

# NW CHD Board Meeting Summary Notes 23<sup>rd</sup> January 2023

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist



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## Item 1 – Welcome & Apologies

### Present:

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
Helen Chadwick (HC)	Service Specialist (Specialised Commissioning Team)	NHS England & NHS Improvement
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
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
Nayyar Naqvi OBE <b>(Chair)</b> (NN)	Emeritus Consultant Cardiologist	Wrightington, Wigan & Leigh NHS FT
Nicola Marpole	Network Manager	NW CHD Network
Paul Willgoss (PW)	PPV Representative	NW CHD Network
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children's Hospitals NHS FT
Richard Palmer	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
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) <b>(On maternity leave until April 2023)</b>	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
Bernard Clarke (BC)	Consultant Cardiologist	Manchester University NHS FT
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Helen Sanderson <b>(On maternity leave until September 2023)</b>	Network Manager	NW CHD Network
Kimberley Meringolo (KM)	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest 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 17<sup>th</sup> October 2022 were circulated prior to the meeting.

One amendment in Item No.5 Cardiac Maternity Update, sixth point, last sentence, 'LG mentioned the upcoming Transition Clinics and invited SV to come along to talk to the teenagers including Fontan patients.' – sentence to be removed.

**Action 33** – Network MOU – IoM and Wales brought to the board today for ratification. Once approved it will be sent out again to all relevant organisations for signing - **IN PROGRESS**.

**Action 36** – Network Operational Delivery Group – proposed this action should be closed as it is now to be incorporated within the current Governance Arrangement and will be discussed in Item No.8 on the agenda – **ACTION TO BE CLOSED**

**Action 37** – Cardiac Maternity Guidelines & Referral Pathways – Nicola Marpole to meet in the new year with Maternal Medicines Manager/LG/SV & Lead Midwife. Update to be discussed in Item No. 5 on the agenda – **IN PROGRESS**

## Item 3 – Network Update & Finances

### Network Update

- LG has now returned following retiring on 16<sup>th</sup> December and returning on 17<sup>th</sup> January.
- The Network are looking at potentially recruiting a job share for LG's role, possibly picking up on the education workstream and a Network Project Manager.

**Finance Update** – GG reported there are no major Network finance issues, and the team are looking at how to utilise the extra funds from Linda's salary before the end of the financial year.



## Item 4 – Regional Updates including Data

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

### Waiting Lists

- Some gaps in the data over the last couple of months due to the loss of our Data Manager. A new manager has successfully been recruited and will commence in post in February.
- Surgical waiting list is at its highest point for a number of years owing to a very difficult winter, with increased emergency neonatal surgical work displacing patients on the elective list.
- Continue to triage P2 cases.
- Intervention list - less pressure on intervention, as less of those children require an intensive care bed after their procedures. Wait list seems to be sitting fairly consistently between 40 and 50.

### New Patients

- Post Pandemic approximately 200-250 patients' referrals per month, at least 95% discharged after their first review in paediatrics.
- Looking into hosting further clinics to cover workload of new patients.

### Follow Up Appointments Backlog

- Starting to climb again possibly reflection on availability of waiting list clinics and the weekends clinics no longer being held. The red line indicates patients who are over 12 months their planned follow up appointment. Capacity in these clinics have increased in the last six months.
- Patients waiting more than 3 months and 6 months currently steady, however, those patients waiting more than 12 months has risen, these are the lower intensity screening patients.

### Transition

- Good numbers coming through, focusing mainly on the patients with moderate to severe CHD.
- Increased engagement with new consultants at LHCH.

### Overall DNA rate (%) & New Patients per month

- DNA rates remain good sitting between 6-8% with rises in school holidays.
- New patients' referral per month approx. 220 possibly a post Pandemic rise between September 2021 and January 2022. Working Informatics and AI colleagues to identify high risk DNA patients.



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

- There has been a rise in the waiting list and a backlog of both new and follow-up patients due to the introduction of the new electronic patient record system HIVE. Elective activity significantly cut back to allow staff to familiarise themselves with the new system. Now running back to full clinic capacity.
- Looking at further Saturday clinics to be run with Alder Hey. Work in progress for Alder Hey consultants to have access to HIVE.
- Sonographer support – one of our sonographers is employed by MUFT rather than RMCH and another sonographer is on maternity leave. We are working the Alder Hey team to fill the gap across the sites.

**Nicola Marpole on behalf of ACHD Manchester University NHS FT for Bernard Clarke, Consultant Cardiologist, Manchester University NHS FT**

**New Patients**

- Overall showing a downward trend, however more data is needed to track this accurately. NM and LG have met with the team at Manchester and going forward will receive data regularly.

**Follow Up Patients**

- Unable to comment due to lack of data, but as above steps have been taken to improve data flow going forward.

LG gave an update from a Manchester ACHD staffing perspective, which is much unchanged from the last board meeting.

- Welcomed new consultant, Julia Jones, attending both Manchester & Liverpool clinics.
- Currently a significant number of backlogs and the patient numbers waiting for over 12 months for a follow-up appointment are over 1000.
- Following the meeting with the team, plans are in place to increase the templates for each clinic, but this is difficult with the added challenge of the lack of sonographers.
- Staff offering weekend support.
- Bookings continue to improve under the secretarial teams rather than the booking team, with additional support from the nursing staff which isn't ideal, but these issues are being addressed.
- Current NHS strikes have not impacted too much on CHD clinics.



**Linda Griffiths, on behalf of Liverpool Heart & Chest NHS Foundation NHS for Damien Cullington, Consultant ACHD Congenital Cardiologist**

- No issues re waiting lists to report.
- Data fairly static for surgery and intervention.
- No staffing issues to report.
- Still concerns with the increasing number of DNA's and cancellations, which are also being discussed with the PPV group.

Blackpool update – backlogs continue to be monitored. There are plans to have an additional half day clinic at Blackpool once a month. LHCH can support this with additional ACHD consultant cover alongside physiologist and ACHD Nurse Specialist. This will hopefully go some way to managing the backlogs there.

**Clinical capacity and effects of DNA's and cancellations**

There are multiple reasons why appointments are not attended or cancelled. There are problems with appointment systems and admin at hospital level in addition to the problem of patients not turning up or cancel their appointment at short notice. This is poorly understood at the moment. Dr Cullington has approached the PPV Group for specific help with the late cancellations of appointment by patients and how to increase awareness of the impact of this problem. In addition to this a piece of work needs to be done to understand all of the root causes to enable solutions to be found.

## **Item 5 – Cardiac Maternity Update**

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

- Maternal Medicines Network, part of the National Initiative, have now appointed Catherine Chimel to the post of Maternal Medicines Midwife, with various leaders also now in place including Charlotte Bryant, Network Manager.
- Guideline and Referral Pathways ratified by this board have been forward to the Maternal Medicine team for consistency in the way patients are cared for across the two Networks.
- Date agreed for a meeting with Sarah, Bernard Clarke and the Maternal Medicines Network team to ensure links between the two networks are as strong as possible.
- Service Delivery – an Obstetrician at Liverpool has had to take a long-term period of sick leave. However, at Manchester an Obstetrician has recently returned from maternity leave, enabling workload to be managed across both sites.
- Good news story – a pregnant patient had a novel cardiac intervention during pregnancy, which meant she was able to avoid termination of the pregnancy. Huge MDT involvement in various aspects of her care, which went well, and the pregnancy is still on-going.





## Item 6 – Level 3 Centres Update

**Matthew Sandman, Consultant Paediatrician, Ysbyty Glan Clwyd Hospital:**

- Q: Is there any scope to collect formal data from Level 3 centres?  
GG responded, in the long-term the 'database' will collect the relevant data. Short term, the PECSIG meetings which are held regularly, are the ideal place to raise any important issues. LG commented that Levels 1 & 2 have been the priority for data collection, however, ways to collect Level 3 data will be discussed until the database is up and running.
- PECSIG meeting – Chairs – GG reported that Sameer Misra and Liz Shakely have offered to rotate chairing the meetings with Gordon and Caroline.
- Q: Are the Educational meetings still going ahead?  
GG responded that these meetings were on hold due to COVID, but plans are being discussed to hold in late autumn 2023.

## Item 7 – Paediatric Cardiology Partnership Group update

- Recently met with NM from the Network to focus on risks at Alder Hey, Manchester and the Network to break down the risks to address how we start to move the service forward and make changes. The next meeting will focus on scoring the risks and agree responsibility i.e., which risk register they should be recorded on.
- Self-Assessment to be facilitated by the Network on behalf of the Commissioners to assess RMCH against the national level 2 centre standards.
- The business case for a single paediatric cardiology service was unfortunately rejected by Commissioners. Following a meeting between Specialised Commissioners and Medical Directors from Alder Hey Children's NHS Foundation Trust and Royal Manchester Children's Hospital, the business case is undergoing review and amendment with the aim to submit a revised bid in the coming weeks.



## Item 8 – Current Governance Arrangements

NM referred to the Governance Structure paper circulated to Board members and summarised its purpose. It has become apparent there is a significant amount of duplication across the current Network board and the ACHD Partnership Board and the Network propose a review of the group with the aim to bring together a single board.

The ACHD Partnership Board have stepped down the frequency of their meetings to six monthly, with their Operational Group, CHOG, continuing to review bed numbers etc, this proposal will not impede on that group.

If the proposal is supported, it will bring together key members of each group to oversee strategic level decisions, delivery, and management of a complex service across the region.

Approval was asked for from the board to take the paper to the ACHD Partnership Board. Approval was granted.

## Item 9 – Single ACHD/PTL Update

NHS England have confirmed and accepted the Network's recommendation to proceed with an All Age database and not the Single PTL. Funding of £96K has been received from NHS England. This will be a one-off payment to help support the project. If additional funding is required this will need to be supported from the Network budget or sought by the Network from another source.

Initial discussions are underway with Ian Gilbertson, Associate Director of Digital Transformation and his team at Alder Hey regarding the work that has already been undertaken with this project.

The Network are to liaise further with the GM Cancer Network regarding their regional database they have developed and implemented. It is unclear if their system would meet the NW CHD Network needs.

A Network Project Manager and Data Analyst are to be recruited. Awaiting advert approval for the Project Manager position. Liaising with the Digital Team for the Data Analyst post to be potentially a job share role opportunity.

A dedicated group is required to lead this project, if anyone is interested in joining, please contact NM.



## Item 10 – Commissioner Update

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

- Currently working on priorities and planning for the next financial year.
- Continuing to monitor capacity and workforce issues at Manchester.
- Working with the Network to support the development of the All-Age Database.
- Working closely with the Contracts Team to work up the contracts for the next financial year, with the focus on elective recovery funding.
- ICS's are still at very different stages, discussions will be taking place with individual ICBs, providers and the Network to look at delegation of responsibilities for CHD from April 2024.

## Item 11 – Patient Public Voice Group (PPV)

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

Update since last board meeting:

- **November meeting:**  
Dr Joyce Lim, Consultant Fetal & Paediatric Cardiologist, Alder Hey, attended talking about antenatal detection. The PPV group still remain concerned that antenatal detection rates in the North West are below national average and that it will take 5-10 years to reach the gold standard of 70-80%. LG & NM have met with Dr Lim to discuss this. CHA have offered to help by funding training by Tiny Tickers. Should this topic be included in the risk register?
- **December meeting:**  
Anna Harrison, Rosie Fawcett, Helen Walker and Laura Jole, Lead CHD Nurses, attended. We discussed how charities can support patient care and how we can firm up relationships with charities and how we can make them more resilient.
- **January meeting:**  
Dr Raj Singh, CEO, Children's Heart Federation, who gave an update from the federation.  
Dr Jessica Green, PICU Consultant, presented 'Vocus Pocus' a study of vocal chord paralysis after CHD surgery.  
Nicola Marpole attended on behalf of the Network as Linda was on Retirement leave.
- **Transition Process:**  
We are very concerned about the Transition process. It is on our work plan to investigate what currently happens and what the PPV Group can do to help make the process more effective.



- **DNAs/Cancellations:**

The group have been approached by Dr Damien Cullington, Consultant Adult Congenital Cardiologist / ACHD Clinical Lead at Liverpool Heart & Chest Hospital NHS FT, to look at the following issues:-

- Last minute cancellations
- DNAs – looking at the Leeds initiative
- Different types of clinics/appointments e.g., similar to the Birmingham model – patients booked for ECG and ECHO prior to appointment followed up by a telephone appointment – not suitable for all patients
- Any other feedback which could help the service to improve or any concerns from patients which can be allayed

The above issues will be discussed at our February meeting and look forward to working with clinicians to improve in these areas.

- **PPV Information Leaflet:**

The group have devoted a lot of time to this piece of work, and it is nearing completion to be published.

- **Upcoming Issues:**

- How do we ensure that patients are aware of the PPV Group?
- Sponsored Walk for British Heart month which will take place from Alder Hey to Liverpool Heart & Chest Hospital on Saturday 25<sup>th</sup> February.
- Succession Planning/new members/DBS

- **Concerns from the Risk Register:**

- Lack of Fetal Nurse at Manchester
- Transfer transport

### **Paul Willgoss MBE (Patient Rep)**

PW suggested that it would be useful to put backlogs into context by looking at the number of surgeries and appointments. This would give a clearer picture of actual activity. PW suggested that a organogram would be useful.



# Item 12 – Risk Register

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

## **(2332) Challenges to finding a solution to providing a "single service" model for paediatric cardiology**

Network to support both providers to agree individual risks associated with this problem and to clearly identify who is responsible for each risk. Meeting planned on 17th Jan 23 to agree what the overall risks are. Network to undertake self assessments with Alder Hey and RMCH against the NHSE Standards to help identify the gaps and where they exist to help inform any future work around the single paediatric service. Email sent to ask for updates with regard to the issuing of honorary contracts for clinicians?

**Current Risk Score (20) →**

**Target Risk Score (6)**

## **(2383) Psychology provision not meeting minimal NHSE Standards**

Risk reviewed. Recent paediatric PREMS survey highlighted gaps in provision of emotional support for families and patients. Network to approach psychology to see if they can provide some basic support in a web-based format for availability on the Network website

**Current Risk Score (16) →**

**Target Risk Score (4)**

## **(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)**

Meeting planned on 24/01/23 to discuss integration of level 1 and 2 CHD providers using the Healthy Liverpool Platform to allow clinicians to view and download TTE + TOE images using ISCV (Phillips) systems across these hospitals.

**Current Risk Score (12) →**

**Target Risk Score (3)**

## **(2331) Fetal Nurse provision is not equitable across the Network and not meeting NHSE Standards**

Risk reviewed. No progress. Incident reviewed at Network clinical Governance Meeting highlighted importance on Fetal Nurse Specialists in ensuring that fetal medical plans are followed so that babies get appropriate care post birth. Paediatric PREMS survey also highlighting gap in availability of fetal nurse provision but that 100% of families who were supported felt they were invaluable. Network to feed this back again at Network CHD Board in January

**Current Risk Score (12) →**

**Target Risk Score (1)**

## **(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.**

Two incidents of HDU patients being inappropriately transferred with junior medical staff and NWAS service rather than NWTS discussed at recent Network clinical governance meeting. Clinical Lead to feed back the concerns raised about these cases to commissioning and NWTS. Network to benchmark NW against national picture to email of CCAN (congenital cardiac anaesthetic network) for information

**Current Risk Score (10) →**

**Target Risk Score (4)**

## **(2465) No access to dental treatment for patients with complex ACHD requiring GA**

No further updates provided. Still trying to agree what equipment is required to be available at LHCH in order for complex dental work to be undertaken there

**Current Risk Score (9) →**

**Target Risk Score (4)**

## **(2276) No Network database therefore unable to collect data and therefore fails to meet NHS England Congenital Heart Disease (CHD) standard F10 (L1)**

Digital Team happy to support project again working towards all age database. Their advice is that a single PTL is not achievable at this stage and that the all age database would provide a list of all patients and where they were cared for. Network manager to discuss with commissioners Network's view

**Current Risk score (12) →**

**Target Risk Score (4)**

## **(2692) Patients may not get their ACHD echo as planned**

No updates to report. Trainee should be in post - but will take before working independently. All mitigations remain in place whilst they train/upskill.

**Current Risk score (12)**

**Target Risk Score (4)**



## Item 13 – Ratification of Network Documents

Linda Griffiths, Lead Nurse, NW CHD Network

Documents for noting, ready to be signed off:

- ACHD Referral Pathway
- ACHD EP & Device Referral Pathway
- Network Memorandum of Understanding
- Media Consent Form
- Self-assessment against NHSE Standards SOP

## Item 14 – Any Other Business

None.

## Date of Next Meetings

*Tuesday 25<sup>th</sup> April 2023 2.00pm-4.00pm via MS Teams*

*Monday 24<sup>th</sup> July 2023 10.00am-12.00noon via MS Teams*

*Tuesday 24<sup>th</sup> October 2.00pm-4.00pm via MS Teams*

