

NW CHD Board Meeting Summary Notes 17th October 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
Gopi Vemuri (GV)	Consultant in Neonatology & Paediatrics	Manchester University NHS FT
Gordon Gladman (GG)	Network Clinical Director & Consultant Paediatric Cardiologist	NW CHD Network
Janet Rathburn (JR)	PPV Representative	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
Kimberley Meringolo (KM)	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
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
Nayyar Naqvi OBE (Chair) (NN)	Emeritus Consultant Cardiologist	Wrightington, Wigan & Leigh NHS FT
Nicola Marpole	Network Manager	NW CHD Network
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
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) (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
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Helen Sanderson (On maternity leave until July 2023)	Network Manager	NW CHD Network
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children's Hospitals NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Richard Palmer	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
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. MOU to be reviewed with new Network Manager, Nicola Marpole and sent out to all NW organisations. - **IN PROGRESS**.

Action 36 – Network Operational Delivery Group – New Network Manager, Nicola Marpole to review the membership of this group and its agenda. – **IN PROGRESS**

Action 37 – Cardiac Maternity Guidelines & Referral Pathways – Nicola Marpole to meet in the new year with Maternal Medicines Manager/LG/SV & Lead Midwife. – **IN PROGRESS**

Item 3 – Network Update & Finances

Network Update - GG welcomed new Network Manager, Nicola Marpole to the team, who is covering for Helen Sanderson whilst on maternity leave.

Finance Update – GG reported there are no Network finance issues.

Item 4 – Regional Updates including Data

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

- In-patient workload under control post COVID.
- Waiting lists remain low for surgery and intervention, however surgery has peaked slightly in previous few months due to an increase in emergency neonatal surgery.
- EP data was missing for July & August, but this has been rectified and is still around 20 on the waiting list.
- New patients' referrals – waiting list initiative clinics have been running. Capacity released with new PECSIGs attending Alder Hey clinics to see new patients. Spikes relate to waiting list initiative work



- Follow up Appointments – excellent progress over first half of the year. However, this seems to have plateaued. A lot of the patients who are more than 12 months overdue are patients sitting in the inherited cardiac conditions clinic and are on normal follow up cycles of somewhere between three and five years. There is a good prioritisation process in place for patients.
- Appointed a new Locum Cardiologist, Dr Barbara Cardoso, who started last month and has an interest in heart failure and has done transplant work previously. She is working in the ICC clinic at both Manchester and Liverpool.
- Transition – steady stream of patients coming through transition hand over clinic run jointly with LHCH. Agreed further help to understand the transition data would be helpful going forward.
ACTION: NM & LG to meet with Emma Powell, Regional Nurse Advisor for Young People's Healthcare Transition.
- New referrals – remains steady sometimes up to 250 per month.
- DNA rates at AH – remain steady between 6%-7%. Not unusual to see a rise during the summer school holidays.

Rachael Barber, Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead, Manchester University NHS FT – Gordon Gladman gave an update on Rachael's behalf:

- New patient back-logs: waiting list initiatives coincide and reflect the data
- Follow-up backlogs: slightly improved following earlier peak of COVID. Team working together to keep at a level status.
- Transition – trend is steady. Many young people have video consultation clinics but this is not the hand over clinic data
- DNA rates – currently between 6% & 18% - the trend is improving.

Reza Ashrafi, ACHD Consultant Cardiologist, Liverpool Heart & Chest NHS Foundation NHS

- Waiting lists static. Not a lot of change to the numbers waiting and lists under control. Surgical lists have gradually decreased from previous high points.
- Backlogs follow up patients – capacity issues with only two rooms available in LHCH. Numbers of patients in ACHD service continue to increase year on year as expected. The numbers are also increased as needing to see patients from Blackpool – although this only contributes a small number.
- Overall DNA rate are around 10% and new referrals are static.

Bernard Clarke, Consultant Cardiologist, Manchester University NHS FT

- Data issues remain and BC has discussed these issues with Elliott Shuttleworth, Divisional Director for Cardiac. LG & NM from the Network will be meeting with him on 23rd November.



- September's data to be sent through next week.
- Staff updates:-
 - Consultant, Paul Atkinson based at North Manchester retired at the beginning of October
 - Matt Daniels has now left to work in the USA
 - Julia Jones from LHCH has now started and is also doing some clinics at Manchester
 - Dr Omar Asghar, Imaging Consultant, has joined the team for a year
- Discussions on going about the need to increase clinic capacity at Manchester

Item 5 – Cardiac Maternity Update

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

- The new EPR system is proving very positive, giving much greater visibility of records from medical specialities and will eventually link to GM care records. A facility is also available to record advice provided either in clinic or via a telephone conversation. MDTs are also recorded.
- Patients also now have access to significant parts of their record.
- NW Maternal Medicine Network now up and running and the Leadership team in place. The Board being reconfigured from the original shadow Board. Lead midwife appointed but not yet started – hopefully January 2023.
- MDTs going well with more members across the North West joining virtually.
- Staff update: Three formally trained maternal medicine physicians have joined the team at St Mary's Oxford Road and a trainee has joined the team in Liverpool.
- Patient Information Day – following the talk at the Information Day concerns were raised around further information being available on pregnancy and contraception for concerned teenage girls and their mothers. LG mentioned the upcoming Transition Clinics and invited SV to come along to talk to the teenagers including Fontan patients.

ACTION: SV & LG to work on some material for the Network website. SV agreed to attend the next Transition clinic in November.

Item 6 – Level 3 Centres Update

Matthew Sandman, Consultant Paediatrician, Ysbyty Glan Clwyd Hospital:

- Locally, clinics getting back on track.
- Clinics variable across the region depending on PECSIGs in place.

GG commented this a fair reflection across the region. Not all hospitals across the region have PECSIG representation. No incidents to report.



Item 7 – Paediatric Cardiology Partnership Group update

- Both Alder Hey & Manchester groups continue to meet monthly, and the Operational Group meet fortnightly.
- Submitted a bid to commissioners for support for next steps, awaiting feedback.
- Meeting to be arranged with the Executives Teams of Alder Hey and Manchester to decide next steps if the bid is not successful.
- Starting to develop pathways. Historically sonographers at Manchester have previously been provided by the adult service. A proposal is being written to ensure collaboration between paediatric sonography teams at Alder and Manchester Children's going forward.
- Concern raised that, resources are very stretched and will require investment to implement major transformational changes such as the single service.
- Most recent adverts have been advertised as joint site working which is more attractive to future candidates.
- Big challenges due to the lack of a consistent commissioner voice. Concerns raised regarding the constant changes within the commissioning team and the impact of that on getting decisions made. Commissioners need to be involved in the big decisions and discussions that need to take place. There is a lack of nurses and physiologists available which impacts on the ability to provide basic outpatient care.
- Suggestion raised to invite Michael Gregory, Regional Medical Director, North West, to a future meeting. Michael Gregory attends the ACHD Partnership meetings. RB suggested bringing him up to speed before inviting him to this board.

ACTION: RB to meet with MG prior to inviting to the NW CHD Network Board

Item 8 – Single ACHD/PTL Update

Update provided:-

- Discussions are still on-going between commissioners and clinicians regarding the drive towards a single PTL (Patient Treatment List).
- Following the meeting organised by Jalibani Ndebele (commissioner), it was agreed to postpone the paediatric PTL. Commissioners are still keen to go ahead with the ACHD PTL.
- Clarity is still required regarding how the list will function. Is it just a list of patients and who is responsible for their care and where do they receive their follow up or is it a managed PTL.



- Questions regarding who would host the PTL and who would be responsible for it.
- Helen Chadwick has taken over as our lead commissioner and will be able to provide an update at our next Board meeting.

Points raised from board members discussions:

- If the PTL is just a list of patients in our region – isn't this the same as having a database?
- A database already exists at Alder Hey. Therefore, why is it necessary to pay £100k on a database that already exists?
- Previous work done by database Task and Finish Group for the Network carried out options appraisals on current databases at both LHCH and Alder Hey. It was felt that a new build was preferred for the future resilience and options to build upon.
- Current database at Alder Hey currently on AH risk register as needing to be updated.

Item 9 – Commissioner Update

New NHSE Commissioner, Helen Chadwick, could not attend the meeting today. GG presented Helen's slides, which will be circulated to Board members.

ACTION: JM to forward HC's slides.

GG confirmed the Network are due to meet with Helen shortly to bring her up to speed with Network business and will report back at the next board meeting.

Item 10 – PPV Representatives

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

- Great to have Linda back and looking forward to meeting new Network Manager, Nicola at our next PPV Group meeting.
- Information Day on 15th October went very well, thank you to everyone who gave up their Saturday to attend and especially to Linda for all her help with the organisation. The feedback has been very positive with requests for it to be an annual event.
- Transition – very much important issue to the PPV group and we understand the issues especially regarding resources, however, the group are keen to work with the Network to make this experience better for everyone.



Lowri Smith, Member, Patient Public Group (PPV)

- ACHD appointments – the group are concerned that some patients are turning up for appointments only to be turned away due to no Consultant available to run the clinic. Two examples raised where Liverpool and Manchester.

LG clarified one of the incidents raised was linked to a clinic at Manchester Royal Infirmary and was a hybrid clinic, a consultant was on a phased return and patients were attending for Echos and ECGs and the expecting a phone consultation a week later. LG understands that these clinics have now returned to face to face.

The second incident at Liverpool Heart & Chest hospital was something out of their control when, we understand how difficult it is for patients when a consultant is ill or is called away for an emergency.

LG also commented that as a PPV group we are trying to encourage patients that do experience a bad situation to go through the formal PALS path in order to understand the problem and learn going forward. As a group, it is learning how to encourage patients to feedback and go through the formal channels.

Going forward as a Network, we will be asking providers to report on complaints through PALS i.e. what have the complaints been about? How many have they had in relation to CHD, which will help us begin to address the issues.



Item 11 – Risk Register

**Rob Johnson, Consultant Paediatric Cardiologist, Alder Hey Children’s Hospital
NHS Foundation Trust**

CHD Network Risk Register Summary 17.10.2022

<p>(2332) Challenges to finding a solution to providing a "single service" model for paediatric cardiology 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). Signed-off at the Partnership Board Current Risk Score (20) → Target Risk Score (6)</p>
<p>(2383) Psychology provision not meeting minimal NHSE Standards Gap analysis against NHSE standards is required to formally identify gaps in provision. New Network Manager starting in post in September 2022 - therefore <u>time line</u> reflective of their workload and priorities and what can be achieved realistically. Current Risk Score (16) → Target Risk Score (4)</p>
<p>(2536) Significant further reduction in Network Staffing from August 2022 Recruitment process delayed as waiting for confirmation from commissioning that Network has guaranteed income of £200K for the next two years. To allow advertisement for 2 year posts. Current Risk Score (16) → 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) Governance Lead working on this, awaiting feedback as to progress. Risk review delayed slightly due to annual leave. Current Risk Score (12) → Target Risk Score (3)</p>
<p>(2331) Fetal Nurse provision is not equitable across the Network and not meeting NHSE Standards Lack of fetal nurse provision discussed at CHD Network Board on 15th July 2022. Agreed that gap analysis against the standards is important to do. Current Risk Score (12) → Target Risk Score (1)</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>(2280) No effective learning and sharing of outcomes from incidents is occurring at Network Level (F4) Action owner changed to Lead Nurse as PMO has left the Network Current Risk Score (6) → Target Risk Score (4)</p>
<p>(2282) Unable to monitor providers against the required NHS England Congenital Heart Disease Standards (2016) Project on hold pending appointment of replacement Network Manager. Current Risk Score (6) → Target Risk Score (4)</p>



<p>(2692) Patients may not get their ACHD echo as planned Patients being prioritised in clinic as to who needs to an echo and who can wait. Current Risk score (12) Target Risk Score (4)</p>
<p>(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. Discussed this action with Governance Lead for Network. Agreed that action should be closed. Current Risk Score (10) → Target Risk Score (4)</p>
<p>(2465) No access to dental treatment for patients with complex ACHD requiring GA Gap analysis to be undertaken against the NHSE standards for CHD (2016) benchmarking against minimum standards expected for dental care for patients. Audit process is written out and has been piloted. Once current staffing levels allow then audit should be completed Current Risk Score (9) → Target Risk Score (4)</p>
<p>(2336) Not all peripheral centres providing paediatric cardiology services have a Paediatrician with Expertise in Cardiology (PEC). Added the Isle of Man. Risk Score (9) → Target Score (6)</p>

LG commented that since the above Risk Register tables were issued a Risk Register meeting has been held and some of the above risks have now been downgraded and will not feature on the next register.

Item 12 – Ratification of Network Documents

Linda Griffiths, Lead Nurse, NW CHD Network

- **Document:** SOP for Interventional Cardiology for Alder Hey Children’s Hospital NHS FT – this document has now been ratified and seeking Board approval.
All agreed.

Item 13 – Any Other Business

None.

Date of Next Meetings

Monday 23rd January 2023 10.00am-12.00noon via MS Teams

Tuesday 25th April 2023 2.00pm-4.00pm via MS Teams

Monday 24th July 2023 10.00am-12.00noon via MS Teams

Tuesday 24th October 2.00pm-4.00pm via MS Teams

