

NW CHD ODN Board Meeting Summary Notes

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist



Table of Contents

Item 1 - Welcome & Apologies	3&4
Item 2 - Network Update/Finances	4&6
Item 3 - Terms of Reference/Agenda	6
Item 4 - Regional Updates including Data	6-8
Item 5 - Cardiac Maternity Update	9
Item 6 - Level 3 Update	9
Item 7 - Paediatric Cardiology Partnership Group Update	9
Item 8 - Database Update	9-11
Item 9 - Commissioner Update	11
Item 10 - National Update/Data & Workforce/Annual Report	12
Item 11 - Patient Representatives	12-13
Item 12 - Risk Register	13-15
Item 13 - Ratification of Network Documents	15
Item 14 - Any Other Business	15
Date of Next Meeting: Tuesday 28th November 2023 9.00am-11.00am	15



Item 1 – Welcome, Introductions & Apologies

Present:

Alfie Bass (AB)	Medical Director	Alder Hey Children's Hospitals NHS FT
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Elliot Shuttleworth (ES)	Divisional Director for Cardiac Services	Manchester University NHS FT
Gordon Gladman (GG)	Network Clinical Director & Consultant Paediatric Cardiologist	NW CHD Network
Helen Chadwick (HC)	Service Specialist (Specialised Commissioning Team)	NHS England & NHS Improvement
Janet Rathburn (JR)	PPV Representative	NW CHD Network
Jenny Dalzell (JD) (<i>attending on behalf of Abby Prendergast</i>)	Associate Director of Strategy & Partnerships (Acting)	Alder Hey Children's Hospitals NHS FT
Jill Moran (JM)	Network Support Officer	NW CHD Network
John Brennan (JB)	Interim Medical Director	Liverpool University Hospitals NHS FT
Jonathan Mathews (JM)	Chief Operating Officer	Liverpool Heart & Chest Hospitals NHS FT
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Lynn Greenhalgh (LG2)	Medical Director	Liverpool Women's Hospitals NHS FT
Nayyar Naqvi OBE (Chair) (NN)	Emeritus Consultant Cardiologist	Wrightington, Wigan & Leigh NHS FT
Nicola Marpole	Network Manager	NW CHD Network
Paul Willgoss	PPV Representative	NW CHD Network
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Raphael Perry	Medical Director	Liverpool Heart and Chest Hospital NHS FT
Richard Palmer (RP)	Senior Planning Manager - Adults	Welsh Health Specialised Services Committee
Sanjay Sastry (<i>attending on behalf of Sally Briggs</i>)	Consultant Cardiologist	Manchester University NHS FT



Sarah Bowman-Jones <i>(attending on behalf of Chloe Lee)</i>		Liverpool Women's Hospital NHS FT
Sarah Vause (SV)	Consultant Obstetrician in Fetal and Maternal Medicine and Medical Director of Saint Mary's Hospital	Manchester Hospitals NHS Foundation Trust

Apologies:

Abby Prendergast (AP)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Andrea Myerscough (AM)	Director of Operations	Manchester University NHS FT
Beth Weston (BW)	Chief Operating Officer	Liverpool University Hospitals NHS FT
Chloe Lee (CL)	Associate Chief Operating Officer	Alder Hey Children's Hospitals NHS FT
Elizabeth Shackley	PECSIG Chair	Stockport Hospital NHS FT
Gary Price (GP)	Chief Operating Officer	Liverpool Women's Hospital NHS FT
Helen Sanderson (HS) (On maternity leave until September 2023)	Network Manager	NW CHD Network
Kimberley Meringolo (KM)	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
Sally Briggs	Medical Director	Manchester University NHS FT
Sameer Misra (SM)	PECSIG Chair	Bolton NHS FT

Declarations of Interest: None

Item 2 – Network Update & Finances



Gordon Gladman (GG) reported the following network updates:

Network & Board Changes

- Original CHD network established approx. 15-20 years ago, NW one of the earliest to establish such a body. This developed into in to the all-age regional 'CHD network' with oversight from NHS England in 2019.
- New network specification has been released by NHS England outlining the updated requirements for networks. This will be incorporated into provider contracts as of April 24. A copy will be circulated with the minutes – it currently states 'draft', and NHSE have advised this is the copy we should now be working to.
- With the new outlined specification, it was felt a re-structuring of the network and board was required, hence new members, together with streamlining of the various paediatric cardiology and ACHD governance boards/groups that exist around the region.

Network Staffing

- Gail Maguire has been recruited to the post of network Project Manager – currently concentrating on the regional database project.
- Michelle McLaren has been recruited to the post of Lead Nurse for Training, Education & Research starts this month (23rd Aug).
- Liz Devonport has been recruited to the post of network Data Analyst, starting in September.
- Gordon Gladman will be retiring in October 2023. The network will be circulating a request for expressions of interest for Clinical Director role in due course.
- Nayyar Naqvi has kindly agreed to continue to support the next board meeting while the network look to recruit an independent chair.

Network Events 2023

- ACHD Nurse Study Day was held on the 30th June at the Marriott Hotel, Liverpool. It was very well attended and the feedback has been very positive.
- The next clinical governance meeting is scheduled to take place on the 17th August.
- A 'first face to face' PPV (Patient Public Voice) group meeting will take place on 9th September in Liverpool.
- In collaboration with the Somerville Heart Foundation, the network is hosting a young person's outdoor activity day at Outdoor Elements near Burnley on 10th September.
- Our next Patient Information Day in collaboration with the PPV group, will be held on 14th October.

Finance



- Commissioners have confirmed on-going financial support, network budget remains balanced.
- Underspend from last year (due to unfilled posts) has been agreed and assigned to support two 12-month fixed term posts for the project manager and data analyst.
- Network Manager has submitted a paper to NHS England to request additional funding to make these posts permanent – pending outcome.

Item 3 – Terms of Reference & Board Agenda

The Terms of Reference for the new board were circulated with agenda.

Sarah Vause (SV) made the request for reference to be added in the ToR regarding taking a life course approach to the care of people with congenital heart disease and stating care from the fetus through to old age. All agreed.

ACTION: Amend ToR to include “all age”

Item 4 – Regional Updates including Data

**Caroline Jones, Clinical Lead & Consultant Fetal & Paediatric Cardiologist
Paediatrics - Alder Hey Children’s Hospital:**

Waiting Lists

- Following a post COVID rise in surgical and Intervention waiting lists, these are beginning to reduce and currently one of the most manageable in the UK.
- All surgical cases are triaged at time of listing so that urgent cases are prioritised
- Intervention waiting list static with approximately 50 patients.
- Hospital initiated cancellations for surgery are reasonable considering the nature of the work and specialty. Cancellations for non-urgent patients do occur to allow for urgent, often neonatal, cases.
- A new Interventionalist joined the team from the USA.
- Electrophysiologist list, slow rise over the year due to strike action and bank holiday.

New Patients

- A significant rise in new patient referrals which is now at 900 patients waiting for a new appointment, together with clinic capacity issues, number of consultants and having limited access to rooms. Currently investigating more paediatricians with expertise to provide further Alder Hey clinics and currently have a locum advert out to cover a maternity leave and another 12-month locum.



Follow Up Appointments

- Steadily increased since COVID.
- Working on increasing clinic capacity.

Transition

- Transition service is steady, no issues to report.

Overall DNA rate (%) & New Patients per month

- DNA rates remain reasonable between 5 & 7%
- New patients' referrals per month are approx. 220-250 per month.

Rachael Barber, Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead, Manchester University NHS FT

New Patients

- Significant progress made following additional national investment for further sessions.

Follow Up Appointments Backlog

- Significant escalation to basic baseline clinic activity due to COVID-19 funding ending.
- Working with the Network and Commissioners to submit a Business Case to invest in the service and use the data to map additional resource for the service.

Transition

- Patients on the waiting list decreased. Service working well, no issues to report.

Overall DNA rate (%) & New Patients per month

- Continue to encourage cardiology patients to enrol on our new EPR system 'My MFT' which is now starting to improve our DNA rates which are down to 5% instead of 10%.

Damien Cullington, Consultant ACHD Congenital Consultant, Liverpool Heart & Chest NHS Foundation

Liverpool Heart & Chest Hospital NHS FT

Waiting Lists

- Waiting lists steady for interventional and EP lists.
- Appointed two new consultants within the Trust increasing to seven in total working across the region.
- A fifth congenital surgeon has also been recruited easing resources; however, some services may be interrupted due to the consultant strikes.
- Average wait for surgical patients is just under thirty weeks.
- Interventional waiting lists remain low.



Follow Up Patients

- Compared to many services around the UK this is currently a very small back-log for approximately 4000 patients who are under 'follow-up' at Liverpool Heart & Chest.
- DNA rates between 9-19% - since the text messaging service was introduced to patient's DNAs have dramatically reduced.

Manchester Royal Infirmary

New Patient Appointments

- Making excellent progress working closely with the management team.
- New efficient ways of working introduced to maximise clinic capacity e.g., specific ECG and ECHO patient selected for telephone call appointments instead of face to face.

Follow Up Appointments

- Currently addressing the issue of long term follow up appointments. 700 outpatient slots per year for approximately 3000 patients. The only way to address this is to have more clinics.

DNA Follow Up Appointments

- There remains a substantial number of patients that are overdue appointments.
- 'My MFT' is helping to decrease DNAs.
- Additional resources for further clinics required.

Question from Janet Rathburn re the adult backlogs in Manchester – Response from Elliot Shuttleworth:

- Manchester is working with LHCH to look at how additional support can be provided to increase clinical capacity.
- The issue is not just consultant capacity but also the nursing and ECHO teams etc. There is an overarching workforce issue which needs to be addressed, and this is being mapped nationally by the CHD networks.
- There are no immediate plans in place to make drastic inroads into the backlogs but there are plans to look in to how the workforce can be increased.

Item 5 – Cardiac Maternity Update

Sarah Vause, Consultant Obstetrician in Fetal and Maternal Medicine and Medical Director of Saint Mary's Hospital:

- St Mary's is looking at the possibility of increasing their preconception capacity by separating women that are coming for preconceptual care from the overall clinic. It would mean that those women would receive a better service and also free up clinic slots for the other women. Currently looking at whether this is possible with the current resource available.



Item 6 – Level 3 Centres Update

GG commented that there were no issues from around the region to report.

Item 7 – Paediatric Cardiology Partnership Group Update

- Business case now submitted to the Commissioners to support the funding progression and scoping toward the single paediatric cardiology service, awaiting decision.
- Work in progress to include a Paediatric sonography service across the two sites.
- Significant improvements have been achieved around sharing information, ECHOs and medical records.

Item 8 – Database Update

Gail Maquire, Project Manager, NW CHD ODN

What is the business problem we are looking to solve?

- Patients within CHD services are currently managed by individual trusts patient treatment lists, there is no single list which contains all the patients currently being seen within the service.
- This creates a number of silos across the network which results in a lack of oversight into exactly how many patients with CHD there are across the North West.
- There is a lack of oversight on the management of clinic activity and capacity on a day-to-day basis, no region wide understanding of RTT pathways, no single source of patient demographics as well as an increased risk that patients will be lost to follow up.
- Loss to follow up is a serious issue and without this information we're unable to evidence this as a concern, understand the size of the problem in order to provide the resources to resolve it.
- In addition, development and deployment of an all-age database for the CHD North West Network is a requirement of the standards set by NHS England Special Commissioning, for the CHD service in the North West region.
- The complexity of the system and lack of oversight of a region wide picture results in duplication of appointments which in turn reduces clinic capacity and inappropriate use of a limited specialist resource.

In Scope



- The creation of a single database with the ability to source CHD (from EPR & PAS systems) data from Level 1 and Level 2 trusts across the North West region.
- The database will be read-only.
- The database data fields will include the KPIs used by the Network.
- The database will leverage existing clinical systems already used within the individual trusts.
- The database will leverage existing shared clinical records functionality already used by the individual member trusts, i.e., Share2Care.

Out of Scope

- The project excludes non-CHD cardiac conditions, i.e., Inherited Cardiac Conditions, acquired cardiac conditions for adults.
- This project will not be establishing a single PTL.
- This phase of the database will not be 'live' and inputting of data will not be possible.

Benefits

- Improved understanding of range & extent of CHD across the region.
- Ability to generate data & compile reports which accurately reflect the resource needs.
- Assurance that patients are not lost to follow up.
- Improved understanding of flow of patients in NW, manage system capacity.
- Network will be able to download data from trusts instead of requesting thus reducing time spent requesting data from centres.
- Improved coding will positively impact income for specialist services.
- Single source of all patients currently and/or previously seen by NW CHD centres.
- More sustainable service which provides equity of access to specialist CHD services.
- Identify patients for research studies.

Disbenefits

- New cost of maintaining the CHD database.
- Database is read only.

CHD Database Progress to date

- An external company, Mindwave have been awarded the contract to design the database.
- Colleagues from our member trusts and the Network have met with Mindwave and attended several workshops to outline our requirements for the database, establishing a list of users, KPI and information sources which they will use to design and build the database.



- The network is working closely with our IT and coding colleagues from Alder Hey and LHCH trusts to establish the technical requirements to access the EPR and PAS systems at trusts and to understand which set of diagnostic codes we will be using in the database. The codes being used will be the ICD-10 codes.
- We're in the process of getting Manchester on board and technical meetings will be set up with the required teams to ensure Mindwave can access the information they need from the Hive system.
- Mindwave are currently working on user stories and developing the test database which will be made accessible to us to provide feedback.
- Mindwave have advised we will be involved in the testing of the database, ensuring UAT is complete, enabling us to progress to full implementation once testing is completed and signed off.

ACTION: Presentation slides to be circulated with the meeting notes.

Item 9 – Commissioner Update

Helen Chadwick, Service Specialist (Specialised Commissioning Team, NHS England & NHS Specialised Commissioning

- Paediatric business case currently being reviewed for Levels 1 and 2 confident a decision will be made in due course.
- Nationally, awaiting instructions regarding the new 'road map for delegation' and what this will look like for Cardiac ODNs including congenital heart disease. Reviewing whether they are part of the single integrated care system and care board or sit under multi-integrated care boards?
- Awaiting plans of NHS England's consultation change and priorities.
- Starting to set up initial stakeholder meetings of single and multiple ICS's.

Item 10 – National Update – Data & Workforce & Annual Report

Nicola Marpole, Network Manager, NW CHD ODN

Update on National Data

- ACHD surgical total numbers showing a slight improvement between April and May, with only a 1% reduction in January from the beginning of the year.
- A decrease in the P2 and P4 patient numbers, but the P3 numbers have increased by 4% from January.



- Intervention numbers also show a slight improvement, with 3.4% reduction between April and May, marginally higher than January, the number of patients in each category remains fairly static, although some improvements were seen in each category between April and May.
- Paediatric surgical numbers show an improvement with the 2.5% decrease in total waiting list between April and May. The overall list remains slightly higher than it did in January.
- P2 waiting list shows an increase against April of 7% but has decreased by 14% in comparison to January.
- P3 waiting list shows a 7% decrease against April but is static compared to January and all P4 waiting lists show a marginal decrease against April but is increased by 12% in comparison to January.
- Interventional waiting list – not all data for January & February was available for submission. There was an improvement between April & May with overall 1% decrease from March. There was a slight decrease in P2 and P4 patients, which appears quite high at 7.4% increase in P3 patients from March.

Annual Report

The Network Annual Report 2023 is now available to download from the Network website: [Education & Resources - Northwest, North Wales, Isle of Man Congenital Heart Network \(northwestchdnetwork.nhs.uk\)](https://www.northwestchdnetwork.nhs.uk/education-resources)

Item 11 - Patient Public Voice Group (PPV)

Janet Rathburn, Chair, Patient Public Voice Group (PPV)

- **Role of the PPV Group**

To ensure that the patient experience is the best it can be.

There have been a number of individual issues raised and although patients are aware to first approach the PALS team, this has not always proved effective. The group would welcome recommendations from the Board to improve the patient experience and to ensure that concerns are heard.

Linda Griffiths (LG) proposed for a forum to be created specifically for patient experience. This would meet approximately every 6 months and will alternate with the Clinical Governance meeting. Using outputs from our PREMS survey, this forum will work with the PPV group to ensure the right people attend and can make the necessary decisions to address the issues raised in a positive way.

Raphael Perry (RP) was concerned to hear that the PPV group were reporting that the PALS service was not working effectively and would feed that back to the Liverpool Partnerships team. RP supported the importance of the forum and suggested a quarterly summary report be presented at the board.

ACTION: LG & PPV Group to set up a patient experience forum



ACTION: RP to feed back at the next Board following discussions with the Liverpool Partnership team

- **Alder Hey Issues**

- Patients are long overdue for follow up.
- Patients waiting up to 2 hours for an Echo.
- Problems with discharge after surgery taking too long.
- Notice for the information day didn't go out to families who attend peripheral clinics. Short notice for invited charities. Also booking system not very helpful and slow response from staff.
- Transition day only aimed at single ventricle patients, what about other complex conditions. Only 6 families attended.
- Concern about the appropriateness of using the area next to the staircase for critical care for fun activities on NHS birthday.
- Situation with the charity office and Team 1C – hopefully to be resolved in due course.

- **Manchester Issues**

- Waiting list, update on plans to manage and reduce?
- HIVE – is it having a positive impact?

Item 12 – Risk Register

Linda Griffiths, Lead Nurse, NW CHD ODN

Background

The Network has met with managers both at Alder Hey Children's Hospital and Manchester Children's Hospital in 2023 to review the risks particularly associated with the current service model for paediatric cardiology in NW.

The individual risks identified have been mapped, scored and designated to responsible owners both with Commissioners and the Network.

There are 17 risks in total on our register.

Risks scored 12 and above

- **Lack of resources to support the transformation work required to develop a single paediatric cardiology service for the NW (20)**

In addition to looking at the risks, the Network carried out a self-assessment against the standards on a risk-based approach with Manchester Children's Hospital. A draft final report has been written and shared with the managers at Manchester Children's however, we are still awaiting a response.

ACTION: request for Board to support and encourage engagement from RMCH
Backlogs at Manchester University NHS FT (16)



Lack of engagement with MRI to discuss backlogs with the Network on a regular basis along with the strategies for mitigating against this risk.

ACTION: Request from Board to encourage engagement from MFT

- **Psychology Provision (12)**

The Network are aware this has been included in the Business Case; however, it would be beneficial to understand if there are any plans for the Royal Manchester Children's hospital to recruit into vacant posts.

- **Cardiology Staffing at RMCH (12)**

Included in the Business Case.

- **Database (12)**

Back on track with new Network Project Manager, Gail Maguire, now in post. The Network have also recruited a Data Analyst due to start in September.

- **Fetal Cardiac Nurse Specialist – RMCH (12)**

Has been included in the Business Case. Following Manchester's self-assessment, it was made clear that the responsibility of this post lay with St Mary's hospital however, this is yet to be clarified.

ACTION: Board confirmed responsibility for this post lies with RMCH

- **Insufficient number of cardiac nurse specialists at RMCH (12)**

Included in the Business Case.

- **Cardiac Physiologists (12)**

Lack of infrastructure at RMCH. AH offering mutual support but is not sustainable in the long term.

- **Lack of capacity at RMCH & AH Follow Up Appointments (12)**

Discussed as part of the regional updates. Once implemented the regional database should provide robust data to enable an accurate capacity and demand review to be carried out.

ACTION: Request from Board to support the database project and ensuring local expertise for technical support be available when required

- **Lack of Transition Nurse – RMCH**

Discussed as part of the regional updates. There is a lack of understanding around transition services in the level 3 centres. The Network is undertaking a project to look at current services, with the aim to implement a consistent process across the region.

ICC service

- Provision of ICC Service & lack of funding for paediatric ICC is currently scoring a 10 (catastrophic/rare) LG would like to bring it to the board's attention. Is not currently reaching a threshold to be discussed at Board level. Do we need to review this score to ensure board has sight of this risk.

Board response:

1. Rachel Barber responded to LG – the team will respond this week regarding the engagement from Manchester, apologies for the delay.
2. Caroline Jones confirmed the responsibility for the recruitment of the Fetal Cardiac Nurse sits with RMCH under the CHD Standards.



3. Board agreed to increase ICC risk score to 15 (catastrophic/possible). When the original CHD standards were conceived the Paediatric ICC service was not included. The current service specification for ICC is only related to adult services although this is currently being updated to include paediatrics. Therefore, we have a duty of care to ensure service risks around this group of patients is addressed. The responsibility for delivering this service will sit within the paediatric cardiac services and ultimately the Network moving forward.

Item 13 – Ratification of Network Documents

Linda Griffiths, Lead Nurse, NW CHD Network

Documents for noting, ready to be signed off:

- Mortality Reporting Form
- Incident Reporting Form
- Clinical Governance SOP V2
- Open Access Letter
- Operational Policy
- Board ToR

A memorandum of understanding (MOU) setting out the responsibilities of Network members is now included in all NHSE contracts. The Network has asked for the opinion of the Board as to whether we use the NHSE MOU or whether we should continue to circulate a network specific MOU to all member organisations going forward? The Network MOU will continue to be used for the Isle of Man and those centres in Wales who are not contracted by NHSE.

ACTION: A copy of the NHSE MOU and the Network MOU will be circulated with the minutes for review. Item will be added to the next agenda for approval.

Item 14 – Any Other Business

None reported.

Date of Next Meetings

Tuesday 28th November 2023 9.00am-1.00am via MS Teams

Monday 26th February 2024 2.00pm-4.00pm via MS Teams

Tuesday 21st May 2024 1.30pm-3.30pm via MS Teams

Monday 12th August 2024 2.00pm-4.00pm via MS Teams

