



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

Annual Report 2020



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Foreword

We are delighted to report on the Network progress and achievements in 2020/21.

It is my privilege to be the Chairman of the newly established North West, North Wales and Isle of Man Congenital Heart Disease Network. The Network is made up of twenty-nine hospitals capable of caring for Paediatric Cardiology patients, whilst Adult Congenital services are centred around eight hospital sites. The Board is made up of doctors, nurses, managers, and experienced patient representatives. The first meeting of the newly formed Operational Delivery Network Board took place on the 13th January 2020. Our vision is to provide the best possible care and service to our 'all age' CHD population and to maintain and strengthen relationships with all our Network partners. The Board will strive to support providers of care in the whole region this Network serves and ensure equality of care throughout. I am fortunate to have a highly dedicated and specialised team on the Board. We are acutely aware of the numerous challenges facing us during this pandemic and we are determined to face these challenges head-on and deal with them effectively, efficiently, competently, and to the best of our ability. There are on-going priorities for this year including development of a Network database, gap analysis against standards, development of a link nurse role, PPV development and considering ways to ensure people with learning disabilities have a voice and are able to contribute. Along with clinical effectiveness and reviewing of Network incidents and mortalities to ensure shared learning takes place, establish pathways to support the patient journey, audits and improved patient information. We will do our very best to fulfil our vision of providing patients the highest quality of care.

Dr Nayyar Naqvi OBE
MBBS FRCP FRCPE FESC FACC FACP
Chairman NW CHD Network Board



Network Year Review

2020 has been a busy and productive year for the network. Despite the challenges created by the COVID 19 pandemic, we have managed to expand our core team with Dr Nayyar Naqvi OBE joining us as Chair of the Network Board and in addition we have recruited a new Network Administrator, a Lead Nurse, a Data Manager and Project Managers. Following a request for expressions of interest from members to represent their service/local provider on the network board, we fully recruited to all vacancies. I feel the Board is now fully representative of all regional providers of paediatric cardiology/Adult Congenital Heart Disease (ACHD) services and also encompasses good representation of patients and their families. We are fortunate to have a very active PPV (patient and public voice) group who come with a broad wealth of experience and are keen to assist in taking the network forward.

The ACHD service has continued to re-establish itself, providing a complete regional service, with most patients now receiving their care close to home. Maternity services for mothers with Congenital Heart Disease has continued to be provided across the region on a 24/7 basis despite Covid. Supported by local NHS Commissioners and with a renewed co-operation between the main providers of paediatric cardiology in the two main urban developments of Manchester and Liverpool, the network has assisted in facilitating discussions around a proposed regional 'single service' for paediatric cardiology, a move that would help with recruitment and retention of staff, provide better rationalisation of resources and ultimately improve patient care and experience.

Coronavirus has created unique problems regarding the provision of care, with at the peak of the pandemic, adult patients being cared for on the two main regional Paediatric Hospital ICUs!! Inevitably a lot of work will be required to 'catch up' with outpatient reviews etc. and the network has worked closely with providers throughout the region to monitor and triage care on a monthly basis. I'm pleased to report emergency and urgent work has continued throughout the year without any delays.

I feel optimistic that the network will continue to move forward and over the next decade, taking a leading role in maintaining standards and over-seeing the delivery of both paediatric cardiology and ACHD care throughout the region, whether this is in a hospital setting or the wider community.

Dr Gordon Gladman
Lead Clinician/Network Director



Network Team

The Network is pleased to report that despite the unprecedented challenges during the ongoing COVID 19 pandemic and managing competing national, regional, and local priorities, that business continuity and development of the Network has been maintained and we were able to meet our work plan priorities continuing into 2021. All providers of CHD services within our Network have engaged with the network and we continue to have wide representation at our board meetings and educational events.

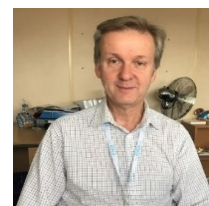
We would like to express our thanks to members for their contributions to the ongoing network development and work programme during 2020 with particular thanks to all those who have contributed to the work of clinical pathway development, task & finish groups, and workstreams.



Meet Our Team



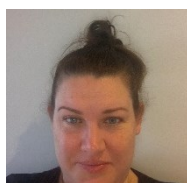
Chair Network Board
Dr Nayyar Naqvi OBE



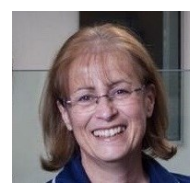
Network Clinical Director
Dr Gordon Gladman
Consultant Paediatric Cardiologist



Network Manager
(Job Share 0.4)
Denise Szpunar (retired
from post, Spring 2021)



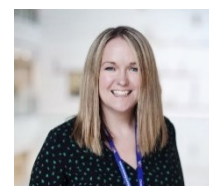
Network Manager
(Job Share 0.6)
Helen Sanderson



Lead Nurse (1wte)
Linda Griffiths



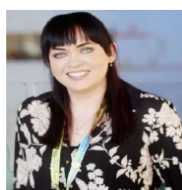
ACHD Clinical Lead (Board Member)
Dr Damien Cullington
Consultant Adult Cardiologist



Paediatric Cardiology Lead (Board Member)
Dr Caroline B Jones
Consultant Paediatric Cardiologist



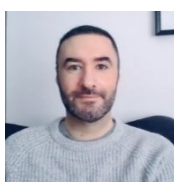
Network Support Officer (0.6)
Jill Moran



Data Manager (0.4)
Jemma Blake



Primary Care CHD
Project Lead (0.2)
Sarah Ellison



Project Manager (1wte)
Kenny Ward

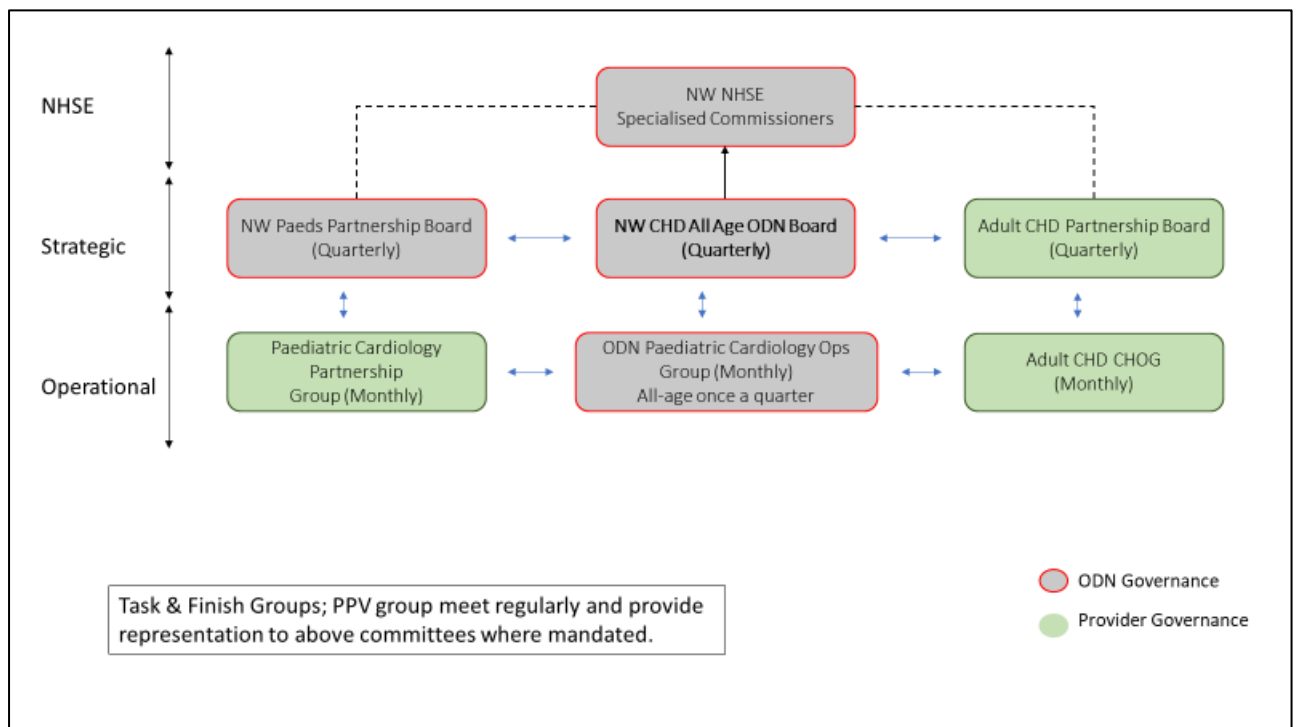


About the Network

The Network is an ‘all age’ network encompassing every aspect of congenital heart disease from antenatal care through to supporting adult patients born with congenital heart disease. We work collaboratively with our partner organisations (including patient groups) to facilitate shared learning and support the implementation of best practice for our patients and their families. The network oversees workforce and service development.

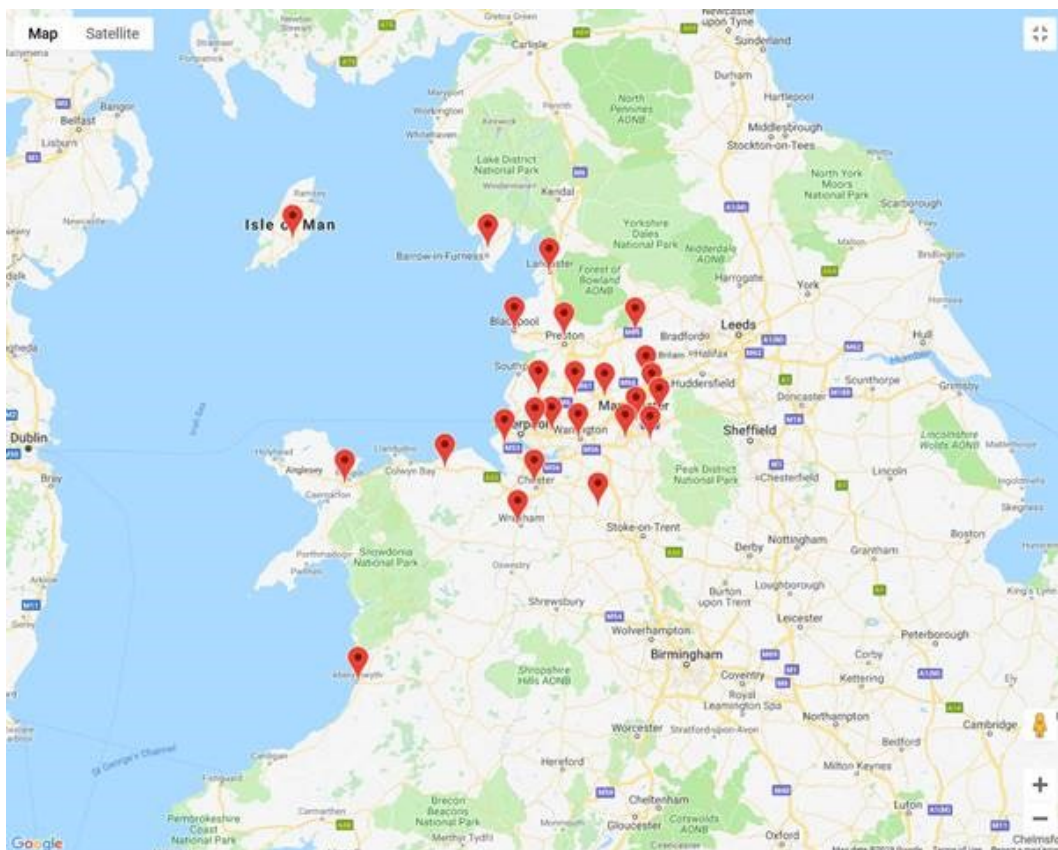
Governance

The North West, North Wales & Isle of Man Congenital Heart Disease Operational Delivery Network is commissioned by NHS Specialised Commissioning and is hosted by Alder Hey Children’s NHS Foundation Trust. The day-to-day business of the network is directed by the senior management team and is agreed with commissioners and the network board that convenes four times a year. The network board is responsible for the activities of the network including agreeing and overseeing the work programme each year. Working relationships between commissioners, operational and strategic groups can be summarised as follows:



Network Footprint

The map below demonstrates the geographical area covered by the Network.



- The network covers a population of approximately **8** million people.
- The North West has high concentrations of deprivation. **19.6%** of neighborhoods in the region are in the top **10%** most deprived in England.
- Clinical services are centred around 29 hospitals capable of providing care for paediatric patients with Congenital Heart Disease, whilst 8 hospitals within the region are involved in the provision of ACHD care.
- Antenatal care for pregnant mothers with cardiac disease (congenital and acquired) is centred around St Mary's hospital Manchester (the designated NHSE Level 2 provider) supported by Liverpool Women's Hospital. Fetal cardiology services are provided on both sites.



Our Vision

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.

The 'all age' CHD Operational Delivery Network will:

- Deliver excellent care and treatment for patients with congenital heart disease, along the whole patient pathway, improving outcomes, quality of care and patient and family experience.
- Deliver the key National aims of an all-age CHD Network
- Deliver excellent care and treatment for patients with congenital heart disease, along the whole patient pathway, improving outcomes, quality of care and patient and family experience.
- Support the delivery of Level 1 Adult Congenital Heart Disease (ACHD) services across the Network.
- Implement patient tracking / database systems which enable the North West CHD services to better manage patient care needs.
- Ensure that nationally set specifications and standards of service are consistently met across the network.
- Develop and ensure the operation of common referral, care and transfer pathways and other policies, protocols, and procedures across the network.
- Ensure that as much care and treatment is provided as close as possible to home and that the patient and their family travel only when essential, while ensuring timely access for interventional procedures (surgery, catheter) and the best possible outcomes for the patients.
- Ensure that there is an integrated, coordinated, multidisciplinary approach to the care of patients with congenital heart disease.
- Ensure the safe and effective transition of young people from paediatrics to adult services.
- Identify the ongoing needs of level 3 services (paediatric and adult congenital) and to support their operation and development.
- Establish and maintain systems for the collection, analysis and reporting of data on outcomes, quality of care and patient and family experience.
- Undertake audit, and other service improvement activities including reflecting on and responding to suboptimal outcomes, care and patient experience.



- Ensure efficient and appropriate flow of patients along the pathway, managing system capacity and improving system resilience.
- Support effective workforce planning across the network, including training and the professional development of all clinical staff involved in the care of patients with congenital heart disease.
- Undertake audit, and other service improvement activities including reflecting on and responding to suboptimal outcomes, care and patient experience;



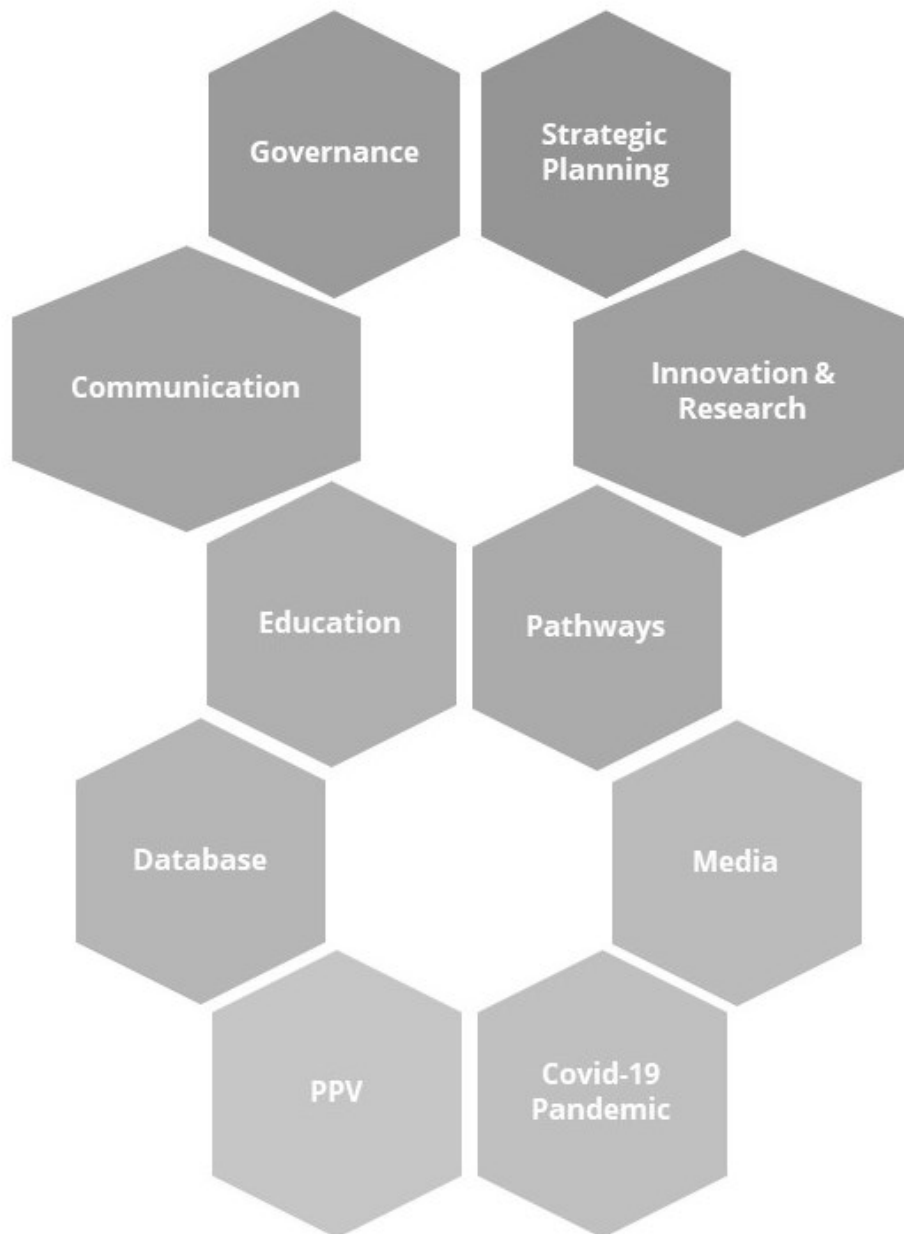
Aims

- To provide a high quality, fit for purpose capable network, demonstrating value & providing strategic direction.
- To provide seamless care across the region, ensuring equity of access and egress 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 services standards are being met across the network, ensuring quality & safety.
- 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.
- Network to respond to unusual and unexpected events in a professional and logical manner to ensure the safety of patients and professionals.



Report on the Year

The work programme comprised of the following projects:



Governance

We continue to strengthen and integrate our network governance arrangements which include:

- Regular reporting to National and Regional NHS England commissioners
- Network Board Meetings
- Senior Manager Team meetings
- Financial management
- Project development and implementation
- Information
- Clinical Effectiveness
- Clinical Governance
- Quality

Workplan

Progress against workplan include:

Risk

- Risk register finalised and operational
- Risk Procedure- operational
- Refined document control and tracking procedure operational

Clinical Effectiveness

- Appointed project manager (commencing 2021)
- Recruited Network Governance leads (shared post Adult Congenital & Paediatric Cardiology commencing 2021)
- Incident and mortality data reporting processes and shared learning approaches in development-2020/2021



Website

Website Development continues and work in progress this year includes:

- Development of a new site map
- Access to Network Documents
- Information for parents/families if your unborn baby is found to have a heart problem
- Clinical Guidelines and forms made available
- Patient information leaflets
- Up dated contact page

Education/Research/Innovation

- Free study days continue to be provided and offer an excellent opportunity to share good practice and innovation, disseminate knowledge and continue to assist the network moving forwards
- Multi-disciplinary Team (MDT) meetings are held regularly to review patient cases and plan treatment in addition Quality Assurance and Quality Improvement (QAQI) meetings are held to review congenital cardiac quality indicators, service efficiency, incidents, difficult cases, audit and research. Telemedicine technology for MDT and QAQI meetings allows all Network members to engage and take part in paediatric/ACHD/obstetrics MDTs and QAQI meetings where there is an opportunity for wider discussion and comprehensive learning and quality improvement
- The network continues to work closely with Liverpool John Moore's University and helps to deliver the Adult Congenital Heart Disease Master's Programme with delegates attending from across the UK
- The Network has led a UK wide survey into the education needs of nursing staff relating to CHD and is working with LJMU to analyse the results, which should be available later this year
- The network commissioned a project to identify 'lost to follow up' patients in primary care settings who may require additional support and to prioritise health care provision and ensure appropriate utilisation of specialist services. The development of a primary care risk register, coding development and educational opportunities for primary care colleagues have been developed. Additionally, a doctoral research project will commence during 2021 to further explore the role of primary care and CHD patients



Database

A network task & finish group was implemented to support the Network wide data-base requirements as per National Congenital Heart Disease standards. The network task & finish group commissioned a data-base champion (six-week project) to audit and compile an options appraisal (completed). Data manager to lead a further scoping and website development (eighteen months contract recruited during the latter end of 2020).

Audits undertaken by the Network include:

National CHD Standards

We are required to re-audit all Level 1, Level 2 and Level 3 CHD service providers against the National Standards. The development of an online dashboard is in early development to support a more streamlined and more manageable approach for service providers to self-assess their performance against the standards, - pilot phase commencing 2021.

Patient Public Voice

We are delighted to report that we have an active Patient and Public Voice group (chaired by Janet Rathburn) that is fully representative of the 'all age' network. The group is represented on the network board and allied committees, with members of the group actively involved in task & finish groups, data base development, communication audit. The contribution of patient representatives in keeping the network updated on patient issues, developing and reviewing patient information, developing patient information leaflets and ensuring that patients can make the most of their clinic appointments has been invaluable. The PPV group has supported patient events delivered during the pandemic using Facebook-live and Zoom. The PPV Group meets regularly, meetings are jointly facilitated by Linda Griffiths (Lead Nurse for the Network) and Dr Emma Twigg (Consultant Clinical Psychologist).



The PPV Group remains actively involved in reviewing outcomes for both ACHD & paediatric cardiology patients, being in the unique position of being able to highlight areas of concern noted by the members they represent. In the past year, they have highlighted deficiencies and inequality surrounding the availability of paediatric cardiology outpatient appointments within the region (presently identified as one of the leading areas of concern within the network) and supported their ACHD members as the newly re-configured service has 'bedded in'.

Communication

A communication audit supported by the network PPV group has been conducted for Level 1 Paediatric cardiology services, focus groups have been held in late 2020 and transcripts prepared. A draft questionnaire has been developed based on the focus group response. The agreed questionnaire to be developed into an online tool and all level 1 patients will be invited to participate in 2021.

Development of Clinical Pathways and Guidelines in 2020

- Kawasaki Disease Guidelines.
- Acute Neonatal Cardiac Pathway.
- PDA Referral Guidelines.
- Clinical Urgency Update Form



Covid-19 Pandemic – Network Response

The Network engaged fully on a weekly basis with National NHS England and CHD Networks for national up-dates and to provide assurance of access to clinical services and staff ensuring continuity of patient care. Provided dashboards for both Paediatric and Adult clinical services and plans for restitution of services between national lock downs.

Engaged with Northern CHD Networks planning for shared services and human resources if required to ensure continuity of services for patients.

The Network recognises the continual hard work and dedication of all staff in providing high quality CHD care during the global pandemic. We have continued to provide high quality consistent information in-line with national guidance throughout. This has been available online via the Network website alongside the delivery of patient focussed webinars and Facebook Live events to keep patients and families updated. We would like to take the opportunity to thank all of our patients and their families and carers for their ongoing support and patience during these very challenging times.

Facilitated regular meetings with Paediatricians with a special interest in Cardiology from District General Hospitals (level 3) and the specialist paediatric Level 1 & Level 2 centres (Alder Hey Children’s Hospital and Royal Manchester Children’s Hospital)

Facilitated meetings with Paediatric Cardiology Level 1 centre and Level 2 centre for assurance that shared staff resources were available, and patients’ needs managed.

Engaged with Adult Level 1 (LHCH) and MFT ensuring that adequate staffing availability and patient needs appropriately managed.



Networks

We continue to engage and work with other CHD Networks across the UK including other CHD networks, to share education opportunities, on-going challenges, review updates and learn from one another. The Network is hosting a national CHD network event in early 2021.

Conclusion

As a newly formed Operational Delivery Network and despite the COVID 19 pandemic the Network has continued to grow, develop and work towards the delivery of its aims and objectives. We have increased the network team considerably and welcome all our new staff to the team.

The Network work plan for 2021-22 has been agreed by commissioners and the Network Board and we look forward to a successful second year as CHD Operational Delivery Network.



Contact Us

Email: NorthwestCHDNetwork@alderhey.nhs.uk

Website: www.northwestchdnetwork.nhs.uk

Twitter: @NwchdN



Appendices

Appendix 1- Hospitals in CHD Network

Paediatric/Neonatal Cardiology Care

Level 1: Specialist Children's Surgical Centre

- Alder Hey Children's Hospital NHS FT

Level 2: Specialist Children's Cardiology Centre

- Royal Manchester Children's Hospital (part of Manchester University NHS FT which also includes St Mary's Hospital, Manchester see below)

Level 3: Local Children's Cardiology/Neonatal Centres

- Wythenshawe Hospital (part of Manchester University NHS FT)
- Royal Albert Edward Infirmary (Wigan Infirmary) Wrightington, Wigan & Leigh Hospitals NHS FT
- Wrexham Maelor Hospital
- Whiston Hospital (St Helens and Knowsley Teaching Hospitals NHS Trust)
- Warrington & Halton Teaching Hospitals NHS FT
- Glan Clwyd Hospital
- Royal Preston Hospital (Lancashire Teaching Hospitals NHS FT)
- Stepping Hill Hospital (Stockport NHS FT)
- Leighton Hospital (Mid Cheshire Hospitals NHS FT)
- Royal Lancaster Infirmary (University Hospitals of Morecambe Bay NHS FT)
- Nobles Hospital Isle of Man (IOM)
- Countess of Chester Hospital NHS FT
- East Lancashire Hospitals NHS Trust (incorporating Burnley General Hospital and Royal Blackburn Infirmary)
- Royal Bolton Hospital (Bolton NHS FT)
- Blackpool Teaching Hospitals NHS FT
- Furness General Hospital (University Hospitals of Morecambe Bay NHS FT)
- Bangor Ysbyty Gwynedd Hospital
- Arrowe Park University Teaching Hospitals NHS FT
- Aberystwyth / Bronglais General Hospital
- The Royal Oldham Hospital (Part of the Northern Care Alliance NHS Group which includes Salford Royal, Rochdale Infirmary & Fairfield DGH, Bury)



- Macclesfield District General Hospital
- North Manchester General Hospital
- St Mary's Hospital, Manchester & Liverpool Women's Hospital (both offering tertiary neonatal services) provide regional postnatal NICU care for those babies identified on antenatal assessment to have a very complex congenital heart disorder likely to require an early intervention. Following an antenatal diagnosis of complex CHD in a fetus, on-going obstetric care may be transferred to one of these centres where felt necessary.

Other Hospitals within the Region providing a level of paediatric cardiac care but with no designated PECSIG or Neonatologist with an interest in paediatric cardiology.

- Tameside General Hospital (Tameside & Glossop Integrated Care NHS FT)
- Ormskirk DGH / Southport and Ormskirk Hospital NHS Trust

ACHD services

Level 1: Liverpool Partnership of Trusts providing Specialist ACHD Level 1 care

- Liverpool Heart and Chest Hospitals NHS FT - in partnership with:-
 - Liverpool Women's Hospital NHS FT
 - Liverpool University Hospitals NHS FT
 - Alder Hey Children's Hospital NHS FT

Level 2: Specialist ACHD Cardiology Centres

- Manchester Foundation Trust incorporating Manchester Royal Infirmary and Wythenshawe Hospital

Level 3: Local ACHD Cardiology Centre's

- Wrexham (NHS Wales)
- Blackpool (Blackpool Teaching Hospitals NHS FT)

Other Hospitals – Fetal Cardiology/Obstetric-Cardiology clinics

- St Mary's Hospital, Manchester is the nominated lead provider of maternity services for women with Congenital Heart Disease
- Liverpool Women's Hospital NHS FT

A regionally agreed pathway regarding where best to deliver a baby with an antenatal diagnosis of CHD is available. If urgent operative/interventional care



post-delivery is felt to be likely, obstetric care may be transferred antenatally to Liverpool Women's Hospital.

Regional guidelines regarding the management of pregnant women with known cardiac disease (congenital or acquired) are well established and currently being updated.



Appendix 2 – Network Membership

Below is the network membership by role. The distribution list including name and email is a separate document and available on request.

Invitee - Paediatric	Invitee - ACHD
CHD Level 1 Centre Paediatric Cardiologists	CHD Level 1 Centre ACHD Cardiologists
CHD Level 2 Centre Paediatric Cardiologists	CHD Level 2 Centre ACHD Cardiologists
CHD level 3 Centre Paediatric Leads (could be paediatrician or neonatologist or both)	CHD level 3 Centre ACHD Leads
Cardiac specialist nurses	Cardiac specialist nurses
Congenital Cardiac Surgeons	Congenital Cardiac Surgeons
Other clinicians with a declared interest	Other clinicians with a declared interest
Other Networks (neonatal, neurosurgery, cleft etc...)	Other Networks (neonatal, neurosurgery, cleft etc...)
Community nurses	Community nurses
Paediatric service managers	ACHD Hospitals and service managers
Professions allied to medicine/psychology	Professions allied to medicine/psychology
Patient representatives	Patient representatives
Data managers	Data managers
Network staff	Network staff
NHS England specialised commissioning	NHS England specialised commissioning
Cardiac Physiologists	Cardiac Physiologists
Trainees with a declared interest	Trainees with a declared interest
Obstetrician	Obstetrician



Appendix 3 – Peripheral Hospital Clinics (Paediatric Cardiology)

Trust / Hospital Site	Frequency	Clinics per Year
Blackpool Teaching Hospital	Monthly	12
Bolton Hospital	Monthly	12
MFT (St Mary's Hospital fetal)	Twice weekly	80
MFT (Obstetric/ACHD)	Weekly	52
Countess of Chester	Monthly	12
East Cheshire (Macclesfield)	Every 6 weeks	9
East Lancashire Hospitals (Blackburn)	Monthly (all day)	24
East Lancashire Hospitals (Burnley)	Monthly	12
Lancashire Teaching Hospitals (Preston)	15 Clinics per year	15
Liverpool Heart & Chest (undertaken by paediatric cardiologist with an interest in ACHD)	Weekly	50
Liverpool Women's Hospital (Obstetric/ACHD)	Monthly	12
Liverpool Women's Hospital (Fetal)	Weekly	75
Mid Cheshire (Leighton, Crewe)	14 Sessions (all day)	28
UHMB (Lancaster Hospital)	15 All day Sessions	30
UHMB (Barrow)	11 All day Sessions	22



Warrington and Halton Hospitals (Warrington)	Monthly	12
Wrightington, Wigan and Leigh (Wigan)	Monthly	6
WUTH (Arrowe Park)	Fortnightly	24
Ysbyty Bronglais (Aberystwyth)	Quarterly (all day)	8

Trust / Hospital Site	Frequency	Clinics per Year
Noble's Hospital, IOM	Bi-monthly (all day)	12
Ysbyty Gwynedd (Bangor)	12 per year	12
Wrexham Hospital	16 per year	16
Ysbyty Glan Clwyd (Rhyl)	18 per year	18

Tameside	Every other month	6
Stepping Hill	Every other month	6
Wythenshawe	Fortnightly	24

