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

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1. Introduction

Congenital Heart Disease services within the North West are provided within three localities within England. This includes Lancashire & South Cumbria, Cheshire & Merseyside, and Greater Manchester. In addition to this we also support services for patients living in North Wales and the Isle of Man which together form the North West, North Wales and the Isle of Man Congenital Heart Disease Operational Delivery Network (NW CHD Network).

Congenital Heart Disease Operational Delivery Networks (ODNs) operate within an increasingly integrated health and care system. The Network works collaboratively with NHS England Specialised Commissioning, Integrated Care Boards (ICBs), providers, patients and partner organisations to support equitable access to high-quality congenital heart disease services across the North West, North Wales and the Isle of Man.

The Network provides clinical leadership, quality assurance, service improvement, workforce development and collaborative working across organisational boundaries to support delivery of the national Congenital Heart Disease Service Specification and Standards.

In order to offer assurance to both providers and commissioners the four key success factors for ODNs, set out by the Chief Nursing Officer and Chief Medical Officer are utilised to review the Network.

- Improved access to and egress to/from services at the right time
- Improved operating consistency
- Improved outcomes
- Increased productivity

2. Purpose

The purpose of this document is to outline the Operational Plan for the NW CHD Network. It describes how the range of services function and the scope of the services offered. It also aims to clearly define the governance and assurance processes in line with national guidance, the Memorandum of Understanding (MOU) for networks and national CHD service specifications.

3. CHD service model

Congenital Heart Disease Services in the North West, North Wales and the Isle of Man are provided through a network model of care, as outlined in the 2016 NHSE Congenital Heart Disease Standards and Specifications document. The model establishes three tiers of providers of clinical care, working in partnership to ensure high quality and consistent care. The Network 'oversees' delivery of care from antenatal diagnosis through to provision of end-of-life care when required.

The recommended model of care including NHSE Standards

- Level 1 centres: Specialist ACHD or Children's Surgical Centres
- Congenital-Heart-Disease-Standards-Level-1-Specialist-Surgical-Centres-Adult.pdf (england.nhs.uk)
- Congenital-Heart-Disease-Standards-Level-1-Specialist-Childrens-Surgical-Centres-Paediatric.pdf (england.nhs.uk)

- Level 2 centres: Specialist ACHD or Children's Cardiology Centres
- Congenital-Heart-Disease-Standards-Level-2-Specialist-Centres-Adults.pdf (england.nhs.uk)
- Congenital-Heart-Disease-Standards-Level-2-Specialist-Childrens-Cardiology-Centres-Paediatric.pdf (england.nhs.uk)

- Level 3 centres: Local ACHD or Children's Cardiology Centres
- Congenital-Heart-Disease-Standards-Level-3-Local-Centres-Adults.pdf (england.nhs.uk)
- Congenital-Heart-Disease-Standards-Level-3-Local-Childrens-Cardiology-Centres-Paediatric.pdf (england.nhs.uk)

Providers of CHD Care in NW CHD Network

Paediatric CHD Care

- **Level 1 Centre:** Alder Hey Children's NHS Foundation Trust
- **Level 2 Centre:** Manchester University NHS Foundation Trust (Royal Manchester Children's Hospital)
- **Level 3 Centres:** Twenty-four paediatric peripheral cardiology centres (see appendix 1)

Adult Congenital Heart Disease (ACHD) Care

- **Level 1 Centre:** Liverpool Heart and Chest Hospital NHS Foundation Trust
- **Level 2 Centre:** Manchester University NHS Foundation Trust (Manchester Royal Infirmary & Wythenshawe Hospital)
- **Level 3 Centres:** Wrexham Maelor Hospital and Blackpool Victoria Hospital

A full list of all the centres involved in providing care (level 1, 2 and 3) to CHD patients is available on the Network website:
Our Hospitals - Congenital Heart Network

Fetal Cardiology

The Network supports two Fetal Cardiology services at St Mary's Hospital in Manchester and The Liverpool Women's Hospital working closely with their respective Fetal Management Units.

Cardiac Maternity Care

Cardiac maternity care is located at St Mary's Hospital in Manchester and the Liverpool Women's Hospital. They care for a wide variety of women with cardiac problems including patients with ACHD. There is provision of pre-conceptual counselling, intrapartum reviews, MDT discussion and management of complex deliveries.

Transitional Care

The Network has a regional transition pathway that provides care at both Royal Manchester Children's Hospital (MFT) and Alder Hey Children's NHS Foundation Trust, preparing patients and their families to move on to adult care

4. The Network as an ODN

The North-West, North Wales and The Isle of Man Congenital Heart Disease Network was conceived as an operational delivery network (ODN) as set out in "Delivering operational delivery networks – the way forward, 2012".

In line with NHS England guidance, the Network provides a framework through which providers, commissioners, patients and partner organisations work collaboratively to:

- Improve quality and patient outcomes
- Reduce unwarranted variation
- Share learning and best practice
- Support workforce development
- Deliver service improvement
- Provide assurance against national standards and service specifications
- Promote equity of access and reduce health inequalities

The network is funded by regional NHSE specialised commissioning and as such is an independent body with no affiliation to any one provider of clinical care. It is felt that maintaining this independent identity remains an important aspect of the Network.

5. Hosting arrangements

The NW CHD Network is hosted by Alder Hey Children's NHS Foundation Trust. Within the agreed envelope of funds, the role of the NW CHD Network 'host' is to enable, oversee and performance manage the Network. This is achieved by establishing a facilitative, supportive framework to ensure clear lines of responsibility and reporting arrangements to provide assurance.

The host provider has a dual role as host and contributes to the NW CHD Network internal governance processes. The host is not accountable for the compliance of other Network member organisations, accountability for this rests with the NW CHD Network Board and the Assistant Director of Specialised Commissioning in NHS England's North of England Specialised Commissioning Team (North-West Hub).

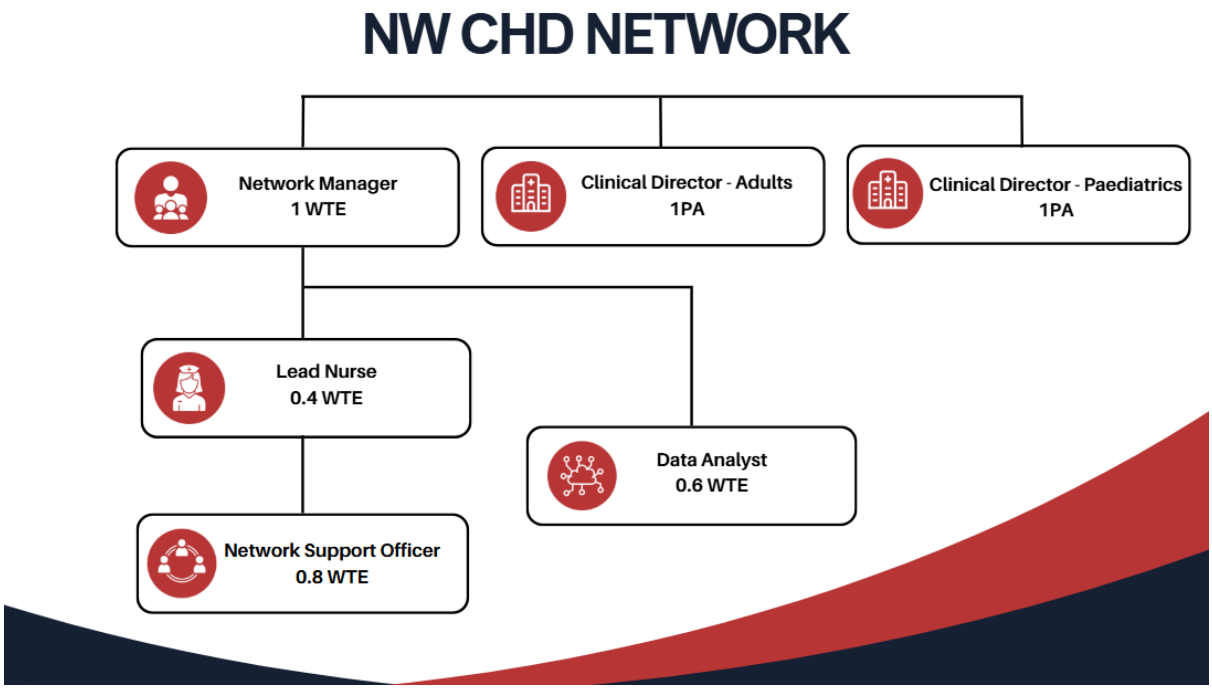
The host provider is also required to document their position as a Network host in their 'statement of purpose' and to make a notification of practice to the CQC register of their position as the host of a Network.

6. Commissioning arrangements

The North West, North Wales and Isle of Man Congenital Heart Disease (CHD) Operational Delivery Network is currently jointly commissioned by NHS England and the North West ICBs. NHS England's North West Specialised Commissioning Team works alongside ICB partners to oversee delivery against agreed objectives and assure network performance. Subject to legislative change, commissioning responsibility is expected to transfer fully to ICBs from April 2027, reflecting the wider delegation of appropriate specialised commissioning functions.

7. Network team

The network team is overseen by the NW CHD Board and is accountable to NHS England Specialised Commissioning. The network team acts as a resource, coordinator, and facilitator for all its stakeholders to achieve a collaborative approach to safe, equitable and effective specialised services. It consists of a small and dedicated workforce which is outlined below.



Network Team Roles & Responsibilities

7.1 Network Manager

The Network Manager provides overall leadership, strategic direction and management for the NW CHD Network. This includes ensuring effective engagement of patients, professionals and constituent organisations in Network activities that support the delivery of national outcome ambitions in line with local needs and resources. The Network Manager strives to ensures that CHD services meet national, local and Trust standards by optimising resources. They ensure continuous progress is made in service improvements, ensuring service users experience the best possible care, and care is delivered in line with commissioning strategies. The Network Manager is required to deliver a whole system work programme for CHD services across the North West of England, North Wales and The Isle of Man working collaboratively with commissioning leads, quality leads, national outcome leads, providers and patients and families.

7.2 Network Clinical Directors

The Clinical Directors (CDs) work as part of a dynamic network support service across the northwest footprint. The CDs will support the strategic and operational development of the Network providing coherent and effective strategies to ensure activities are aligned to and support commissioners in achieving high-quality outcomes for patients including benefits to population health. The CDs will have responsibility for clinical leadership, advice, and engagement.

7.3 Network Lead Nurse

The Network Lead Nurse works in partnership with the Network Manager and Clinical Leads to support the strategic and operational development of the Network. The role provides professional and clinical leadership to support the delivery of safe, effective, equitable and patient-centred congenital heart disease services.

The Lead Nurse plays a key role in identifying, developing and implementing programmes of work that support the delivery of national standards, service specifications and local priorities. They provide expert advice and leadership on nursing, quality improvement, patient safety, clinical governance and workforce development, ensuring that services are responsive to the needs of patients, families, carers and healthcare professionals.

The Lead Nurse is responsible for leading the development, planning, commissioning and delivery of the Network's education and training programme, supporting a competent, capable and sustainable workforce. This includes facilitating high-quality multidisciplinary learning opportunities, promoting the sharing of best practice and lessons learned, and supporting service improvement initiatives across the Network.

The Lead Nurse also promotes and supports research and innovation, working collaboratively with provider organisations, academic partners and clinical teams to increase awareness of research opportunities and encourage participation by patients and healthcare professionals.

The role is responsible for ensuring effective engagement with patients, families, carers professionals and constituent organisations in Network activities, while upholding the values and standards of the nursing profession and contributing to the achievement of national outcome ambitions and local priorities.

7.5 Network Support Officer

The Network Support Officer provides a comprehensive administrative, communications and project support service to the NW CHD Network team. The role is central to the effective functioning of the Network and supports the planning, organisation and coordination of Network activities, meetings, events and programmes of work.

The Network Support Officer is responsible for providing high-quality administrative support to the Network team, including managing meetings, maintaining records, supporting governance processes, coordinating stakeholder communications and assisting

with the delivery of the Network work programme. The post holder may also lead on specific projects or workstreams as required.

In addition, the Network Support Officer plays a key role in promoting the Network, its activities and achievements across the region. This includes supporting the development and dissemination of communications through digital channels, maintaining and updating the Network website, coordinating social media activity and creating content to raise awareness of Network initiatives, events, educational opportunities and patient information resources.

The role supports engagement with patients, families, carers, healthcare professionals and partner organisations by helping to ensure that information is accessible, timely and presented in a clear and engaging way. The Network Support Officer also contributes to the development of digital resources and communication tools that support collaboration, education, patient involvement and service improvement across the Network.

Through these activities, the Network Support Officer helps to strengthen stakeholder engagement, promote the work of the Network and support the delivery of its strategic objectives.

7.7 Data Analyst

The Network Data Analyst leads on the development and provision of a comprehensive information, analytics and business intelligence service to support the work of the NW CHD Network. The role is responsible for the collection, management, analysis, interpretation and presentation of complex clinical, operational and performance data relating to congenital heart disease services across the Network footprint.

The Data Analyst works closely with providers, commissioners and Network stakeholders to develop meaningful data products, reports, dashboards and performance metrics that support quality improvement, service development, assurance and informed decision making. They are responsible for ensuring that data is transformed into actionable intelligence that can be used to monitor outcomes, identify variation, support service improvement and demonstrate compliance with national standards and service specifications.

The role also supports the development and implementation of digital solutions that improve the collection, management and utilisation of information across the Network. This includes supporting the development of network databases, reporting systems, performance dashboards and other digital tools that facilitate collaboration, benchmarking, quality surveillance and strategic planning.

The Data Analyst provides expert advice on CHD data, information management and reporting requirements, acting as the primary point of contact for data-related queries on

behalf of the Network. They work collaboratively with provider organisations and external partners to improve data quality, consistency and accessibility, ensuring information is used effectively to support patient care, service improvement and population health outcomes.

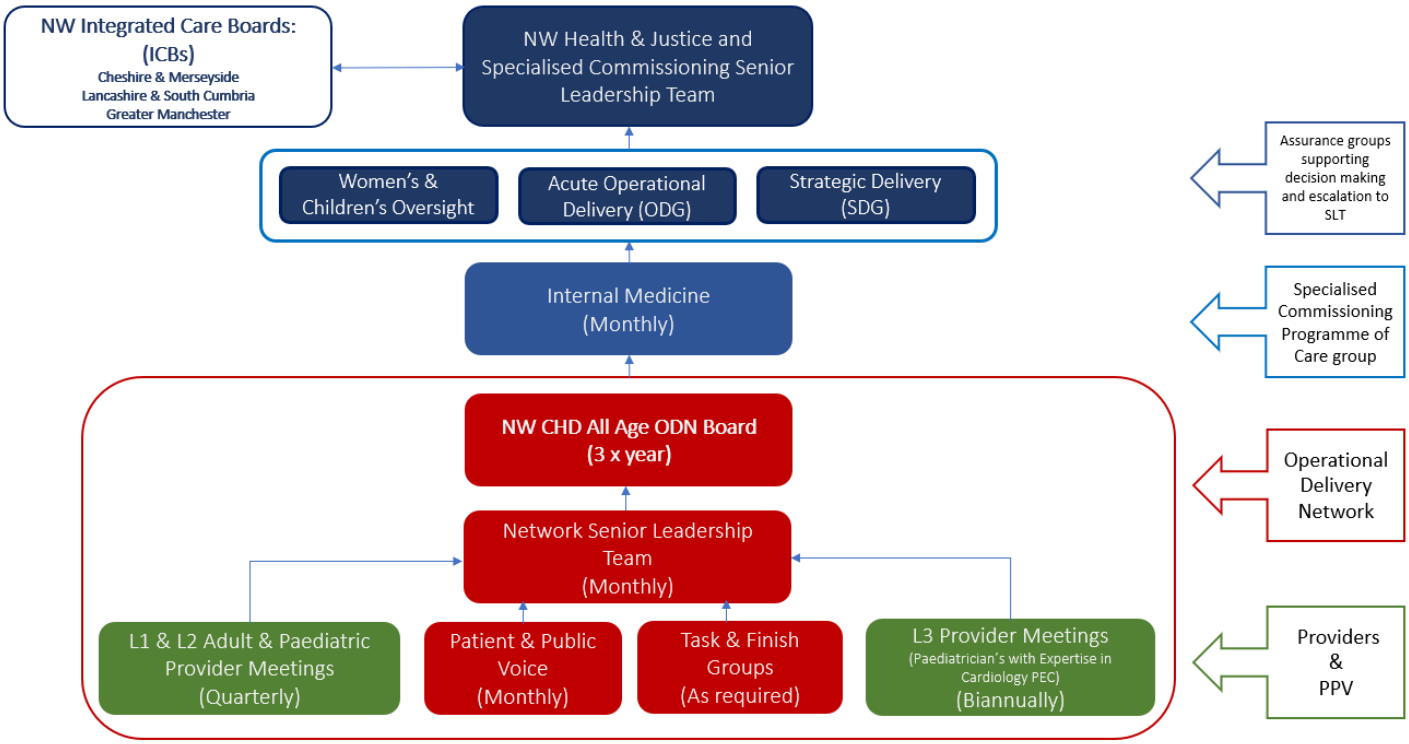
In addition, the Data Analyst contributes to audit, research, evaluation and assurance activities, supporting the Network's commitment to evidence-based practice, innovation and continuous improvement.

8. CHD Network Governance

The Governance Framework is underpinned by an annual work plan which sets out the aims and objectives of the NW CHD Network and enables the Network to monitor progress and implement action plans to address issues as required. This is completed on an annual basis and submitted to the NW CHD Network Board and NHS England Specialised Commissioning for review and approval.

Network Governance Structure

Northwest, North Wales and the Isle of Man Congenital Heart Disease Operational Delivery Network Governance



8.1 Network Board

The primary role of the NW CHD ODN Board is to facilitate, through Network activity, high-quality individualised care for patients requiring CHD services. It will identify and monitor strategic aims, align service development to national and local priorities and ensure identification of future needs to maintain and improve patient access and equity of service delivery to the required standards.

The Board consists of executive representatives able to authorise plans and commit resources on behalf of their organisations. Collectively they provide clear direction and leadership for the NW CHD Network team and functions within the North-West of England, North Wales and The Isle of Man.

NW CHD Network Board members are chosen to represent their particular group of organisations (e.g. provider, commissioner, ODN) on behalf of the patient pathway, to facilitate improved service delivery and outcomes on behalf of service users.

The Chair of the Board is independent of the ODN and of North West CHD providers.

Board meetings are held three times a year.

8.2 Senior Leadership Team (SLT)

The Senior Leadership Team (SLT) provides strategic and operational leadership for the NW CHD Network and is responsible for overseeing the delivery of the Network's objectives, priorities and work programme. The SLT provides direction and oversight to ensure that Network activities support the delivery of safe, effective, equitable and sustainable congenital heart disease services across the North West, North Wales and the Isle of Man.

The SLT is responsible for developing and monitoring the Network's strategic priorities, ensuring alignment with national standards, service specifications, commissioning requirements and local health system priorities. The group provides oversight of quality, patient safety, workforce development, education, digital transformation, service improvement, research, patient and public involvement, financial management and risk management activities undertaken on behalf of the Network.

The SLT supports the identification of emerging risks, opportunities and future service requirements, ensuring that appropriate assurance, governance and escalation processes are in place. The group monitors progress against the Network work programme and provides assurance to the Network Board regarding delivery, performance and outcomes.

The NW CHD Network SLT comprises the Network Clinical Directors, Network Manager and Network Lead Nurse. The group is supported by representatives from the host organisation and other members as required. The Network Manager chairs the group and meetings are held monthly.

8.3 Risk

The Network supports the timely identification, review and escalation of clinical quality, patient safety, workforce and service delivery concerns that may impact congenital heart disease services across the Network footprint.

Concerns may be identified through provider organisations, commissioners, incident reporting processes, complaints, mortality reviews, self-assessment processes, peer review activity, Network governance forums, patient and public feedback, service reviews or routine performance monitoring.

Provider organisations are responsible for the identification, management and mitigation of risks within their own services and organisations. The Network is not responsible for provider risks but works collaboratively with providers, Integrated Care Boards and NHS England Specialised Commissioning to support the identification of potential mitigations, facilitate system-wide collaboration and promote the sharing of learning and best practice where appropriate.

Where concerns potentially impact multiple organisations, affect delivery of services across the Network footprint, or require regional or national intervention, the Network may coordinate discussions, provide oversight of agreed actions, and escalate concerns through the appropriate governance and assurance processes in accordance with the Network's Risk Escalation and Assurance Procedure.

The Network maintains its own risk tracker for risks associated with Network-led functions, programmes, projects and activities. Responsibility for the management and mitigation of these risks sits with the Network, with oversight provided through the Network's governance arrangements. In addition, Network risks are recorded on InPhase to provide transparency and ensure that Alder Hey Children's NHS Foundation Trust, as host organisation, has appropriate visibility of Network risks. Risks scoring 12 or above are reviewed through the Bring Me The Future (BMTF) System Risk meeting, providing an additional level of oversight and an established mechanism for escalation where required.

The Network Board maintains oversight of significant Network risks and receives assurance regarding the management of risks escalated through Network governance processes, whilst recognising that accountability for provider-specific risks remains with the relevant provider organisation.

8.4 Clinical Governance

The NW CHD Network Clinical Governance meeting is held every 6 months and provides a forum for centres to discuss incidents regardless of level of harm if there is a potential for lessons to be learnt to prevent harm and mortalities where a diagnosis of congenital heart disease has been the cause of death. It is an opportunity to share best practice and lessons learnt and to agree any changes in pathways as a result.

These requirements do not replace an individual provider's responsibility to report and act upon incidents and mortality reviews within their own institution. The reporting to the Network should be seen as additional to and not instead of local reporting and actions.

8.5 Patient and Public Voice group (PPV)

The Patient and Public Voice (PPV) Group plays a vital role in ensuring that the experiences, views and priorities of patients, families and carers are embedded throughout the work of the NW CHD Network. The group acts as a key partner in shaping the strategic direction of the Network and supports the development, delivery and evaluation of services across the North West, North Wales and the Isle of Man.

The PPV Group provides insight and challenge to help ensure that services are designed around the needs of patients and families. Members contribute to service improvement initiatives, policy and pathway development, quality improvement programmes, educational resources, communication materials and Network governance activities. The group also supports the identification of priorities for future work and helps ensure that patient experience is considered alongside clinical and operational outcomes. The Lead Nurse engages with the PPV group to provide a patient story which opens the Board meeting. This ensures the Board hear directly from patients and their families, and this sets the tone for the meeting.

Drawing on a diverse range of lived experiences, the PPV Group helps the Network engage effectively with its communities, improve the accessibility of information and promote equitable involvement in service development. The group works collaboratively with healthcare professionals, commissioners and Network leaders to identify opportunities to improve care, challenge areas of concern and celebrate examples of good practice.

In addition, PPV members act as advocates for patient and family involvement across the Network, supporting engagement events, awareness campaigns, educational activities, recruitment processes and relevant task and finish groups. Through these activities, the PPV Group helps to ensure that the voice of patients and families remains central to decision making and continuous improvement across the Network.

8.6 Document Management

The Network has a dedicated procedure for the writing and development of Network documents. This is to ensure that all material produced is up to date, evidence based and relevant. As part of this process the NW CHD Network has two Ratification Groups. One for paediatric documents and one for ACHD documents.
The ratification group members represent the MDT across the Network footprint and provide strategic oversight with responsibility for promoting appropriate, safe, rational and effective clinical and non-clinical policies to be used across the Network. They are accountable to the NW CHD Network Board. There is an expectation that recommendations made by the Ratification Groups will be implemented.

The Network has a robust system of monitoring documents in circulation to ensure that they are reviewed and kept up to date on a regular basis.

9. Outcomes & Reporting

The Network reports regularly on data, and provides updates on progress through the following means:

- Monthly regional & national data submissions to commissioners
- Annual report to regional commissioners
- Annual report
- Annual newsletter

The wider network of providers performance will be monitored through a combination of:

- Clinical outcomes
- Service performance indicators
- Workforce metrics
- Patient and family experience
- National standards compliance
- Programme delivery measures
- Quality and safety indicators

The reports and dashboards are a means of monitoring activity and clinical outcomes throughout the year, with measures being aligned to national standards where appropriate.

10. Engagement

10.1 Provider Engagement

The NW CHD Network operates in accordance with the principles set out within the NHS England Operational Delivery Network Memorandum of Understanding and works collaboratively with providers, commissioners, patients and partner organisations across the Network footprint. The Network facilitates engagement across all levels of congenital heart disease services, supporting collaboration, shared learning and service improvement across organisational boundaries.

The Network maintains strong relationships with providers across Levels 1, 2 and 3 services, ensuring that clinical, operational and strategic perspectives inform the development of Network priorities and programmes of work. This includes supporting regular forums, task and finish groups, educational events, governance meetings and quality improvement initiatives that bring together multidisciplinary professionals from across the region.

The NW CHD Network works closely with the Paediatricians with Expertise in Cardiology (PECSIG), ACHD clinicians, specialist nurses, allied health professionals and other clinical and non-clinical stakeholders to promote the sharing of best

practice, lessons learned, innovation and service developments. Through these collaborative arrangements, the Network supports the delivery of equitable, high-quality care and facilitates coordinated approaches to addressing regional and national priorities.

10.2 Patient, Family and Public Engagement

The NW CHD Network is committed to ensuring that patients, families and carers are actively involved in shaping the planning, delivery and evaluation of congenital heart disease services. Patient and public involvement is embedded throughout the work of the Network and is recognised as an essential component of quality improvement, service development and decision making.

The Network provides ongoing support to the Patient and Public Voice (PPV) Group, including recruitment, training, communication, administration and facilitation of meetings and events. PPV members contribute to Network governance structures, service improvement initiatives, policy and pathway development, patient information resources, patient stories, education programmes and project work. The Chair of the PPV Group is a member of the CHD Network Board and provides regular patient and family perspectives to support decision making.

The Network also supports a Learning Disability Forum, which provides a dedicated opportunity for patients with additional needs, their families and carers to contribute to service development and identify opportunities to improve accessibility and patient experience. The Network will continue to develop opportunities for meaningful engagement that ensure a wide range of patient and family voices are represented across its activities.

10.3 Equality, Diversity and Inclusion

The NW CHD Network is committed to promoting equality, diversity and inclusion in all aspects of its work. The Network recognises that people may experience different health outcomes and barriers to accessing care and is committed to working with patients, families, providers and partners to reduce health inequalities and promote equitable access to services.

The Network seeks to ensure that its governance structures, engagement activities, communications, events and programmes of work are inclusive, accessible and representative of the diverse populations it serves. Consideration of equality, diversity and inclusion will be embedded throughout service improvement initiatives, patient and public involvement activities, workforce development and policy development.

The Network will actively seek feedback from underrepresented groups and work collaboratively with patients, families, community organisations and healthcare providers to identify and address inequalities in access, experience and outcomes. Through this approach, the Network aims to ensure that all patients and families have equitable opportunities to influence the development of congenital heart disease services and benefit from high-quality care.

11. CHD peripheral clinics – Level 3 (see Appendix 1)

Paediatric peripheral clinics are provided throughout the region by Level 1 and 2 Paediatric Cardiology Consultants. Usually, these clinics are undertaken in conjunction with a local Paediatrician with Expertise in Cardiology (PEC).

ACHD clinics are supported throughout the region by the Level 1 ACHD Consultant Cardiology Team based at Liverpool Heart and Chest Hospital. Support is also offered locally by cardiologists with a special interest in ACHD. Clinics are supported by the ACHD Specialist Nurses from Liverpool Heart and Chest Hospital and Manchester Royal Infirmary with Wrexham Maelor providing their own ACHD Specialist Nurse.

12. Network work programme

The work programme sets out the Network's aims and objectives as agreed with regional specialised commissioners and local ICBs. The work programme includes:

Data, Database, Dashboards & KPI's
Clinical Pathways, Policies & Protocols
Training & Education
Clinical Governance & Risk Management
Communication & Engagement
Finance
Research
Service Improvement
Digital Transformation and Information Management
Equity, Diversity and Inclusion

13. Network Core Documents

The Network maintains a suite of governance, assurance and operational documents that support the delivery of its objectives and ensure compliance with national standards and local requirements.

Core Network documents include:

Document	***Frequency***
Operational policy	Reviewed every 3 years
Annual report	Produced annually
Work programme	Produced annually
Risk tracker	Ongoing review
Network Strategies, Plans and Procedures	In line with individual review dates
Clinical Guidelines, Pathways and Standards	In line with individual review dates

14. Network policies, procedures and guidance documents

The network has developed, approved, and adopted a number of policies, protocols, pathways and guidance documents. These are produced by individual members, or through collaboration of small groups of experts (often for use within their own Trusts) and following ratification by the Network, are adopted regionally. The Network has responsibility for keeping version control and monitoring when documents require further reviews and updates.

The Network expects individual hospitals to ratify 'adopted network documentation' in line with their own hospital required processes. There is an expectation for Network members to engage with the development, review and improvement of these documents to ensure that all patients in the network catchment area receive standardised, equitable care/treatment.

15. Audit

All level one, two and three cardiology units within the catchment area have a commitment to audit with respect to the following national standard:
"Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually."
The Network has and will continue to collate regional audit programmes when shared as well as undertake regional audits/self-assessments to improve quality.

16. Training & Development

The Network delivers a varied education programme which includes several training opportunities delivered either remotely or face to face. These range from Network study days, bespoke training for individual specialities e.g. psychology or sonographers and link nurses, right through to helping to design and deliver a bespoke ACHD masters module delivered in collaboration with Liverpool John Moore's University.

More specifically the Network has developed a competency-based training programme for the role of the paediatric and ACHD nurse with a special interest in CHD. This includes providing a regular forum for networking and support and includes all the regional CHD specialist nurses who provide individual mentorship to nurses wanting to expand this role.

The Network has a designated Education Task and Finish Group that meets as required to collaborate on and agree on educational priorities for the whole MDT and region. This is chaired by the Lead Nurse.

The Network collaborates nationally with other Networks to provide specialist educational events. In addition, the Network has driven the development of eLfH CHD Modules that are available on HEE portal and are accessible to all health care and social care professionals in England. These modules provide basic information for the non-specialist.

The NW CHD Lead Nurse will continually work with the Network team and CHD service providers to identify, plan, facilitate and deliver multidisciplinary CHD education and training that, amongst other things; is responsive to changes in clinical practice, shares learning from clinical governance and supports quality improvement.

17. Communication & Engagement

The Network recognises that effective communication and engagement are essential to the delivery of safe, high-quality, patient-centred care. The Network is committed to promoting open, transparent and inclusive communication with patients, families, carers, healthcare professionals, partner organisations, commissioners and other stakeholders across the region.

The Network supports engagement through a range of mechanisms including governance meetings, clinical and professional forums, educational events, conferences, patient and family/carer events, newsletters, digital communications and targeted stakeholder engagement activities. These channels facilitate collaboration, the sharing of best practice, dissemination of learning and support the development of consistent approaches to care across the Network. The Network also supports the NWACH Facebook Support Group, a closed and private online community for adults with congenital heart disease across the North West, North Wales and the Isle of Man. The group is owned and governed by the Network and moderated by ACHD Nurse Specialists from Liverpool Heart and Chest

Hospital and Manchester Royal Infirmary, alongside the Network Lead Nurse. It provides a safe and supportive environment for peer support, information sharing and patient engagement, operating in accordance with Network standards and governance arrangements.

The Network website serves as the primary source of information for patients, families, carers and healthcare professionals, providing access to information about services, pathways, policies, educational resources, events and Network activities. Digital communication channels and social media platforms are utilised, where appropriate, to promote key messages, raise awareness of congenital heart disease, share opportunities for engagement and celebrate achievements across the Network.

Communication and engagement activities are developed in partnership with patients, families, carers, healthcare professionals and stakeholders to ensure that information is accessible, relevant and responsive to the needs of the diverse populations served by the Network. Through this approach, the Network aims to strengthen relationships, promote collaboration and support continuous improvement in congenital heart disease services.

18. National networking engagement

The North-West, North Wales and the Isle of Man Congenital Heart Disease Network participates in the national CHD Network meetings, highlighting concerns and sharing solutions with colleagues to improve services across all regions.

19. Affiliated academic institutes & research

The NW CHD Network recognises the importance of research, innovation and evidence-based practice in improving outcomes for patients with congenital heart disease. The Network works collaboratively with provider organisations, higher education institutions, academic partners and research networks to promote research activity and support the translation of evidence into clinical practice.

The Network supports the dissemination of research findings, encourages participation in regional and national research initiatives and seeks opportunities to facilitate collaboration between clinical, academic and patient communities. Research and innovation activities are aligned, where possible, to Network priorities and national congenital heart disease objectives.

The Network promotes awareness of research opportunities amongst patients, families and healthcare professionals and supports the sharing of emerging evidence, best practice and service innovations across the region. Research, audit and quality improvement activity are routinely incorporated into Network educational events and work programmes to support continuous improvement in patient care.

20. Providers of specialised pulmonary hypertension care

Paediatrics

The service for Pulmonary Hypertension (PH) in children provides care for children with all forms of pulmonary hypertension, excluding PPHN presenting within the neonatal period.

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) is the only UK centre funded to design treatment plans and to authorise the prescription of the specialised medication.

Paediatric patients diagnosed with significant pulmonary hypertension, may either be assessed directly at GOSH, or maybe reviewed in specialised PH outreach clinics staffed by GOSH clinician and a local Paediatric Cardiologist (in the North-West, such a clinic is undertaken at Royal Manchester Children's Hospital).

ACHD

Specialised services for patients with PH related to ACHD are held at the Level 2 Centre at Manchester Royal Infirmary (Manchester University NHS Foundation Trust).

This is separately commissioned as a shared care Level 2 Service with the Level 1 Centre for PH being based at Sheffield Pulmonary Vascular Disease Unit (Royal Hallamshire Hospital).

This clinic has two dedicated ACHD Consultants who specialise in the monitoring and treatment of PH in ACHD, and the clinic is supported by a Consultant in PH from Sheffield.

This service initiates and titrates specialist oral treatments for PAH. It is responsible for inputting data into the national PH Database. It does not provide support for patients requiring escalation of therapy to nebulised, subcutaneous or intravenous routes.

The service is also supported by the ACHD Nurse Specialist Team at Manchester Royal Infirmary.

Appendix 1. Providers of CHD Care

Paediatric

Level 1: Specialist Children's Surgical Centre

- Alder Hey Children's NHS Foundation Trust

Level 2: Specialist Children's Cardiology Centre

- Manchester University NHS Foundation Trust (Royal Manchester Children's Hospital)

Level 3: Local Children's Cardiology Centre's

Greater Manchester

- Royal Albert Edward Infirmary (Wigan Infirmary) Wrightington, Wigan & Leigh Hospitals
- Stepping Hill Hospital (Stockport NHS Foundation Trust)
- Royal Bolton Hospital (Bolton NHS Foundation Trust)
- The Royal Oldham Hospital (Pennine Acute Hospitals NHS Trust)
- North Manchester General Hospital (Manchester University NHS Foundation Trust)
- Wythenshawe Hospital (Manchester University NHS Foundation Trust)

Lancashire & South Cumbria

- Royal Preston Hospital (Lancashire teaching Hospitals NHS Foundation trust)
- Royal Lancaster Infirmary (University Hospitals of Morecambe Bay)
- Burnley General Teaching Hospital (East Lancashire Hospitals NHS Trust)
- Blackpool Victoria Hospital (Blackpool Teaching Hospital NHS Foundation Trust)
- Furness General Hospital (University Hospitals of Morecambe Bay FT)
- Ormskirk District General Hospital (Mersey and West Lancashire Teaching Hospitals NHS Trust)
- Royal Blackburn Teaching Hospital (East Lancashire Hospitals NHS Trust)

Cheshire & Merseyside

- Whiston Hospital (St Helens and Knowsley teaching Hospitals NHS Trust)
- Warrington Hospital (Warrington & Halton Hospitals NHS Foundation Trust)
- Leighton Hospital (Mid Cheshire Hospitals NHS Foundation Trust)
- Countess of Chester Hospital NHS Foundation Trust
- Arrowe Park (Wirral University Teaching Hospital NHS Foundation Trust)
- Macclesfield District General Hospital (East Cheshire NHS Trust)

North Wales

- Wrexham Maelor Hospital (Betsi Cadwaladr University Health Board)
- Glan Clwyd Hospital (Betsi Cadwaladr University Health Board)
- Bangor Ysbyty Gwynedd Hospital (Betsi Cadwaladr University Health Board)
- Aberystwyth / Bronglais General Hospital (Hywel Dda University Health Board)



The Isle of Man

- Nobles Hospital

Adult

Level 1: Specialist ACHD Surgical Centre

- Liverpool Heart and Chest Hospital NHS Foundation Trust

Level 2: Specialist ACHD Cardiology Centre's

- Manchester University NHS Foundation Trust (Manchester Royal Infirmary and Wythenshawe Hospital)

Level 3: Local ACHD Cardiology Centre's

- Wrexham Maelor Hospital (Betsi Cadwaladr University Health Board)
- Blackpool Victoria Hospital (Blackpool Teaching Hospital NHS Foundation Trust)

Fetal

The following hospitals provide care for women until the birth of their child. The hospital the woman delivers in maybe one of these units or a local hospital to the women. If the baby requires immediate operative or interventional care post-delivery delivery should be booked for the Liverpool Women's Hospital.

- Liverpool Women's NHS Foundation Trust (LWH)
- Manchester University NHS Foundation Trust (St Marys Hospital)



- **Level 1: Specialist ACHD or Children's Surgical Centre's**
- **Level 2: Specialist ACHD or Children's Cardiology Centre's**
- **Level 3: Local ACHD or Children's Cardiology Centre**