

Document Control

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

Memorandum of Understanding

Date: 19th December 2022

1. Overview

The 'all age' Congenital Heart Disease Operational Delivery Network (CHD Network ODN) was formally established in September 2019. NHS England advises that membership of the CHD Network ODN is mandatory for all providers of CHD services. The purpose of this Memorandum of Understanding (MOU) is to describe the role and function of the North West, North Wales & the Isle of Man Congenital Heart Disease Network and the role and function of its interdependent organisations. It is not intended to be legally binding, but all parties should enter into the MOU intending to meet their obligations.

The NHS England Congenital Heart Disease Standards and Specifications (2016) describe the role and function of Congenital Heart Networks and establish that each network should be hosted by an agreed lead provider, which in most cases will be the Level 1 Specialist Surgical Centre.

The North West, North Wales & the Isle of Man Congenital Heart Disease Network (NWCHDN) is hosted by Alder Hey Children's NHS Foundation Trust. The Network functions are independent of the host organisation, and its functions are enabled, not directed, by the host.

1.1 Vision

The North West, North Wales and the Isle of Man 'all age' Operational Delivery Network is committed to supporting the provision of world class congenital heart disease services for patients and their families ensuring that all patients receive the best standard of care as close to home as possible.

1.2 Objectives

- To identify, monitor and act on any identified strategic or operational risks across the network. To ensure adequate controls are in place to manage risks and to agree actions with providers to ensure risks are managed effectively
- To benchmark CHD providers against the NHS Standards (2016). To identify gaps in provision and work with providers to agree actions plans. To ensure an ongoing cycle of audit to ensure a commitment to continuous quality improvement.
- Improve health outcomes, reduce mortality and disability, and improve quality of life for people with CHD in line with national and international standards
- Meet, sustain and exceed nationally defined CHD standards and performance indicators
- Plan service strategy for CHD services which meet national expectations and those of the local population in the North West, North Wales & the Isle of Man

- Oversee and facilitate seamless pathways of care throughout the entire pathway, from prenatal diagnosis, transition from childhood to adulthood and ongoing to elderly care
- Provide good quality education and training opportunities for all staff working within CHD across the Network
- Monitor backlogs and work with providers to develop appropriate action plans where appropriate.
- Provide access to high quality information for patients and families

1.3 Engagement Principles

- Work together openly, transparently and constructively with patients and their families to achieve shared objectives of the network
- Ensure relevant metrics, measures, milestones, audits and accountabilities are developed and agreed so as to understand and assess progress and delivery of CHD services.
- Through its robust governance infrastructure, the network will be accountable for monitoring individual organisational aspects of the service and escalating any issues either through organisational management, or to commissioners, as appropriate
- Be proactive and responsive to queries, concerns, and network communications
- Ensure that accurate and valid data and information, which is mutually relevant, is shared in a timely manner
- To support providers to deliver CHD care in line with NHSE Standards (2016) across the Network footprint
- Participate in evidence-based design, ensuring patients, their families and the public are consulted and involved in service development and evaluation
- Be open and transparent in areas of risk, concern, or difficulty where services and patients may be compromised
- Make decisions based on evidence and the needs of the CHD population
- Be considerate of the impact on the whole system, care pathways and organisational interdependencies
- Escalate, investigate, and manage incidents which compromise the service and/or patients ensuring learning is shared
- Maintain open and transparent relationships with commissioners. Alert NHSE/I and neighbouring ODNs of significant challenges to delivery of paediatric and ACHD services within our organisations ensuring service specifications and standards are maintained

2. Network constituents, roles & responsibilities

The key relationships which underpin the effective workings of the Network are:

- > Relationship between host provider and commissioner
- > Relationship between host provider and Network
- > Relationship between member Trusts and the Network
- > Relationship between commissioners and member provider organisations

2.1 Relationship between host provider and commissioner

- 2.1.1 Alder Hey Children's NHS Foundation Trust (AHCH) provides hosting arrangements for the NW CHD Network on behalf of NHS England. The role of the 'Host' is to enable, oversee and performance manage the Network by way of establishing a facilitative, supportive framework to ensure clear lines of responsibility and reporting.
- 2.1.2. The host provider (AHCH) will be accountable to NHSE/I for the performance of the Network in terms of its functions and work programmes but not for the activity or quality performance of member organisations.
- 2.1.3. NHSE/I will monitor key milestones through quarterly reporting provided by the Network and escalate any concerns to the NWCHD Network Clinical Directors and Network Manager.
- 2.1.4. NHSE/I will hold a permanent position on the Network Board and will provide a management representative to attend all Network Board meetings.
- 2.1.5. NHSE/I will provide advice and clarification in the event of any Network issues or proposed changes that affect its function and/or operation, as defined by its Terms of Reference.

2.2 Relationship between host provider and Network

- 2.2.1 Put in place a contractual agreement between Network and Host defining clear rules of engagement and decision-making processes.
- 2.2.2 Provide relevant accommodation, facilities and corporate services to the NW CHD Network team.
- 2.2.3 Devolve responsibility for the performance management of the Network via Network objectives and work plan to the Network Board.
- 2.2.4 Ensure HR support for Network employees is in line with NHS HR Policies.

- 2.2.5 Provide clear lines of professional accountability and reporting arrangements for the members of the Network team.
- 2.2.6 Develop a good understanding of the structure and functioning of the Network.
- 2.2.7 Establish and support the Network within an agreed financial envelope. The Network Manager will be accountable for financial performance and budgetary control in accordance with AHCH's Standing Financial Instructions.

2.3 Relationship between Member Trusts and NW CHD Network

- 2.3.1 Each member Trust will actively work towards compliance against the CHD Service Specifications and Standards 2016 and update the Network on a regular basis as to its performance and progress against any action plans.
- 2.3.2 Participate in transparent benchmarking and audit as directed by the ODN to ensure equity for all our patients.
- 2.3.3 Contribute and engage in events and multi-disciplinary meetings (partnership agreement NHS England pg. 9).
- 2.3.4 Provide a representative to attend the quarterly meetings of the Network Board.
- 2.3.5 Report any significant risks, adverse incidents, complaints, morbidity/mortality issues to the Network (following investigation in line with the organisations policies and procedures. The Network Board will liaise with provider organisations to ensure that lessons learned, actions and improvements from incidents and untoward events are shared across the network footprint to help improve services and quality of care for CHD patients.
- 2.3.6 Work towards compliance against the CHD Service Specifications and Standards 2016 and update the Network on a regular basis on action plans.
- 2.3.7 Follow and develop network ratified policies and guidelines where appropriate to standardise and drive up the quality of care for CHD patients.
- 2.3.8 Comply with Network recommendations and guidelines and disseminate relevant information locally as appropriate.
- 2.3.9 Comply with agreed Network data and information requirements and timetables in order to support the work of the Network Board and agreed annual work programmes.
- 2.3.10 Engage in information sharing and digital solutions to improve patient care and delivery of care closer to home where possible.
- 2.3.11 Participate in research, innovation, and evidence-based practice to improve quality of care and patient outcomes.

2.4 Relationship between commissioners and member provider organisations

- 2.4.1 Provide governance through commissioning contractual arrangements where provider organisations consistently fail to attain objectives relating to compliance with national and local service specifications.
- 2.4.2 Support host provider CEO regarding ODN functions and performance, board functions and delivery and if necessary mediate between parties in dispute.
- 2.4.3 NHS England and NHS Wales will monitor key milestones through the Quarterly CHD Review Meeting with the Network core team and representatives from the level 1 and 2 centres and report progress through internal governance.
- 2.4.4 NHSE will be responsible for providing advice and clarification in the event of any cross-network boundary issues or proposed changes.
- 2.4.5 The NW CHD Network ODN will work in partnership with commissioners from NHS England, NHS Improvement and NHS Wales. This includes providing advice to support commissioning decisions.

3. Resolution of Network Issues or Concerns

A staged approach will be followed in the event of issues or concerns relating to:

- > Non-compliance with the CHD Service Specifications and Standards
- > Member Trusts not complying with Network guidance or recommendations
- > Member Trusts not acting in accordance with this MOU

The same approach will be followed regarding issues or concerns with all member Trusts (including the host). At all stages of this process the member trust will have the full support of the network in meeting any challenges.

Stage 1: CHD Network Management Team to arrange informal face to face meeting to discuss issues and offer support.

Stage 2: CHD Network Management Team to arrange formal meetings between The CHD Network Clinical Director to discuss issues and produce agreed actions.

Stage 3: CHD Network Clinical Director to outline issues in a letter to member Trust Chief Executive Officer, requesting support within an agreed timescale.

Stage 4: CHD Network Clinical Director to notify NHSE/I of significant issues and/or inability to meet agreed actions.

4.Data Sharing

This document sets out how the Network team will receive, store, analyse and share data submitted by the organisations in the network, as agreed in the Network Memorandum of Understanding.

4.1 Purpose, objectives of the information sharing

- 4.1.1 **Data Controller** - North West, North Wales & The Isle of Man Congenital Heart Disease Network (NW CHDN)
- 4.1.2 **Data items to be processed** - Any data relating to the work programmes of the NW CHDN as outlined in the Memorandum of Understanding. This may include activity data, waiting list data, outcome data, patient experience reports and financial information. Patient-level data will be anonymised.
- 4.1.3 **How shared data will be managed** - The Network Manager will have oversight of receiving, sorting and analysing any data shared. The Network will request patient-identifiable data from participating Trusts. The type of data, method of collection and storage will be covered by this data sharing agreement and a Standard Operating Procedure following a Data Protection Impact Assessment. Data reports and outputs will be generated and shared in an anonymised format.
- 4.1.4 Data must be sent securely via the following recommended routes only
 - 4.1.4.1 Between NHS email accounts where both providers have been accredited to the DCB1596 secure email standard. This confirms that their email systems meet the minimum requirements that will enable the secure transmission of personal confidential data and sensitive information to other secure email domains without the need for encryption.
 - 4.1.4.2 The Network NHS email account that meets this standard is:
northwestchdnetwork@alderhey.nhs.uk
 - 4.1.4.3 Between NHS email accounts that are accredited to the DCB1596 secure email standard and any NHS.net accounts
 - 4.1.4.4 If none of the above methods are available, then confidential emails must be encrypted
- 4.1.5 The following links provide access to the list of accredited organisations and the DCB1596 Conformance Statement. More information regarding NHS secure email can be found of the NHS Digital website.

<https://digital.nhs.uk/services/nhsmail/the-secure-email-standard#list-of-accredited-organisations>

<https://nhs-prod.global.ssl.fastly.net/binaries/content/assets/website-assets/services/nhs-mail/secure-email-standard/conformance-statements/dcb-1596-conformance-statement-for-nhsmail>

- 4.1.6 Data will be stored on secure AHCH servers, in a folder that is only accessible to members of the NW CHD Network Team employed by AHCH. All employees will have up-to-date Information Governance training and will comply with their contractual requirements.
- 4.1.7 Any data that is shared will be for Network work programme and ODN purposes only. Analysis that shows activity, outcomes, patient experience by provider, will be shared in aggregate form with no underlying patient-level data included.
- 4.1.8 Any requests to the Network from providers for data sharing beyond the NW CHD Network work programme will be discussed on a case-by-case basis with all providers implicated in the data sharing request.
- 4.1.9 Data will be retained by the Network for the duration that it is commissioned by NHS England.
- 4.1.10 If the Network ceases operation, data will be securely deleted in accordance with guidance outlined in the NHS Records Management Code of Practice.
- 4.1.11 **Signatories** - By becoming a signatory to this agreement (section 5), Partner organisations are committing to:
- 4.1.11.1 Apply the standards that are prescribed in guidance and Codes of Practice issued by the Information Commissioner's Office and <https://ico.org.uk/for-organisations/>
 - 4.1.11.2 Comply with the provisions of Data Protection legislation which includes, but not limited to:
 - 4.1.11.3 The UK General Data Protection Regulation (UKGDPR)
 - 4.1.11.4 Data Protection Act 2018 (DPA)
 - 4.1.11.5 Privacy and Electronic Communications Regulations (PECR)
 - 4.1.11.6 Digital Economy Act 2017 (DEA)
 - 4.1.11.7 Follow the standards prescribed by the Agreement document which includes processes for sharing information on both a routine and ad-hoc basis.
- 4.1.12 All Partner organisations agree to be responsible for ensuring measures are in place to guarantee the security and integrity of data and that staff are sufficiently trained to understand their responsibilities and comply with the law. Organisations will recognise that this document

encourages sharing of data but does not alter the statutory duties of those organisations signed up to it.

5. Agreement Signature

CHD provider Details

Name of Provider: Click or tap here to enter text.

Address of Provider: Click or tap here to enter text.

Medical Director Name: Click or tap here to enter text.

Signature: Click or tap here to enter text.

Date: Click or tap to enter a date.