

# NW CHD ODN Board Meeting Summary Notes 21<sup>st</sup> May 2024

**Chair: Nicola Marpole, Network Manager, NW CHD ODN**



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## Item 1 – Welcome, Introductions & Apologies

### Present:

Alfie Bass (AB)	Medical Director	Alder Hey Children's Hospitals NHS FT
Angelique Bray (ABr)	PPV Representative	NW CHD ODN
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist / Joint Clinical Director NW CHD ODN	Alder Hey Children's Hospitals NHS FT
Chloe Lee (CL)	Associate Chief Operating Officer	Alder Hey Children's Hospitals NHS FT
Elizabeth Shackley (ESh)	PECS Chair & Consultant Paediatrician	Stockport NHS FT
Helen Chadwick (HC)	Service Specialist (Specialised Commissioning Team)	NHS England & NHS Improvement
Janet Rathburn (JR)	PPV Representative	NW CHD ODN
Jill Moran (JM)	Network Support Officer	NW CHD ODN
Jonathan Mathews (JMa)	Chief Operating Officer	Liverpool Heart & Chest Hospitals NHS FT
Krasimir Atanasov (KA)	Consultant Paediatric Cardiologist and Clinical Lead	Manchester University NHS FT
Manoj Kuduvalli (MK)	Divisional Medical Director for Surgery/Consultant Cardiac & Aortic Surgeon	Liverpool Heart & Chest Hospital NHS FT
Mohammed Hussain (MH)	Interim Divisional Director Air Cardiac Services	Manchester University NHS FT
Linda Griffiths (LG)	Lead Nurse	NW CHD ODN
Louise Weaver-Lowe (LW-L) <i>(covering for Abby Prendergast whilst on mat leave)</i>	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS FT
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Richard Palmer (RP)	Senior Planning Manager - Adults	Welsh Health Specialised Services Committee
Sameer Misra (SM)	PECS Chair & Director of Medical Education Consultant Paediatrician and Lead for Cardiology	Bolton NHS FT



## Apologies:

Abby Prendergast (AP) <i>(currently on maternity leave)</i>	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
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead / Joint Clinical Director NW CHD ODN	Liverpool Heart & Chest Hospital NHS FT
Elliot Shuttleworth (ES)	Divisional Director for Cardiac Services	Manchester University NHS FT
Gary Price (GP)	Chief Operating Officer	Liverpool Women's Hospital NHS FT
John Brennan (JB)	Deputy Chief Medical Officer	Liverpool University Hospitals NHS FT
Kimberley Meringolo (KM) <i>(leaving post June 2024)</i>	Specialised Planner, Cardiac Services	CTM UHB - Welsh Health Specialised Services Committee
Lynn Greenhalgh (LGr)	Medical Director	Liverpool Women's Hospitals NHS FT
Sally Briggs (SB)	Medical Director	Manchester University NHS FT
Sarah Vause (SV) <i>(retiring June 2024)</i>	Consultant Obstetrician in Fetal and Maternal Medicine and Medical Director of Saint Mary's Hospital	Manchester Hospitals NHS Foundation Trust

**Declarations of Interest:** None

### Chair of the Board

NM explained that it is proving a challenge to find a new chair of the network board following Nayyar Naqvi's retirement. We have reached out to Alder Hey as our host to ask if any non-executive directors would be interested and we are working with other networks, which are in a similar position, to recruit chairs.

If anyone has any recommendations, please contact the network and in the interim NM has agreed to take on the chair role of the meetings.



## Item 2 – Network Update/Finance Workplan / Assurance Reporting / Maturity Matrix

### Assurance Reporting Pack

NM gave an overview of the Assurance Reporting pack which is submitted to NHS England twice a year. The reporting slide deck summarises the network priorities, risks and financial position. As a network we are in a strong position regarding meeting our objectives with one exception, which is the All-age database.

There has been some slippage on the timeline due to resource pressures, particularly digital teams however, progress is now being made with MFT looking at the infrastructure support to bring in data from both adult and paediatric services. Alder Hey and Liverpool Heart and Chest will follow in June/July. Initial data flow expected to be set up with level one and two providers by early autumn.

Unfortunately there was no strategic forecast for the ongoing funding of the database when NHS England first commissioned the network to set up this project, so currently the network is funding the running costs of the database to enable go-live and allow operation for the next twelve months. The network will continue to collect metrics to look at cost versus benefit and make a decision on further funding to develop the system and bring in level three centres. At that point, if it is agreed that the database is proving beneficial, the network will review the options for a new business case and possible innovation or digital grants.

The assurance pack also includes the network work plan which was agreed at February's board along with the network's annual report 2023-24. The new Impact report is a summary of three to four projects which the network feel has had a significant impact over the last year, they are; PREMS surveys, All-age database, reconfiguration of the network board and the Learning Disability Forum.

The assurance reporting pack is to be submitted to NHS England in June.

### Maturity Matrix

The Maturity Matrix for 2023-24 has been reviewed with input from our PPV group.

Learning and improvement score has decreased from four to three as the network feel there is still work to be done to reach a state where providers volunteer feedback and view the network as a point of contact. The network will continue to encourage members to send through their lessons learnt working towards a point of automatic engagement.

Sustainability and renewal remains at a score of two which reflects a deficiency in financial stability and leaves the network vulnerable i.e. staff absences, meeting objectives.

Following the rejected business case of 2023 requesting additional funding to support the core network team, the network is continuing to look at alternative avenues to supplement funding going forward and have planned 2024-25 workstreams accordingly.



## Annual Report

The network's annual report for 2023-24 was circulated with the board papers. NM asked if any board members have any comments or feedback to please notify the network within the next few days before the final copy is published on the website.

## Item 3 – Regional Updates including Data

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

### Waiting Lists – Surgery & Intervention

- Urgent neonatal surgical work has led to cancellations on the elective surgical programme which has had a great impact on our surgical waiting list with over 100 patients waiting.
- Similar impact on the intervention list because of the urgent neonatal work. Has improved over the last couple of weeks, in particular the elective work.
- Some issues with theatre slots, scrub and theatre staffing at Alder Hey, however, there is a plan in place to get back on track in terms of the elective surgical programme.
- The EP list is steady with 30 patients waiting for an electrophysiology appointment or EP study.

### New Patients

- Waiting lists remain high and work continues to increase availability of appointments.

CJ commented this last month has seen a start to the murmur clinic which will hopefully have a positive impact on backlog numbers.

### Follow Up Appointments

- Data now coming through more reliably following the EPR service upgrade.
- Taken approximately 600 patients off the overdue follow up.
- A business case to recruit additional consultants is being drawn up which will enable us to run further clinics, although capacity and facility issues remain a challenge.

### Surgical Wait Times / Intervention

- Difficult to analyse wait times in elective congenital heart surgery, many of the patients will be listed around four months for the operation to be planned at six months. So waiting times are variable.

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

- DNA rates slightly increased in March 24 as the new patients are waiting longer and our secretarial team have been calling all new patients prior to clinic to check they still plan to attend.
- No issues with transition service to report.



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

**New Patients**

- Slight rise in new patient numbers and team working really hard to bring back down to around 500.
- Follow-ups steady around 1000 with a slight increase in 12 months follow-up due to capacity issues with small cardiology team.
- There have been a number of urgent referrals that are being prioritised over the 12 month follow-ups.

**DNAs**

- DNAs still reducing. Proxy issues have been rectified which means families can log on and register with 'my MFT' and we are working on various workstreams across RMCH looking at ways patients will be able to move and select appointment times and dates that work for them using the app. In other areas where this is working DNA rates have dropped by 5%.

**Transition**

- No issues to report.

**New Referrals**

- Regular PEC clinics now in place in North Manchester and Oldham.
- Neonatal consultant led clinic to be launched in Oldham.
- An additional ECHO sonographer starting in post which will help increase the capacity of the ECHO clinics over the next few months.

**Krasi Atanasov said:**

- Re clinic at Oldham – offer to have joint clinic support – managers decided against business case.
- CJ agreed to discuss this at the next senior leadership team meeting and requested a letter from the Network.

**Damien Cullington, Consultant Adult Congenital Cardiologist / ACHD Clinical Lead / Joint Clinical Director NW CHD ODN, Liverpool Heart & Chest Hospital NHS FT**

**Jonathan Matthews provided the following update in Damien's absence:**

- Waiting list has grown towards the end of the financial year going into April. Our focus is on the long wait targets.
- Follow-up outpatients looking good in terms of reducing backlogs. Continuing to look at space and capacity on site.
- Apologies for the error on the ACHD referral slide, numbers have been doubled for January, February and March. Referrals are actually in line and there should not be a spike in the last end of the financial year.
- Similar picture at Blackpool, no concerns.



- Looking at capacity and demand for radiology and diagnostics department, have seen an increase ACHD scanning sites, putting an investment in for the next financial year for ACHD imaging.

## Item 4 – Cardiac Maternity Update

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

- Sarah Vause conveyed her apologies for the meeting. No issues to report.

## Item 5 – Level 3 Centres Update

**Sameer Misra, PEC Joint Chair and Director of Medical Education, Consultant Paediatrician and Lead for Cardiology**

- No issues to report.

## Item 6 – Database Update

Covered above under item 2.

## Item 7 – Commissioner Update

**Helen Chadwick, Service Specialist for Internal Medicine Programme of Care (Specialised Commissioning), NHS England – North West**

- As of April the services identified by NHS England have now been delegated to ICBs including congenital heart disease for adults and paediatric cardiology.
- Three specialised commissioning oversight groups, each one reports into the Integrated Care Board system, they are Greater Manchester, Lancashire, South Cumbria and Cheshire & Merseyside.
- NW Specialised Commission and Oversight Committee is the forum which brings together all three ICBs to make joint decisions.
- Finance - all funding has been distributed to ICBs, and contract negotiations are now complete.
- Currently overspending in GM and C&M so there will be some ‘levelling up’ work going on over the coming years to bring this in line with budgets.
- This will be achieved using population based formula, NM happy to share slides from the meeting for those interested.
- NM asked if there has been any development regarding the hosting fee? HC responded that she is aware of a letter that has been received to confirm a hosting fee should not be taken from the network and will let the network know.

**ACTION:** NW Specialised Commission and Oversight Committee is the forum which brings together all three ICBs to make joint decisions.

**ACTION:** Cheshire & Merseyside hosting their first cardiac meeting, HC to attend and see if this is a relevant forum for CHD representation.





## Item 8 – Welsh Commissioners Update

**Richard Palmer, Senior Planning Manager – Adults, CTM UHB - Welsh Health Specialised Services Committee**

- As of the 1<sup>st</sup> April Welsh Health Specialised Services Committee (WHSSC) was relaunched as NHS Wales Joint Collaborative Commissioning Unit incorporating the Emergency Ambulance Services Committee, ISC and the National Collaborative Commissioning Unit (NCCU). The organisation has responsibility for the commissioning of level one and two CHD services.
- No major changes anticipated to commissioning governance, however the organisation is fundamentally different and moving forward consideration will be addressed as to how we integrate and align with those services that we commission, this is work in progress.
- Prior to decommissioning of WHSCC, the last integrated commissioning plan was approved. This includes a number of commitments relating to cardiology provision. The future of the planning process within the JCC is yet to be confirmed and that includes the process for securing money for new investments such as that identified in our plan in previous years to support the development of CHD services in South Wales. A similar process is to be developed for North Wales, awaiting planning process and approval of additional monies.
- Risk and assurance meetings with Liverpool Heart & Chest Hospital reconvened following COVID and met on 12<sup>th</sup> April. Agreed significance assurance across a number of services it provides for the population of North Wales and a number of actions were agreed. This meeting will encompass the monitoring of those CHD Services commissioned by JCC for North Wales and gives us a really useful forum for discussion going forward.
- Kimberley Meringolo, Senior Planning Manager – Paediatrics, is leaving on 23<sup>rd</sup> May to take up a new role in NHS Wales. Kimberley's successor has been appointed but not due to commence post for at least three months. In the interim Richard will be covering any related matters.

## Item 9 – Patient Representatives

**Janet Rathburn, Chair, PPV Group and Angelique Bray, PPV Group Member**

JR gave the following PPV group update:

- March meeting we welcomed NW CHD ODN Clinical Directors, Caroline Jones and Damien Cullington to discuss backlogs and communication to parents.
- In April we welcomed Nathan Askew, Chief Nursing Officer and Fiona Ashcroft, CEO, both of Alder Hey. We discussed family support, in particular paediatrics. Nathan and Fiona gave the group a comprehensive update and ideas of ways we can work together.
- JR recently attend an Alder Hey charities meeting which also included some of the smaller charities. The group was informed that there was to be a new well-being hub in the hospital to centralise information for families and plans are underway to develop and implement this. This will be beneficial for parents to get the information required and great exposure for the smaller charities.
- At our May meeting we had a Network update from Nicola Marpole and also discussed sustainability of the group. There are number of projects planned



including drop-in sessions for patients to talk to PPV reps and find out what the role involves. It is hoped that this will encourage new membership.

- The group have contributed to the Network's Annual Report and Maturity Matrix.
- Developed a new job description for the role of PPV Chair along with updating the PPV Terms of Reference.
- Three members of the group attended the National PPV inaugural meeting in Leicester along with Nicola Marpole and Linda Griffiths from the network. Encouraging to see how far ahead our PPV group and network are compared to others across the country.
- We recently welcomed two new members to the group. Looking at sustainability of the group, we are working on reaching out to different group in the community and hoping to welcome CEO of the Children's Heart Federation to a future meeting.
- Due to unforeseen circumstances the group now has the opportunity to extend the terms of office for another year to those members that were due to step down in the summer. We are keen to maintain the four year term of office, it remains key to welcome new members whilst retaining the experience and knowledge of current members.
- Improved engagement with RMCH has led to invitations to their charities to attend our July meeting.

## Item 10 – Risk Register

### Linda Griffiths, Lead Nurse, NW CHD ODN

The senior leadership team (SLT) have recently reviewed the risk process for the network. Historically the Network risk register has included provider risks that the network have no control over.

The Network has discussed this issue with Alder Hey as our host and have reviewed what other Networks in our region are doing, including benchmarking against other CHD Networks nationally. The Network SLT have therefore agreed to remove all provider risks from Network risk register. In its place they have developed a "risk tracking system" that allows the Network to monitor provider risks that are scoring a 12 or above so that these risks can be accurately reported to the Board.

There are only two network risks:-

- Network funding – scoring 12
- Database – scoring 12

Going forward we will meet quarterly with operational and clinical leads to provide assurance that the risks we are tracking are an accurate reflection of provider risks.

### Alder Hey risks identified with a scores over 12:

- Lack of funding to support the development of a single paediatric cardiac service for the North West (shared risk with RMCH) (20)
- ICC service (15)
- Alder Hey backlogs (16)
- Psychology provision (12)



### **Royal Manchester Children's Hospital (RMCH)**

- Lack of funding to support the development of a single paediatric cardiac service for the North West (shared risk with AH).
- Backlogs (12)
- ICC (15)
- Psychology provision (12)
- Cardiac nurse specialist provision (12)
- Cardiac physiology (12)

A fetal cardiac nurse specialist has now been appointed at RMCH and this risk has been removed from the register.

### **Manchester Royal Infirmary (MRI)**

- Backlogs (12)

### **Liverpool Heart & Chest Hospital (LHCH)**

- Psychology (12)

The risk for ACHD dental care has now been removed - SLA is now in place between LHCH and the dental hospital. The risk for cardiac physiology at LHCH has been removed – staff now in place and sickness has improved.

## **Item 11 – Ratification of Network Documents**

### **Linda Griffiths, Lead Nurse, NW CHD Network**

“Clinical Urgency Update Form” has now been ratified and is ready to publish on our website. This form is used for paediatric cardiology, for patients who have been listed, on the waiting list for surgery or intervention and there is a concern that their clinical status may have changed, and they need to alert Alder Hey as level 1 provider.

## **Item 12 – Any Other Business**

JR asked whether the Board felt optimistic that the move to using a population based formula would improve funding in the North West

HC summarised that the approach goes beyond numerical data to consider various factors like deprivation, population health, educational status, and digital transformation. This comprehensive analysis has already identified overspends in two out of three regions, particularly in cardiac care and chemotherapy.

HC acknowledged that addressing these issues requires more than quick fixes. Instead, it necessitates systemic and integrated conversations. Emphasis was placed on collaboration with public health and integrated care professionals. A key initiative highlighted was the "shift left agenda," which focuses on early intervention in health pathways to improve outcomes and efficiency.



AB raised whether this was an appropriate approach for CHD, as this is a condition you are born with as opposed to something you can avoid through prevention or intervention.

HC agreed that shift left isn't a complete solution. There may be areas for efficiencies, but a broader system approach is necessary. Collaboration among clinicians and system leaders is crucial to determine effective strategies.

Financial allocations are given to trusts like Manchester Foundation Trust and Liverpool Heart and Chest, who then decide on spending priorities, such as CHD and cardiac surgery, within their overall budget.

The approach encourages system leaders to adapt to new structures, take control, and make necessary investments, while also addressing potential savings.

Immediate changes are not expected; rather, the next few years will involve forming groups to make and discuss these decisions.

## **Date of Next Meetings**

***Monday 12<sup>th</sup> August 2024 2.00pm-4.00pm via MS Teams***

