

# NW CHD Board Meeting Summary Notes 25<sup>th</sup> April 2023

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist



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## Item 1 – Welcome & Apologies

### Present:

Abby Prendergast (AP)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
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
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
Jill Moran (JM)	Network Support Officer	NW CHD Network
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Nayyar Naqvi OBE <b>(Chair)</b> (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
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:

Bernard Clarke (BC)	Consultant Cardiologist	Manchester University NHS FT
Debbie Rigby (DR)	PPV Representative	NW CHD Network
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
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
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
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest 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 23<sup>rd</sup> January 2023 were circulated prior to the meeting. No further amendments or further comments made.

### Matters Arising

**MOUs update** – all centres are now covered by the Contract sent out by NHS England. A copy of the Network Operational Policy will be shared with all centres, along with a copy of the Network MOU for level 3 centres, as it is not clear how widely the NHS England contract will be shared within those organisations.

**National Data Backlogs** – information shared with supporting papers. To be discussed further at item 4 on the agenda.

**New governance structure** – GG gave a brief update on the new board structure which is to be discussed at item 13 on the agenda.

### Action Tracker

**Action 48** – NW ACHD Referral Pathway - The new Maternal Medicines Midwife now in post. NM to meet with her once in post. **TO BE CLOSED AT TODAY'S BOARD.**

## Item 3 – Network Update & Finances

### Network Update

- Gail Maguire starts with the Network as Project Manager on 5<sup>th</sup> June and Michelle McLaren has recently been appointed new Lead Nurse focussing on education and working part-time jointly with Lead Nurse, Linda Griffiths.
- Mindwave have been contracted to deploy the database initially producing functionality for levels 1 and 2 by the autumn with 3 to follow.
- Self-Assessments (National Standards) – Royal Manchester Children's Hospital's assessment review will take place on 3<sup>rd</sup> May. Alder Hey Children's Hospital review will follow.
- Maturity Matrix Review – the Network has currently completed this for 2023. This review assesses against benchmarks to agree a plan for developing the Network for the next year.

**ACTION: Review to be shared with PPV Group and the Board.**

**Finance Update** – GG reported there are no major Network finance issues. The current underspend is being allocated towards the Project Manager's salary, Sonographers Fetal training, Network Study Days and Learning Disability Forum support.



## Item 4 – Regional Updates including Data

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

### Waiting Lists

- Paediatrics surgical waiting list continually grown since May 2022.
- The recent nurses and junior doctors' strikes have impacted on throughput of surgery in last six to eight weeks.
- There has been a rise in surgical waiting lists, however when benchmarked against other Level 1 providers across the country this is manageable.
- Intervention waiting list stable between 35 and 55.
- A new Intervention Consultant joining the team in July 2023.
- Slight rise in EP waiting list with some impact from the strikes and bank holidays.

### New Patients

- Waiting times show some unreliability in the data and some issues around seeing new patients.
- Additional PECSIG clinics required.

### Follow Up Appointments Backlog

- Steadily decreasing after a rise between October and February.

### Transition

- Transition service is steady.

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

- DNA rates consistent around 6%.
- New patients' referrals remain per month approx. 200-220 per month.

**Caroline Jones on behalf of Rachael Barber, Consultant Paediatric  
Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead, Manchester  
University NHS FT**

### New Patients

- No further 'extra' clinics since COVID-19 funding for Waiting Initiative clinics was withdrawn.
- New patient referrals to paediatric cardiology, only around 1% have a significant pathology that requires follow-up.
- Waiting list for new patients continues to be significantly high.

### Follow Up Appointments Backlog

- Significant escalation to basic baseline clinic activity due to COVID-19 funding ending.



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

- Consistently significantly higher due to lack of resources for administration and cardiac nurse specialists.
- Referrals similar to Alder Hey between 200-220 per month.

### **Damien Cullington on behalf of ACHD Manchester University NHS FT for Bernard Clarke, Consultant Cardiologist, Manchester University NHS FT**

#### **New Patients**

- Progression made reducing the number of new patients.
- Still a significant number of new patients referred waiting more than twelve months.
- Currently 1800 patients overdue for an appointment, with between 700 & 800 clinic slots per year there is no chance of clearing the backlog with current resources. There is a need to look at more innovative solutions.

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

#### **Waiting Lists**

- Waiting lists remain steady.
- Drop in surgical waiting list numbers with two surgeries per week.

#### **Follow Up Patients**

- Data is respectable compared with other centres across the country.
- Currently 30 patients more than twelve months overdue follow up appointment.
- Currently have two locum consultants in post. Recruiting two substantive posts, a Cardiac Imaging post for CT and MRI and the other a generic ACHD post with interest in transition.
- New Physiologist now in post.
- Working on securing new clinic space in Willow.

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

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

- Some members of this board recently met with the NW Maternal Medicines Board. The meeting discussed sharing of guidelines, referral and escalation pathways, building communications and consistency across ACHD and Obstetric services.



## 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

- The second iteration of the business case requires specific information regarding the immediate need, particularly Manchester but also across services in general.
- The group have set a deadline of the 19<sup>th</sup> May for the completion of the second draft. Following agreement of the group this will be resubmitted to NHS England for review.

## Item 8 – Database Update

All database updates covered in GG's Network update above.

NM asked if any members of the board have been invited to join the core database meetings, that priority is given to attendance as your support is key to making decisions and the delivery of the service database.

## Item 9 – Commissioner Update

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

- Continuing to work on priorities and planning for the next financial year.
- MOU's taking precedence in terms of getting these embedded into provider contracts.
- Regional commissioners are in discussion with the transformation leads for each ICB as they start to work together in preparation for the delegation of some of the services from specialised commissioning.
- Further updates will be shared regarding timelines and priorities as they become available.





# Item 10 – Patient Public Voice Group (PPV)

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

Update since last board meeting:

- **Role of charities supporting cardiac services:**  
On reviewing the work that Team 1C and CHA (Children's Heart Association) do with the hospitals, an application form has been developed to be used by both charities when approached by the hospitals for funding. Looking specifically at paediatrics with adults to follow.
- **Hospital Volunteers:**  
The PPV group are keen to arrange more volunteers into the hospitals. Some members of the group recently met with Anne Doyle, Volunteer Manager at Alder Hey to ascertain the processes involved. Still awaiting response from RMCH.
- **Charities – sharing information:**  
The PPV group are looking at ways to share information about different charities and how to advertise them in the hospitals. Every charity has different aspects and methods of supporting families and the PPV group want to ensure that information is out there for everybody. Although the charities provide a lot of support already, the group also liaised with specialist nurses who provided a comprehensive list of further ideas.
- **Information Boards:**  
The PPV group would like to see these boards on display again in clinics in order for families to be aware of the help and support available.
- **Sanitary Products:**  
A PPV group member has put out an appeal for sanitary products to be made available for hospital patients when required. The group are looking into how this can be supported through charity funding.
- **PPV Members:**  
Working on ways to promote the PPV group so that patients know that it exists.
- **PPV Group Succession Planning:**  
The PPV group have recently welcomed two new members and some members' membership is soon to expire. The group are meeting to review and reflect on the current membership and structure to ensure that it is fit for purpose.
- **DNAs & Last Minute Cancellations:**  
Following on from Damien Cullington's request to look at support for DNAs and last minute cancellations, the group are working on creating a video similar to the one produced by Leeds.
- **Patient Information Day:**  
A smaller focus group are organising another Patient Information Day.



- **Charity Walk:**  
The charity walk took place in 'Heart Month' between Alder Hey & Liverpool Heart and Chest hospitals. Thank you to all the clinical staff that supported it, the event was a great success with some amazing costumes, however, we are looking at ways to improve support from Alder Hey.
- **Transition:**  
LG gave a useful presentation to the group on transition. This topic is high on the group's agenda and keen to monitor its progress.

## Item 11 – Risk Register

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

<p><b>(2332) Challenges to finding a solution to providing a "single service" model for paediatric cardiology</b> 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 <a href="#">self assessments</a> 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 <a href="#">with regard to</a> the issuing of honorary contracts for clinicians? <b>Current Risk Score (20) →</b> <b>Target Risk Score (6)</b></p>
<p><b>(2383) Psychology provision not meeting minimal NHSE Standards</b> 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 <b>Current Risk Score (16) →</b> <b>Target Risk Score (4)</b></p>
<p><b>(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)</b> 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. <b>Current Risk Score (12) →</b> <b>Target Risk Score (3)</b></p>
<p><b>(2331) Fetal Nurse provision is not equitable across the Network and not meeting NHSE Standards</b> 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 <b>Current Risk Score (12) →</b> <b>Target Risk Score (1)</b></p>
<p><b>(2339) Back logs in Blackpool could result in risk of delayed treatment resulting in potential harm to patients</b> Network has approached commissioner for clarification of what the process is <a href="#">with regard to</a> commissioning level 3 centres. Is this something that commissioners need to take a lead on or is the level 1 provider able to independently seek other alternatives and providers. Currently waiting on a reply from commissioners. <b>Current Risk score (12) →</b> <b>Target Risk Score (4)</b></p>
<p><b>(2667) Back logs in Manchester Heart Centre (MFT) could cause delays to treatment resulting in potential harm to patients</b> No further updates. MFT have committed to providing the Network with regular data regarding updates. Network to continue to monitor. <a href="#">Self assessments</a> against the standards will take place later this year <b>Current Risk Score (12) →</b> <b>Target Risk Score (2)</b></p>



<p><b>(2276) No Network database therefore unable to collect data and therefore fails to meet NHS England Congenital Heart Disease (CHD) standard F10 (L1)</b></p> <p>Digital Team happy to support project again working towards all age <u>database</u>. Their advice is that a single PTL is not achievable at this stage and that <u>the all</u> age database would provide a list of all patients and where they were cared for. Network manager to discuss with commissioners Network's view</p> <p><b>Current Risk score (12) →</b> <b>Target Risk Score (4)</b></p>
<p><b>(2692) Patients may not get their ACHD echo as planned</b></p> <p>No updates to report. Trainee should be in post - but will take before working independently. All mitigations remain in place whilst they train/upskill.</p> <p><b>Current Risk score (12)</b> <b>Target Risk Score (4)</b></p>
<p><b>(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.</b></p> <p>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</p> <p><b>Current Risk Score (10) →</b> <b>Target Risk Score (4)</b></p>
<p><b>(2465) No access to dental treatment for patients with complex ACHD requiring GA</b></p> <p>No further updates provided. Still trying to agree what equipment is required to be available at LHCH <u>in order for</u> complex dental work to be undertaken there</p> <p><b>Current Risk Score (9) →</b> <b>Target Risk Score (4)</b></p>

## Item 12 – Ratification of Network Documents

Linda Griffiths, Lead Nurse, NW CHD Network

Documents for noting, ready to be signed off:

- Referral Proforma for Urgent Advice (Paediatric Cardiology)
- Website – Moving on to Adult Services

## Item 13 – Governance Arrangements

Following the presentation of the paper at the last board meeting it is now agreed that the membership of the board is to change. The paper is being presented at the ACHD Partnership Board for final approval and ratification on Friday 28<sup>th</sup> April.

On behalf of the Network, NM thanked all current board members for their support and attendance. A formal communication will be sent out after the ACHD Partnership meeting, with invitations to new board members to following in the next few weeks.



## Item 14 – Any Other Business

### **NN enquired about links and communications with the Isle of Man and North Wales:**

- NM responded that the Network has not had a great deal of involvement with the Isle of Man, however, we have been working with Wales regarding their action plans on the self-assessment. Invites to the Isle of Man colleagues will be sent out as part of the new board structure.
- DC commented many patients attend Liverpool Heart & Chest Hospital. The ideal scenario would be for patients to attend as 'day case' with all tests/procedures arranged in one day.

### **Coronation Volunteer Champions:**

- LG submitted a nomination for JR to attend the Coronation Concert as a volunteer champion and she has successfully been chosen to attend. Congratulations Janet.

### **PREMS Survey:**

- Paediatric and Adult patient experience questionnaire is now live.
- Launch event planned for 15<sup>th</sup> May.

### **Clinical Governance Meeting:**

- Next meeting arranged for 13<sup>th</sup> July.

## Date of Next Meetings

**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**

