

NW CHD Board Meeting Summary Notes 15th July 2022

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist



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Item 1 – Welcome & Apologies

Present:

Bernard Clarke (BC)	Consultant Cardiologist	Manchester University NHS FT
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT
Gordon Gladman (GG)	Network Clinical Director & Consultant Paediatric Cardiologist	NW CHD Network
Jalibani Ndebele (JN)	Lead Service Specialist (Specialised Commissioning)	NHS England
Janet Lamb (JL)	PPV Representative	NW CHD Network
Jemma Blake (JB)	Clinical Data Manager	NW CHD Network
Jenny Dalzell (JD)	Associate Director of Strategy & Partnerships (Acting)	Alder Hey Children's Hospitals NHS FT
Jill Moran (JM)	Network Support Officer	NW CHD Network
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Lowri Smith (LS)	PPV Representative	NW CHD Network
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Nayyar Naqvi OBE (Chair) (NN)	Emeritus Consultant Cardiologist	Wrightington, Wigan & Leigh NHS FT
Phil Rigby (PR)	Service Specialist (Specialised Commissioning Team)	NHS England and NHS Improvement – North West Region
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest NHS FT
Rob Johnson (RJ)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT



Apologies:

Abby Prendergast (AP) (On maternity leave until April 2023)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Anna Harrison	Lead ACHD Nurse Specialist	Liverpool Heart & Chest Hospital NHS FT
Clair Noctor (CN)	Cardiac Specialist Nurse	Manchester University NHS FT
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Gopi Vemuri (GV)	Consultant in Neonatology & Paediatrics	Manchester University NHS FT
Helen Sanderson (On maternity leave until July 2023)	Network Manager	NW CHD Network
Janet Rathburn (JR)	PPV Representative	NW CHD Network
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children's Hospitals NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Vasileious Papaioannou (VP)	Consultant in Neonatology & Paediatrics	Liverpool Heart & Chest Hospital NHS FT

Declarations of Interest: None



Item 2 – Board Notes & Action Tracker

Meeting notes from NWCHD Network Board meeting on 27th April 2022 were circulated prior to the meeting. No comments or amendments required, and all agreed an accurate record.

Action 33 – Network MOU – IoM and Wales still outstanding. There have been changes to the Welsh commissioning team following Andrea Richards' semi-retirement. Richard Palmer (Adult Cardiac Services) and Kimberley Meringolo (Paediatric Cardiology) will attend future board meetings. LG has agreed to do a review of the outstanding MOUs. - **IN PROGRESS.**

Action 36 – Network Operational Delivery Group – It is the expectation that once the new Network manager takes up post in September this group will progress. - **remains ON-HOLD.**

Action 39 – NCARDRS – GG proposed for this action to be closed. NCARDRS have agreed to share the data – **ACTION TO BE CLOSED**

Action 45 – PPV Commissioner Update Request – Phil Rigby is moving on as Commissioner to the Network. Going forward Jalibani Ndebele, will be the Network's Commissioner liaison and attend the Board – **ACTION TO BE CLOSED**

Item 3 – Network Update & Finances

Network Manager & Team Update - GG welcomed Linda back who has returned to work on a phased return. A new Network manager has been appointed to cover Helen Sanderson's maternity leave and will commence in September.

Jemma Blake, our Network Data Manager, Kenny Ward, Project Manager and Dan Short, Project Manager, Clinical Governance, will all sadly be leaving the Network in August.

Item 4 – Data Update

Jemma Blake, Clinical Data Manager, NW CHD Network presented a summary of the data returns for paediatrics from Alder Hey and MFT (paediatrics) and ACHD from Liverpool Heart and Chest Hospital and MFT (adults). **ACTION: Slide pack shared with board members.**

Further discussion on data collection:

- Challenges remain in getting accurate and comparable data from across providers. This is often because individual PAS systems have difficulty in pulling the data being asked for by commissioners.
- Suggestion made that it would help if commissioners and providers could work together to agree what data is needed/required considering what can be



provided via PAS systems and agree a standardised data set that is useful and easy to collect for everyone.

- Funding arrangements to enable recruitment to replace the data manager for the Network remains a challenge.

Item 5 - Regional Updates

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

- Waiting lists are low and clinics progressing well.
- Challenges regarding funding around how services are provided over the next couple of years.
- New patient clinics being covered by some paediatricians with expertise (PECSIG).
- Follow-up patients – still some challenges ahead but gradually decreasing each month. Most of the patients overdue an appointment by 12 months are ICC patients and not CHD patients. Interviews for a new locum consultant are taking place next week to provide further capacity to follow-up patient clinics and will be working within the ICC service.
- Approximately 50 new patient referrals per month of which probably 95% of them get discharged straight away and the vast majority don't have a cardiac problem.
- DNA rates are very good – no issues.
- ICC Specialist nurse now recruited at Alder Hey.
- Database business case for Alder hey is on-going
- 'Healing Little Heart' app nearly ready to launch following a £500k grant from NHS Digital in conjunction with the Innovation Hub. It will show live data of our patients with a single ventricle, particularly when they are small between their second stage of surgery. Second grant to be applied for looking into digital sensors. We have also had talks with Great Ormond Street Hospital who are interested in the app.
- Patient initiated follow-up – to be implemented soon. This will give patients and families the ability to arrange an appointment if they are concerned about their child.
- Outpatients current funding model challenges – Alder Hey will only be funded to 85% of follow-up patients for 2019, which means we need to reduce the number of follow-up patients we see by 15%.

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

- New EPR system going live in September which will improve future data submissions.



- Still have a very high number of referrals, approximately 250 a month, however, plans are in place to reduce this. Working on developing PECSIG's at North Manchester & Oldham.
- New patients & follow-up numbers have reduced to improved levels thanks to the Saturday clinics at Manchester and Alder Hey, as a result new patient wait now approximately 20 weeks.

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

- Guideline documents was being developed by the CHD Network that included referral pathways for pregnant women with CHD including preconceptual and post-natal care.
- In parallel to this document in Greater Manchester & East Cheshire there is the local maternity system which has its own guidelines for various conditions in pregnancy. This includes care of pregnant ladies with cardiac conditions.
- In addition, the GMEC guidelines for cardiac disease in pregnancy have also been revised recently. This is mainly a clinical document but there is also some information about referral pathways in the appendices within the GMEC area
- The Greater Manchester and East Cheshire and GMEC documents are complimentary.
- Since April the Maternal Medicine Networks have been formalised nationally. The aim of these Networks is to care for pregnant ladies with underlying medical conditions including those patients with CHD. There is now a North-West Maternal Medicines Network covering Greater Manchester and Eastern Cheshire, Cheshire & Mersey, Lancashire & South Cumbria. A NW medical lead and manager have been appointed with a Lead Midwife shortly to be recruited. The aim of these networks is to have referral and escalation pathways for the various different medical conditions including CHD. For ladies with complex medical conditions and where appropriate they will be referred to three specialist centres (facilities slightly different in each cenytre):
 - St Mary's Hospital in Manchester
 - The Liverpool Women's Hospital
 - Preston

Proposal:

- The CHD Network Board to agree and ratify the NW CHD Network referral pathway. Once ratified to be made available on Network website
- Board to acknowledge the GMEC referral pathways & guidelines
- Work with the Maternal Medicine Network to develop a joint NW heart disease in pregnancy guideline to include ACHD. Sarah Vause happy to liaise between the two Networks. This guideline would be owned by the Maternal Network but be agreed by the CHD Network. Links to this guideline can be placed on the CHD network website

ACTION:

- **SV to send LG the GMEC guidelines**



- **LG to re-send the draft ACHD guidelines alongside the GMEC document to the authors of the Network ACHD referral document.**
- **Once finalised document will go through a process of being ratified and shared with Board members for final sign off**

Level 3 Centres:

- No major problems to report

Item 6 – Risk Register (risks scoring 12 & above)

Discussion of risks included:

CHD Network Risk Register Summary 15.07.2022

<p>(2332) Challenges to finding a solution to providing a "single service" model for paediatric cardiology This may result in potential harm due to inequitable service provision across the paediatric congenital heart disease operational delivery Network in the North-West Business case submitted to commissioning to support project moving forward Current Risk Score (20) → Target Risk Score (6)</p>
<p>(2383) Psychology provision not meeting minimal NHSE Standards Currently only able to focus on more severe presentations or crisis management Gaps will be identified when audit of CHD Centres are undertaken – which should result in action plans Current Risk Score (16) → Target Risk Score (4)</p>
<p>(2536) Significant further reduction in Network Staffing from August 2022 The network does not have the financial resources to backfill senior leadership posts to the level needed Network Finances to be reviewed Suitable candidate found for Network Manager role – secondment being sought Current Risk Score (16) → Target Risk Score (4)</p>
<p>(2276) No Network database therefore unable to collect data and therefore fails to meet NHS England Congenital Heart Disease (CHD) standard F10 (L1) Project temporarily on hold as focus on ACHD single PTL has taken priority PMO due to leave post beginning of August 2022 Current Risk score (12) ↑ Target Risk Score (4)</p>
<p>(2339) Back logs in Blackpool could result in risk of delayed treatment resulting in potential harm to patients Update required Current Risk score (12) → Target Risk Score (4)</p>
<p>(2284) Inability to store and share images in a suitable format may result in potential delays in clinical decisions and management plans being made for patients. (D8) Not a problem for adult services Situation in paediatrics improving but audit to be done to understand issues in more detail. Will improve when ISCV available at AH for sharing of Echo/TOE's</p>



<p style="text-align: center;">Current Risk Score (12) → Target Risk Score (3)</p> <p style="text-align: center;">(2331) Fetal Nurse provision is not equitable across the Network and not meeting NHSE Standards Results of communication audit >50% did not receive any support from fetal/cadiac nurse specialist when antenatal diagnosis made across Network</p> <p style="text-align: center;">Current Risk Score (12) → Target Risk Score (1)</p>
<p style="text-align: center;">(2375) NWTs not commissioned to transfer high dependency (non-ventilated) patients with complex heart failure who need to be assessed in transplant centres across the UK.</p> <p style="text-align: center;">Potential delay or inability to transfer patients for transplant assessment in a timely manner No updates to report</p> <p style="text-align: center;">Current Risk Score (10) → Target Risk Score (4)</p>
<p style="text-align: center;">(2465) No access to dental treatment for patients with complex ACHD requiring GA risks causing delays in congenital heart surgery/intervention where dental treatment is required prior to their procedure. Patients will have an increased risk of developing endocarditis SLA between LHCH and Dental Hospital agreed from September 2022</p> <p style="text-align: center;">Current Risk Score (9) → Target Risk Score (4)</p>
<p style="text-align: center;">(2535) Network Lead Nurse off sick Inability to maintain numerous work streams effectively Lead Nurse back at work – part time Priorities agreed</p> <p style="text-align: center;">Current Risk Score (9) ↓ Target Risk Score (2)</p>
<p style="text-align: center;">(2336) Not all peripheral centres providing paediatric cardiology services have a Paediatrician with Expertise in Cardiology (PEC). Welsh Audit of level 3 centres now complete and results available Need to extend Audit to level 3 centres in England and The IOM (on hold due to staffing issues)</p> <p style="text-align: center;">Risk Score (9) → Target Score (6)</p>
<p style="text-align: center;">(2285) Impact of COVID-19 Pandemic on the ability of providers within the North-West Congenital Heart Disease Network to continue to provide normal services Backlogs continue to be monitored Quality of data still needs to improve from certain providers Data manager leaving network in August 2022</p>

2284: RB asked if the image sharing risk could potentially be reduced given that processes are in place for a system to share images (ISCV) across both Manchester & Liverpool – CJ agreed this will be reduced.

Concern raised that summary of Network Risk Register is not detailed enough. Full risk register can be circulated for future meetings.

Many risks have an associated cost to be able to implement. Current funding arrangements in the NHS mean that providers are being given less money whilst being expected to provide the same service. Trying to make a business case is very challenging due the block funding arrangements currently in place. Sharing the cost burden across the Network as we move towards a single service will be helpful however we need to acknowledge that some risks will remain on the RR due to this problem.

ACTION: Full risk register to be circulated with Board papers in the future

Item 7 – Paediatric Cardiology Partnership – Single Paediatric Cardiology Service

- Fortnightly meetings continue with high level involvement from both organisations including Medical Directors.
- Assessing the data to see what services need to be aligned and what support and resources are required to provide a single service. Particular challenges exist with AHP's and PECSIG support across the Network



- Business case to support a scoping exercise to understand what is required to deliver a single paediatric cardiology service in the NW has been completed. This has been finalised and reviewed by both Exec Teams (not a whole service review). Aim to have final sign-off at the Partnership Board next week.
- Three phases identified:
 - Phase 1: Scope out the problem and agreeing what resources are needed
 - Phase 2: Start to put those resources in place where gaps identified against the standards
 - Phase 3: looking towards becoming a single service
- Focus now on resources including teams from Governance and HR to assist with benchmarking.
- Resources are needed to implement this plan across the whole Network.
- Working relationships are improving already and need to work on engaging Level 2 clinicians more in this process.
- CCIOs engaged from both organisations.
- ISCV now working allowing images to be seen at Manchester & Alder Hey.

Item 8 – Single ACHD/PTL Update

Concerns have arisen regarding a regional single PTL versus the previous option of a Network Database. Phil Rigby led the discussions:

- Funding of £96K has been agreed for a single, all-age PTL. This is being driven by commissioner SLT and is in response to the various reviews into patients who have been lost to follow up previously
- There are anxieties amongst clinicians and concerns and risks from a clinician point of view need to be discussed and resolved.
- Need to discuss with clinicians and define and agree what the solution is for the CHD Network.
- Concerns raised regarding the current backlog data from each provider being very complicated already and trying to combine this may increase the risk of patients getting lost.
- CHD is provided by two separate and very different models of care for paediatrics and ACHD. Who would be responsible for the governance of a single PTL?
- Whilst a single PTL for paediatrics may be the long term aim – in line with current partnership work towards a single service this would be one of the last things to tackle not the first
- Clinicians in favour of a Network database would be beneficial to see where the patients are and identify resources.
- ACHD service very concerned about expansion of a single PTL. Have experience of the ACHD level 1 service taking over the PTL of a small level 3 service. The host Trust then has no incentive to improve services and has proved very problematic.



- Like the idea of single PTL or database for information only but would strongly oppose a single managed PTL where the Level 1 service is responsible but without any authority or influence to affect changes to improve patient care.
- Need to clarify whether a database or PTL is required. Original aim of the database was to track every patient in the region and identify who is responsible for their care. The PTL's objective is to do that but to place responsibility for their future care onto one Trust?
- Commissioners need a co-produced solution to this problem and need assurance that no patients are lost to follow up. Accountability for the patients needs to be at the heart of those discussions.
- Important role of DGH's and primary care also discussed
- Need to consider the improvements that will be made when the new HIVE system goes live in September at MFT in tracking patients and managing PTL's there.

ACTION: A meeting is to be set up with Commissioners, lead clinicians and Network representatives to discuss a solution to take this project forward. JD agreed to set up.

Item 9 – PPV Representatives

- Group have continued to meet in Linda's absence and lovely to welcome her back to their July meeting. Group having a break in August and will reconvene in September.
- The PPV Group have requested the following statement to be formally recorded: "There is still no mechanism for dissenting views to be formally recorded in the CHD NW governance structure. This was brought to light during the discussions between the Network and the PPV where significant concerns were aired about the tone and content of the 2020 Annual Report. A clear, open, and transparent mechanism needs to be agreed and implemented to ensure that all views are represented."
- Patient Information Day in October:
 - Venue secured at The Curve, Greater Manchester Mental Health NHS FT, with date to be confirmed for October.
 - Children's Heart Association have offered funding and other funding being sourced.
 - Anne Flear has been working with Linda on the results of the patient surveys which will be the guidance for the workshop topics.
- New patient App has been developed with the Bevan Commission and funding from Welsh Health App to support patients with complex medical problems
 - Designed to have a cross-border potential
 - Ability to upload relevant patient documents
 - It has both clinical and patient sections
 - A prototype has been developed and now going into Beta testing.
 - Once testing is complete proposal to present it to the Board



Item 10 – Commissioners Update

Board updated on the current changes happening in the NHS and the ICS setup. Specialised Commissioning has another 12 months to figure out how the new systems will work. Specialised services will either:

- stay with regional commissioners
- hybrid approach whereby commissioning and ICB's work in partnership
- delegated authority to ICB's

Specialised Commissioning is currently going through some significant changes, and this has obviously caused some financial implications. Concerns raised today have been heard in terms of recruitment and how this will have a significant impact on the way Network work is carried out. They are keen that funding gets extended, and they will liaise with the Network as soon as there is progress to report. Commissioners agreed to attend future Boards and to provide a report at each meeting.

NHS England are currently in the process of updating and reviewing network specifications and what will be expected of them in this new ICS landscape. The CHD networks are included in the first tranche of that process.

Date of Next Meetings

Monday 17th October 10am-12noon

