@alderhey.nhs.uk

Raising awareness of ACHD sessions for non-CHD clinicians

Our Lead Nurse has been providing on-line awareness sessions via Teams. This training runs every 8 weeks. Attendance has been from heart failure nurses, community staff and staff working in district general hospitals across the Network. A total of 79 staff from across our footprint have attended these awareness sessions.

Antenatal training for Sonographers

In response to the most recent NICOR data around antenatal detection pick up rates across the Network footprint we have joined up with Tiny Tickers charity to provide professional training for all of our obstetric units providing the 20-week anomaly scan. The Network has supported with some extra funding to achieve this goal.

The first hospital trust to have received training was St. Helens and Knowsley NHS Trust. They had their training on the 21st of April at their Whiston site. They had one day of training that consisted of sonographers that had never had Tiny Tickers training before alongside newly qualified sonographers.



Training & Education

Cont/d

Hospitals that have confirmed dates for future training are:

St. Mary's Manchester - 3 days are booked in
Royal Preston hospital - 1 day booked in

Hospitals that have applied for training pending confirmed dates:

Salford Royal NHS Foundation Trust
North Cumbria University Hospitals (Cumberland Infirmary, Carlisle)
University Hospitals of Morecombe Bay (Furness)
Wirral University Hospital NHS Foundation Trust (Arrowe Park hospital)

There are 20 remaining hospitals which are eligible for training, and they will be approached by the Network and encouraged to take up the training being offered.

Network Education Task & Finish Group

This group first met in June 2021 and aimed to bring together interested professionals to look at education provision for CHD across the region. This group has not met this year due to the staffing issues described earlier. There is a plan to bring this group together once the Education & Training Lead Nurse post is in place. Group membership presently includes clinicians, physiologists, nursing (all age), ANP and University staff.



Nursing

Previous work undertaken was put on hold until June 2022. This was due to the unavailability of Network Lead Nurse for 6 months. The Lead Nurse has now retired and returned to part time work. This has had implications for the further development of the Nursing strategy over 2022/2023. However the Paediatric and ACHD Link Nurse Forums have gradually started up again. Most notably the ACHD link nurse study day has been planned and is due to take place on 30th June 2023. The appointment of 0.4 WTE Education & Training Lead Nurse to work alongside the existing Lead Nurse will ensure the role of link nurse is further developed in 2023-2024 alongside a tailored education programme to support our nursing workforce across the Network.



- Regular lead nurse meetings including representation from Liverpool Heart and Chest Hospital, Alder Hey Children's Hospital, Royal Manchester Children's Hospital & Manchester Royal Infirmary
- Paediatric Link Nurse forum established and growing with over 40 nurses
- ACHD Link Nurse forum established and growing with over 50 nurses
- Link Nurse competencies and role description written, ratified and circulated
- Link Nurse mentorship programme agreed and supported across the level 1 hospitals and the network
- Link Nurse teams/groups set up - providing educational resources/ videos/teaching materials
- Nurse specialists recognised - involved in supporting link nurse programme, mentorship and teaching

THE FUTURE
IS BRIGHT

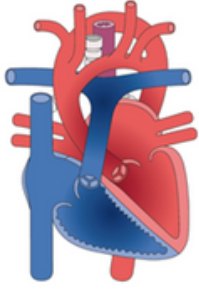
- Create a Link Nurse section on website
- Planning a small working group to look at developing resources for the Link Nurses
- Paediatric face-to-face Link Nurse study day



Clinical Governance

Clinical governance has remained a major focus for the Network over the last year. The SOP was finalised in 2021 and governance leads for both paediatrics and ACHD have continued to support the work.

Our first clinical governance meeting took place on 8th December 2022. This was chaired by our Lead Nurse with support from our clinical governance leads. A total of 28 members of staff from across level one, two and three centres and with representation from paediatrics and adult services attended the meeting. A full programme of incidents and mortalities was discussed resulting in some common themes being identified. The Network agreed what actions needed to be taken following the meeting. The meetings will continue to run every 6 months with the next one being planned for 13th July 2023.

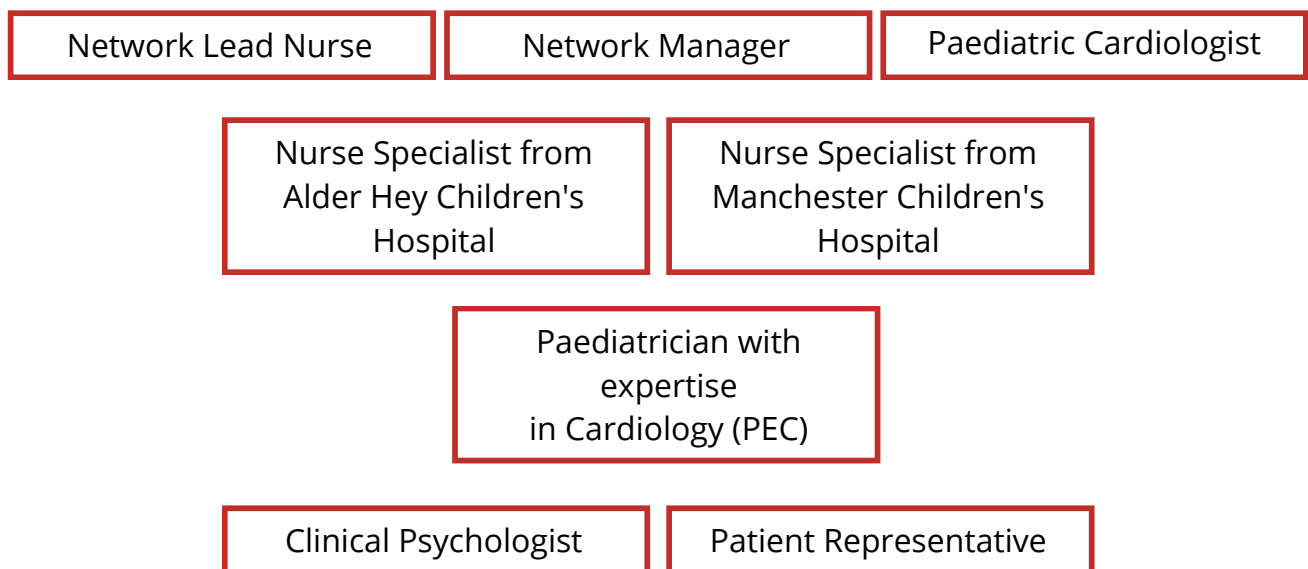
<p>Self Assessments against the NHSE Standards is coming your way! The Network supporting you to identify gaps</p>	<p>Two Themes Identified Transfer of extremely sick and unstable non-ventilated children & babies Lack of Fetal Nurse Specialist at RMCH</p>	<p>Double Aortic Arch do you know what to look out for ?</p>
<p>Confidential Emails The Link ↓ provides the list of accredited organisations and the DCB1596 Conformance Statement https://digital.nhs.uk/services/nhsmail/the-secure-email-standard#list-of-accredited-organisations If both Trusts/organisation are on this register – no need to encrypt!!</p>	<p>Pathways & Documents Cardiac Maternity Pathway Prenatal Diagnosis of CHD and FASP Guidelines (we will be in touch in the New Year!)</p>	
<p>Paediatric Prems Survey We will provide a standardised “Open Access” Letter to enable high risk and vulnerable babies and children to have open access to local paediatric Medical Assessment Units</p>		<p>Vascular Ring Symptoms, Diagnosis & Treatment (cincinnatichildrens.org)</p>



Patient and Family Experience of congenital heart services (PREMS Surveys)

The Network has continued to work closely over the past year with our Patient and Public Voice (PPV) group to further develop our patient surveys. Previously the PPV group had expressed their concerns about communication across the Network. However, it was difficult to pinpoint what needed to improve. We decided to ask patients and families about their experiences. It was a very powerful exercise to listen to their stories. We held two forums with families and used their stories to create a questionnaire based around real life patient and family experiences. This pilot was registered with the audit department at Alder Hey and for the past year the survey has been live. The Network has now completed an audit report and action plan based on the results.

The network set up a small working group to review the results. This comprises:



The outcomes from these meetings were presented at the Network Clinical Governance meeting on 8th December 2022 with ongoing progress reports expected.

Key findings/results:

61 surveys completed fully



Patient and Family Experience of congenital heart services (PREMS Surveys)

Lots of good points:

- 100% of those who had nurse specialist antenatal contact found it helpful
- 100% of those who had a visit to the hospital prior to surgery or intervention found it helpful
- “cardiac nurses are the candle in the dark!”
- It appears that those families who had one to one support – had a good experience

Things that require improvement:

- 71% did not know how to access psychological support
- 48% didn't know emotional support was available
- 47% did not receive any support antenatally (this may be due to lack of fetal nurse specialist at RMCH)
- 70% felt that there was a delay in decisions being made when they were admitted to a non-cardiac setting outside of the specialist centres
- 61% felt they had to repeat information and 93 % would have found hand held records helpful
- 49 % had to contact (alder Hey) and 13% (RMCH) themselves to help with communication when admitted elsewhere
- 100% of families had never seen a cardiac link nurse when in a peripheral clinic
- 57% did not know about local or national charities
- 77% not offered first aid training

You told us!

- Clinical Nurse Specialist role is vital
- Psychological support is very important, but most families don't access this
- We need to provide general advice and support to a much wider audience of families
- Hand held notes are helpful and liked by families
- Need to increase access to first aid training for families.
- Families don't get any support from a cardiac link nurse at level 3 peripheral clinics



Patient and Family Experience of congenital heart services (PREMS Surveys)

Actions identified

- Produce a standardised “open access letter” that can be downloaded from the Network website to support complex patients having open access to paediatric medical assessment units
- Work more closely with charities and PPV group to help support families:
 - Facilitate access to hospital sites
 - Improve communication between charities and clinicians
- Network to look at developing:
 - Use of webinars
 - Patient information days
 - Patient information for the website
- Paediatric Link Nurses:
 - Framework is now in place to support the role of the Link Nurse
 - Network to work with level 3 centres to encourage development of role

Over the past year the Network has undergone the same process with our adult patients creating a separate survey for our ACHD population. We are pleased to announce that both our Paediatric and ACHD surveys have moved on to a digital platform hosted by IQVIA. Both surveys went live on 15th May 2023.

Future plans

- We will continue to analyse the outcomes of both surveys quarterly
- We will feedback results at the Network Clinical Governance Meetings and through our PPV Group
- We will look to develop a new survey specifically for young people going through transition
- We will also engage with our learning disability forum to develop a separate survey for this user group

Link to survey 

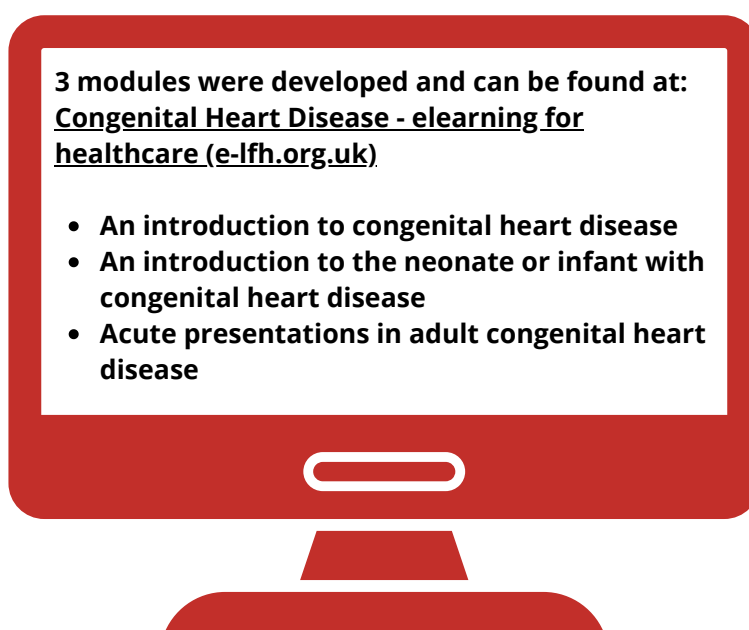
Patient & Family Experience PREMS Survey



e-Learning & Education Project

In the summer of 2020 – the Network Lead Nurse led the sub-group of the British Adult Congenital Cardiac Nurse Association (BACCNA) to undertake a UK wide survey of nurse education. This identified a gap in training and education for band 5 nurses whether they worked in a CHD specialist centre or not, as well as all nurses working in non-CHD centres regardless of their grade. This gap in training correlated with increased anxiety when looking after patients with CHD. It has been assumed that this is probably replicated across all disciplines and not just nursing – although this wasn't studied specifically.

This work was presented at the National CHD Network meeting on 14th June 2021. There was agreement at that meeting that a project solution to bridge this gap should be undertaken. The solution was found to be the creation of three UK wide introductory level e-Learning modules. Expertise from around the UK was brought together to agree the content for the CHD modules. These were aimed at the non-specialist.



The three modules have now been live for one year. Feedback and evaluations of the modules has now taken place:



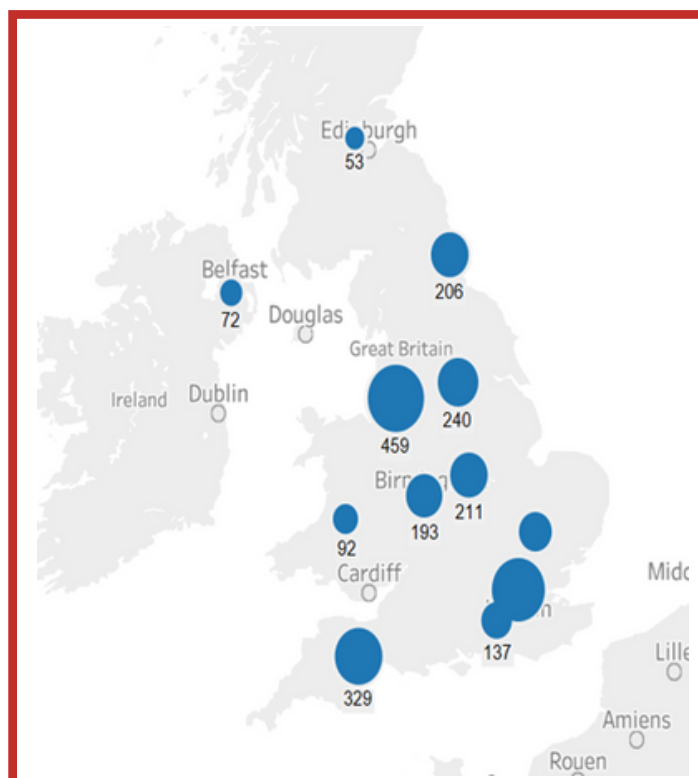
e-Learning & Education Project

Cont/d...

Range of professionals accessing e-Health:

- Nursing & Midwifery Registered
- Medical (GMC) & Dental (GDC)
- Allied Health Professionals
- Health
- Students
- Additional Clinical Services
- Additional Professional, Scientific & Technical
- Additional Clinical Services
- Education
- Social Care Sector
- Unknown
- Healthcare Scientists
- Community
- eLfh Staff

National take up of modules



e-Learning & Education Project

Cont/d...

Next Steps



Review existing modules

Agree curriculum for further modules to be developed



Working group meeting again – to agree next module for development

Source funding to develop



Embed the CHD modules via L&D departments in provider hospitals and to ensure that in key areas they are mandatory

To keep promoting and advertising them across the Network



Communications & Engagement

Effective communication and engagement are essential to ensure that the Network achieves its goals, not only from the perspective of Network staff but also in the eyes of patients, parents, clinicians, nurses, and all professionals involved in the care of CHD patients.

Website

A new site map for the Network has been developed to provide more information and to improve the overall user experience. This will go live once all the patient facing pages have been ratified. The new site will allow greater flexibility and enable more sections to be developed moving forward.

- **“Finding out about a babies heart problem before they are born”** provides information for families who are going through the journey of an antenatal diagnosis
- **“Moving On”** is information for young people growing up with a heart problem and are preparing to move and eventually transfer their care to adult services
- **Education** section on website now live with links to presentations available and useful educational papers and documents
- Link to the **E-Learning for Health CHD Modules** available on HEE website
- Network documents are available and accessible on website
- **Clinical guidelines** and forms that have been ratified are accessible on website
 - Published this year
 - Urgent referral form for paediatric cardiology
 - ACHD Referral pathway
 - ACHD EP and device referral pathway
- **Board documents** available on website
- **Patient information leaflets** available on website
- Information about our **Patient and Public Voice Group** and how to express an interest in joining are available
- **Network contact form** live on website
- There is a **“useful links” page** that can be used to sign post patients and families to help and support for a wide range of issues

Pages being developed:

- “How do we look after children with a heart problem” has been written and is in draft format on the website and is expected to go live later this year
- “How do we look after adults with congenital heart disease” is in draft format and will be ratified by end of Q4 2023



Communications & Engagement

Cont/d...

Future Website Work

- Develop a page for learning disabilities
- Develop a page for our PPV Group
- Develop a Link Nurse section



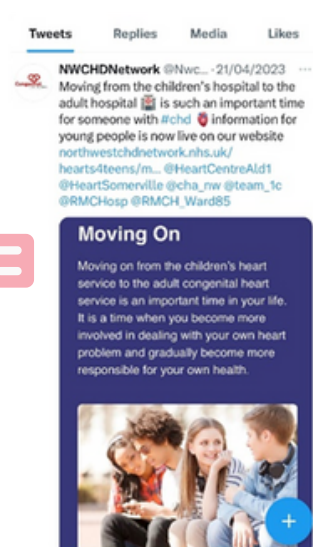
Newsletter

Network newsletter has been delayed due to staffing constraints but will be produced this year and then on a yearly basis thereafter. The Network has purchased a licence for CANVA-Pro to enable high quality adverts, newsletter articles and promotional material to be created.



Social Media

The Network Twitter page remains active with good engagement. @NwchdN currently has 726 followers and is used to promote staff, events and major achievements across our Network. We also use it to link nationally with our partner Networks and wider CHD community to promote education, events, and developments in the field of CHD. The Network has used social media to share its work including promoting and advertising the patient and family surveys via twitter and Facebook.



Communications & Engagement

Cont/d...

Networks

The Network continues to work collaboratively with other CHD Networks around the UK. Participating in national meetings on a regular basis. Our Network Manager meets regularly with their counterparts to consider the national agenda working closely with the National NHSE Lead for specialised CHD services. The Network has worked alongside the South West CHD Network to complete the self-assessment against the NHSE standards across level 3 centres in Wales. The two Networks have been working closely with Welsh commissioners towards adopting these standards across the Welsh providers.

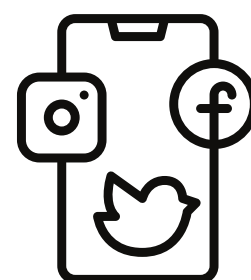


The Network Lead Nurse, Manager and Clinical Lead for Paediatrics met in Birmingham following the BCCA in November 2022 to agree national priorities for the next year and to consider the implications of the new Integrated Care Landscape and how Networks will work alongside ICB's in the future.

Our Lead Nurse meets regularly with CHD Lead Nurses from other Networks. This is to provide peer support for staff new to the role of Lead Nurse as well as working collaboratively on various projects, including education and teaching.

Social Media

The Network has continued to utilise and build on the digital platforms available including Microsoft Teams and Zoom. Online meetings have facilitated greater attendance at meetings and wider representation.



Zoom Licence

Zoom is one of the platforms the network continues to utilise to improve engagement across the area. A Zoom licence was extended throughout 2022 to support patient information days as well as training and education events where MS Teams could not be accessed.



Communications & Engagement

Cont/d...

Patient Information Day

The Network co-produced a patient information day on 15th October 2022. This was an all-age event with both families with children with CHD alongside our adult population. This was in collaboration with the Network PPV Group, The Children's Heart Association and Team 1C. Funding was sourced from The Children's Heart Association who utilised a grant from the Co-Op to be used for such an event. The event was also sponsored by the Alder Hey Charity, Liverpool Heart and Chest ACHD Fund and The Manchester Heart Centre ACHD Fund. The day was a fantastic success with around 100 people attending. There were several talks and workshops for people to choose from. Both local and national heart charities were invited to attend. The chair of our PPV group Janet Rathburn did a superb job of chairing the event and keeping everyone to time. Evaluation was undertaken and it was clear that this type of event was valued by those who attended. The Network are now in the process of planning another event this year.



Delegates welcomed to the Patient Information Day by Chair, Janet Rathburn



"It was a fantastic event and always good to meet other heart patients and compare worries etc, I find it comforting that we are not alone in our worries and challenges with a heart child."

"Brilliantly well organised and informative day. Met some lovely people who had some interesting stories to share. Really nice to speak to people who I had something in common with and who understand our health issues. All the talks were really interesting and relevant. Really looking forward to the next event. Well done to all involved!"



Network Risks & Challenges

The CHD Network risks are hosted on the Alder Hey platform InPhase. The Network risks remain independent of the host children's hospital own risks. All Network risks are updated monthly with the Network governance leads for paediatrics and ACHD. A comprehensive report is provided to CHD Board members once a quarter. Risks scoring >12 are individually discussed at the CHD Board meeting and actions agreed.

Over the past year several risks have been downgraded and eventually closed due to adequate management. This has included the problem with paediatric transport of HDU patients and the inability of the Network to monitor clinical incidents and mortalities. At the end of 2022-23 the following are the highest risks that remain on the network risk register. The risk associated with the single paediatric cardiology service is currently under review with the aim to identify the individual components which are contributing to the overall risk, e.g. communication, imaging, capacity & workforce, including medical, nursing, physiology and psychology. This will allow for a more focused approach to managing each risk, enable progress to be clearly tracked while highlighting those areas which have ongoing actions to address.

Risk Number	Score	Risk	Outstanding Actions/Comments
2332	20	Single Paediatric Cardiology Service	Network is undertaking self-assessment against the NHSE standards for level 1 + 2 centres Work being done to identify the individual risks associated with this and who is responsible The above will help inform business case to support transformation to be submitted to NHSE
2383	16	Psychology	Self-assessment against the standards – on going to identify gaps
2667	16	Backlogs in Manchester Royal Infirmary	MRI submitting data regularly Backlogs continue to be monitored Regular meetings to discuss actions to help reduce
2284	12	Sharing of images	Audit of current practice/issues Minimum standards – Network documents to be written Integration of ISCV imminent
2331	12	Fetal cardiac nurse specialist at Royal Manchester Children's Hospital	Self-assessments to identify gaps Will be included in individual risk scores as per risk number 2332 Antenatal management & FASP Guidelines being written by the Network Project development looking at developing a more robust referral pathway and documentation to support fetal management plans
2339	12	Backlogs in Blackpool Victoria Hospital	Extra half day a clinic to start in May 2023
2276	12	Database To give assurance to NHSE regarding patient lists	Data analyst post to be advertised PMO – interviewed and appointed Mindwave Project back on track with timelines agreed
2692	12	Availability of ACHD Echo's due to staffing constraints	New physiologist in post and being trained up Network continuing to monitor



Finance

Budget for 2022-2023	
Recurrent	Non-Recurrent
£219,004	£96,316

The non-recurrent funding was awarded by NHS England specifically to support the development of the all-age CHD regional database.

2022/23 Month 12	YTD Plan	YTD actual	YTD variance	FOT plan	FOT actual	FOT variance
Income	315,320	315,320	0	315,320	315,320	0
Costs – pay	206,600	206,600	0	206,600	206,600	0
Costs – non-pay	108,719	108,719	0	108,719	108,719	0
Costs sub-total	315,320	315,320	0	315,320	315,320	0
Total	0	0	0	0	0	0
Totals include <u>non recurrent</u> funding received in 22-23						



Learning Disabilities Forum Report 2023

The Learning Disability (LD) Forum was placed on hold until Q3 of 2022. This was due to staffing issues within the Network. However, since then the LD Forum has met monthly on the third Wednesday of every month. The group consists of patients with lived experience of congenital heart disease with additional needs and learning disabilities, their families and carers, as well as representation from SCOPE. One of our PPV members helps to facilitate the group alongside our Lead Nurse.

What's important to the LD Forum












We would like to organise an information day for people with disabilities and their families. We will think of what to include next time we meet.



Is someone with a learning disability coming to clinic? Can the nurse specialist come as well? It's good to talk afterwards. Sometimes we have lots of questions.



The LD Forum have developed a check list. This includes things that are important for hospitals to get right for people who are neuro-diverse or are learning disabled. Over the next year they are planning to visit the hospitals that provide congenital heart services to see how they measure up against the standards they have developed.

	Do you have easy read versions of your patient leaflets to help me understand?	 
	Is your hospital doing the Oliver McGowan Mandatory training to understand the needs of people with autism?	 
	Are you teaching your learning disability champions how to use Makaton?	 

	Do you provide a free parking pass for my family or carer that is staying to help look after me?	 
	Do you provide a sensory area for people who need a quiet and calm place to be?	 
	Do you provide toilets for people with disabilities that includes a changing place?	 

We look forward to receiving the outcomes of this work next year.



Looking forward to the future, what's next?

The hard work that went into the Welsh Health Specialised Services Committee (WHSSC) report and accompanying self-assessment process will be continued by the Network team, who will resume the roll out of the self-assessment programme across providers in England in 2023.

A key focus for the Operational Delivery Network (ODN) in the next year will be the recruitment and development of the Project Manager, Lead Nurse and Data Analyst posts. We are keen to bring together key individuals who can provide the skills and expert knowledge to support the ODN in achieving success in the implementation of the regional all-age database, development of a high-quality training and education programme for clinical colleagues, creation of a Research and Innovation strategy, and the provision of high quality, timely and informative data to improve patient safety and equity of access to services across the North West.

Transition will be a key area of focus, as well as supporting nurses involved with CHD care across the region. Our Clinical Director, Gordon Gladman, who has been with the Network since its inception is coming to the end of his tenure and a new Clinical Director will need to be recruited in the coming months. This role provides clinical medical leadership across the ODN and is vital to the successful running of the Network.

Gordon will be a tough act to follow, his experience and leadership has played a major role in bringing together colleagues across the network to improve care for patients with CHD.

Coming out of the pandemic, we are happy to announce that we will be hosting a number of face-to-face events in 2023. Our ACHD Nurse Training Day, Patient and Public Voice group meeting and Patient Information Day will all be held in Liverpool in the coming months. We are so excited to meet with colleagues, patients, and their families in person again to continue and build upon the fantastic work that has become synonymous with the North West, North Wales, and the Isle of man CHD ODN.

How to get involved

There are many ways to get involved with the network:

Professionals

- Attend one of our training events
- Take part in our virtual annual morbidity and mortality meeting in July 2023
- Attend one of our engagement events

Patients and families

- Visit our website
- Access our newsletter via the website
- Apply to become a patient, family or carer representative for the network
- Attend one of our engagement events



We thank you for your continued support to the Network.

Contact

www.northwestchdnetwork.nhs.uk 

NorthwestCHDNetwork@alderhey.nhs.uk 

[@NwchdN](https://twitter.com/NwchdN) 

**North West, Isle of Man and North Wales
Congenital Heart Disease
Operational Delivery Network
ANNUAL REPORT 2022/23**

