

NW CHD ODN Board Meeting Summary Notes 12th August 2024

Chair: Carolyn Cowperthwaite, Chair, NW CHD ODN Board



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Item 1 – Welcome, Introductions & Apologies

Present:

Andrea Myerscough (AM)	Director of Operations	Manchester University NHS FT
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist / Joint Clinical Director NW CHD ODN	Alder Hey Children's Hospital NHS FT
Cordelia Lieb-Corkish (CL-C) <i>(Guest)</i>	Manager – Surgery	Alder Hey Children's Hospital 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
John Brennan (JB)	Deputy Chief Medical Officer	Liverpool University Hospitals NHS FT
Linda Griffiths (LG)	Lead Nurse	NW CHD ODN
Manoj Kuduvalli (MK)	Divisional Medical Director for Surgery/Consultant Cardiac & Aortic Surgeon	Liverpool Heart & Chest Hospital NHS FT
Marion Eaves (ME) <i>(Guest)</i>	Lead Commissioner CHD Services	National Specialised Commissioning NHS England
Michelle McLaren (MMc)	Lead Nurse	NW CHD ODN
Nicola Marpole (NM)	Network Manager	NW CHD ODN
Mark Kelly (MK)	Director of Operations	Manchester University NHS FT, RMCH
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
Sarah Hardy-Pickering <i>(Guest)</i>	Senior Clinical Network Programme Manager - Cardiac	North West Coast Clinical Network, NHS England – North West



Apologies:

Abby Prendergast (AP) <i>(currently on maternity leave)</i>	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Alfie Bass (AB)	Medical Director	Alder Hey Children's Hospital NHS FT
Beth Weston (BW)	Chief Operating Officer	Liverpool University Hospitals NHS FT
Chloe Lee (CL)	Associate Chief Operating Officer	Alder Hey Children's Hospital 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
Elizabeth Shackley (ESh)	PECS Chair & Consultant Paediatrician	Stockport NHS FT
Gary Price (GP)	Chief Operating Officer	Liverpool Women's Hospital NHS FT
Jonathan Mathews (JMa)	Chief Operating Officer	Liverpool Heart & Chest Hospitals NHS FT
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
Lynn Greenhalgh (LGr)	Medical Director	Liverpool Women's Hospitals NHS FT
Sally Briggs (SB)	Medical Director	Manchester University NHS FT

Declarations of Interest: None

Welcome & Introductions

Carolyn Cowperthwaite, newly appointed Chair, opened the meeting by stressing her commitment to confidentiality, collaborative decision-making, and maintaining open and constructive dialogue.

Carolyn emphasised the importance of focusing on patient outcomes, addressing service delivery challenges such as backlogs, and creating a safe space for discussions. Carolyn reiterated her dedication to the role and her background in NHS management and executive coaching.



Item 2 – Patient Story

Janet Rathburn, Chair, PPV Group

Janet Rathburn presented the first patient story of the meeting, focusing on her daughter Sarah's lifelong experience with congenital heart disease (Tetralogy of Fallot). Key points included:

- Sarah's extensive medical history involving multiple hospitals and surgeries.
- The tragic loss of her son, who also had heart conditions, and her subsequent high-risk pregnancies.
- Recent complications involving high heart rates during her pregnancy with her second son, leading to emergency interventions including cardioversion and delivery via C-section.
- Positive experiences were highlighted, such as effective communication between hospitals and the value of patient portals such as MyMFT.
- Recommendations included improving consultation protocols for district hospital cardiac staff and increasing GP awareness about referral pathways for complex cardiac patients.

The presentation was appreciated for its emotional impact and insights, serving as a poignant reminder of the real-world implications of healthcare decisions.

ACTION: NM & LG to follow up on recommendations

Item 3 – Network Update/Finance/NHS England Assurance report feedback/Recruitment

Nicola Marpole, Network Manager, NW CHD ODN

Recruitment Update

- Michelle McLaren has successfully been appointed as a permanent lead nurse for two days a week, while continuing her role at Alder Hey for three days.
- Elizabeth Devonport has now been employed on a permanent basis as the network Data Analyst.

NHS England – Assurance Report Feedback – June 2024

- **Role & Governance** – green/amber – at the time of submission the Network were still to appoint a new board chair, going forward this will turn green now Carolyn Cowperthwaite has taken on the role.
- **Objectives/Priorities 2023-24** – amber – the feedback reflected the database would be given a one year trial period with a six month review in January 25 to monitor our progress. The objective around PREMs was also noted and the extent of the work that the PPV group, learning disability forum and the newly formed patient experience forum has been fed back since submitting the report and should be green going forward.
- **Key highlights & success** – green – successful completion of the RMCH self-assessment and the integration of those findings into the paediatric cardiology business case has been acknowledge.



- **Achievements against objectives/priority** – amber – this highlighted the need to closely monitor and provide feedback on the progress of the database and recruitment of the board chair, which is now resolved.
- **Finance** – red – costs were out of balance, and this was due to the redundancy payment that we made to the outgoing network manager. This has now been clarified and again should turn green next time.
- **Staff model and updates** – green – no action required.
- **Health equalities, prevention & population health review & feedback** – amber – the work plan did not explicitly reference our contributions to reducing health inequalities. All of the information about the work, events and the support that we are giving through these groups was detailed in the new impact report that was introduced for the June submission. Feedback provided suggested that we add a strapline to our work plan and any future submissions.

As part of our on-going initiatives to provide and celebrate achievements across the network, our summer newsletter has just been released, highlighting some of the fantastic projects and work that the network and wider team has been doing in the first half of the year.

Network Funding

- The network will once again offer funding to support staff to attend education and development events in the coming year.

Item 4 – Network Education & Study Days

Michelle McLaren, Lead Nurse, NW CHD ODN

- The network allocated underspend from the previous financial year to fund educational opportunities, primarily for nurses and allied health professionals. This initiative aimed to bridge gaps for cardiac staff who didn't have access to dedicated budgets.
- Funding supported attendance at various conferences and courses, including the BCCA conference in Dublin, the APEC conference in Porto, and specialised courses like fetal cardiovascular examination and transesophageal echo.
- Due to the success, similar funding opportunities are being continued with a reduced budget for the current financial year.

Network study days 2024

- Paediatric CHD nurse study day – 25th April - focused on 'single ventricle heart defects'. Hosted approximately 80 delegates.
- Inherited Cardiac Conditions (ICC) regional study day – 13th June – for PECS, paediatric consultants, trainees and paediatric nurses in the Northwest. Hosted approximately 80 delegates.
- Transposition of the great arteries (TGA) study day – 27th September at The Reader Mansion, Calderstones Park. All disciplines welcome.
- Future events – the above events have been free however to continue to support such events going forward the network may need to consider charging an attendee fee.



Item 5 – Regional Updates including Data

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

Waiting Lists – Surgery & Intervention

- Significant increase in the surgical waiting list, reaching the highest numbers in recent years.
- Primary causes were identified as reduced theatre capacity due to staffing shortages and unforeseen challenges due to strike actions.
- Alder Hey have recruited a fourth substantive consultant, Dr Tomasso Generali.
- Interventional waiting list has reduced slightly from a paediatric point of view. Dr. Arvind Balaji, an interventional cardiologist with experience from Evelina and St. Thomas's in London, will join in October, enhancing the interventional service.
- Full theatre schedule expected to be back up and running in the next couple of months.
- Patient flow between 45 and 50, which in contrast to the national picture, AH's waiting list is fairly favourable with some other centres at 180 on their waiting list.
- EP service run by Dr Bose, fairly consistent between 20 and 30.

Back logs

- New patients - slow and steady with a long waiting list for a new referral. Now a weekly advanced nurse practitioner clinic being run to see new patients with heart murmurs but recognising the need to build new capacity to deal with the backlog.
- Follow-up patients - Approximately 1500 outpatients overdue their planned follow-up. There is a large backlog of patients with inherited cardiac conditions. Dr Bose sees many of the patients with rhythm problems and Dr Bernie Kadakian has recently been recruited following completion of a fellowship at Great Ormond Street Hospital. Dr Bose will be working at both Alder Hey and at the Royal Manchester Children's Hospital.

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.
- Slight dip in May and June for the number of hospital initiated cancellations for surgery.
- Rise of urgent Neonatal patients in the spring, mainly due to urgent patients being admitted who require surgery.
- Intervention not much affected except by the bed pressures of that neonatal surge in the spring.

Overall DNA rate (%) & New Patients per month

- DNA rates are between 6% & 9%. The majority of DNAs are new patients, with follow-up patients between 1% & 2%.
- Transition service continues to be steady between Alder Hey and LHCH recognising still that we've got some inequity in terms of transition that's provided for our patients who are seen at Level 3 centres around the region.
- New patient referrals are between 200 and 250 per month.



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

New Patients

- Slight rise in new patient numbers, however, this has reduced over the last six months to around 400, which is a reflection of the hard work of the team in Manchester and the increased sonographer support now in place.
- Follow-ups continue to be around 1000 which reflects the number of patients coming to Manchester compared to the resource available.
- New patient referrals continue to be steady, although hoping that this was going to reduce with the new PECs on-board for both North Manchester and Oldham. Need to review the number of referrals.

Transition

- Transition figures are steady
- RB highlighted that RMCH and AHCH seem to be reporting different things for transition.

ACTION: Network to review monthly data returns with a view to align reporting structure across providers

DNA rates

- DNA rates were reported to be stable, with positive impacts noted from the use of patient communication tools like my MFT.

New piece of work pending support from GM to look at paediatric cardiology outpatient services across GM and improving pathways for families. A proposal has been submitted focusing on the elective recovery programme which will hopefully allow for the collection of robust data around what patients are being seen in our clinics across Greater Manchester.

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

Caroline Jones provided the following update in Damien's absence:

- The ACHD Surgical waiting list has remained relatively stable; however, an increase in the interventional waiting list has been noted, primarily due to reduced team capacity. A new member of the team is due to start in October and a fourth congenital interventionist is to be recruited in 2025, which will increase the capacity.
- A new cath lab has opened, with dedicated sessions for ACHD interventions.
- EP – no issues to report.
- Post COVID recovery efforts have been successful in reducing the backlog of follow-up appointments.



Item 6 – Paediatric Cardiology Single Service

Caroline Jones, Clinical Lead & Consultant Fetal & Paediatric Cardiologist Paediatrics - Alder Hey Children's Hospital & Rachael Barber, Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead, Manchester University NHS FT

- Continue to work collaboratively to integrate paediatric cardiology services across the region.
- Response from commissioners highlighted the need for robust data and we will now meet to discuss the requested information and review the progress of the case.
- A primary challenge is the lack of data especially from Level 3 centres. This creates significant gaps in understanding the full scope of paediatric cardiology needs across the region.
- HC acknowledged the difficulties with providing data and advised the team to set a realistic timeline to provide what they can and to be transparent around what isn't available and therefore can't be provided.
- AM reiterated the on-going difficulties around providing data, and to be mindful that patient safety should remain at the forefront of any discussions.

ACTION: Network to feedback following progress meeting

Item 7 – Level 3 Centres Update

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

- No issues to report - backlogs and patient wait times have already been discussed.
- Excellent news regarding the recruitment of two new PECS for Oldham and North Manchester.

CJ comments:

- The current data focus is heavily on level 1 and level 2 centres.
- There are 3,500 patients in the region who are overdue for follow-up at level 1 and 2 centres.
- These numbers exclude the patients seen in 28 peripheral clinics across the region, the number could be more like 5,000 or more.
- The lack of data from level 3 centres, limits understanding of the full patient need.
- CJ suggests discussing this issue at the next network senior leadership team meeting and proposes starting data collection at level 3 centres to help address the gap.

ACTION: Network to include the discussion around level 3 centres as part of the monthly returns review



Item 8 – Database Update

Nicola Marpole, Network Manager, NW CHD ODN

- A demonstration of the user portal has been completed, with the final design and user testing expected to be ready soon. The database aims to provide a comprehensive overview of CHD patients across the Northwest, enhancing equitable care delivery.
- Concerns were raised by NHS England regarding the database's alignment with initial expectations, particularly its role in acting as a single Patient Treatment List (PTL). NM clarified that this was never the intended scope of the initial database phase and highlighted the need for a structured governance framework to support a single PTL if pursued in the future.
- Whilst the database will not provide a single PTL solution, it will still offer some of the same benefits i.e. a comprehensive overview of all our CHD patients and where they are treated across the Northwest.
- The database will run for a trial year, with a six-month review to assess usage and benefits.
- Key stakeholders stressed the importance of giving the system time to demonstrate its value

Item 9 – Commissioner Update

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

- Specialised commissioning, including CHD services, has been delegated to ICBs as of April 2024, with decision-making now aligned with local health systems. This aims to foster a more integrated approach to service planning and delivery, taking into account the entire patient pathway rather than siloed services.
- Helen outlined the structure of Specialised Commissioning Oversight Groups (SCOGs), which will guide CHD service developments, including data collection and resource allocation.
- ICBs are keen to engage and understand the CHD service objectives, prioritising the paediatric single service and the database.
- HC will attend all three SCOG meetings scheduled in August and September discussing major topics including CHD, pressures in cardiology and theatres etc.
- The board discussed the importance of clear communication with ICBs to ensure the ongoing prioritisation of CHD services and the need for realistic, evidence-based planning given current resource constraints.



Item 10 – National Update

Marion Eaves, Lead Commissioner, CHD Services, NHS England

Key National Priorities

- NHS England is working to implement national standards across all CHD service levels to ensure consistent care. While progress has been made, some centres, especially Level 3, face challenges in meeting these standards due to resource constraints.
- There is a national shortage of specialised CHD staff, including cardiologists and nurses, which is affecting service delivery. To address this, NHS England is developing a workforce strategy that includes expanding training programs, improving job retention, and considering international recruitment.
- A key focus is on improving digital systems, to better manage patient data and enhance care coordination across centres. Efforts are ongoing to standardise data collection and improve data quality.
- NHS England is strengthening its quality assurance processes, including regular service reviews and performance monitoring, to ensure high standards of care. Self-assessments and patient feedback are central to identifying best practices and areas for improvement.
- With the shift of specialised commissioning to Integrated Care Boards (ICBs), there is a push for more localised decision-making in CHD services. Despite funding challenges, NHS England is exploring new models like value-based commissioning to support innovative and high-quality care.

Future Directions

- Strengthening collaboration between regional networks.
- Expanding digital tools and technologies in CHD care.
- Promoting research and new treatments to improve patient outcomes.
- Supporting the integration of CHD services to reduce variations in care.

The board supported the national initiatives and emphasised the importance of aligning local efforts with these broader goals. They also discussed the role of ICBs in ensuring consistent service quality across regions.

Item 11 – Welsh Commissioners Update

Apologies received from Richard Palmer, Senior Planning Manager – Adults, CTM UHB - Welsh Health Specialised Services Committee – NM gave an update on his behalf.

- Following the establishment of the NHS Wales Joint Commissioning Committee (JCC) on the 1st April, the English standards are now confirmed as endorsed.
- It is not yet clear what service agreements are in place between the Welsh Health Specialised Services Committee (WHSSC) and English providers to outline how these services will be delivered and funded in alignment with the national standards.



Outstanding action: 'Current pathway for paediatric and adult CHD patients in Aberystwyth is not clear.' RP is chasing a response.

Item 12 – Patient Representatives

Janet Rathburn, Chair, PPV Group

JR gave the following PPV group update:

- Feedback from patient questionnaires included;
 - the value of the specialist nurses
 - the value of everyone having access to the live questionnaire
 - importance of communication
 - importance of engaging with groups especially the 16-20 age group
- July PPV meeting focused on:
 - sustainability of the group and how to promote it. We welcomed Raj Singh, Chief Executive of the Children's Heart Federation, to discuss national processes to support recruitment and sustainability.
 - suggestions for linking into World Heart Day on 29th September.
 - working closely with other network to ensure all groups have access to quality resources, systems and support
 - our promotional video
- The first PPV 'Drop-in Session' via Zoom took place on 11th July. It was very useful despite the low number of attendees and hope this will increase at future events.
- A 'face to face' PPV meeting is arrange for Saturday 5th October at the Village Hotel, Liverpool.

Item 13 – Risk Register

Linda Griffiths, Lead Nurse, NW CHD ODN

- All network risks are now logged on a risk tracker and regular meetings are scheduled with operational leads and nurse managers at the level 1 and 2 centres.
 - From November the network will be asking providers to report any risks scoring 12 or above to the board.
 - The network currently has two risks; finance/sustainability and the all-age database, both scoring 12.
 - Other areas of concern include;
 - the ability to provide a fetal cardiac assessment within three working days of a referral
 - how the organisation of the termination of pregnancy happens in a female with complex ACHD?
- These issues are being discussed at the NW CHD ODN SLT meeting,
- Paediatric cardiology single service, shared between RMCH and Alder Hey (20)



Item 14 – Ratification of Network Documents

Linda Griffiths, Lead Nurse, NW CHD Network

Chair, Carolyn Cowperthwaite asked if any members of the board have any comments regarding the documents for ratification which were emailed with the board papers, to please email Linda Griffiths.

Item 15 – Any Other Business

Chair, Carolyn Cowperthwaite concluded the meeting by thanking all members for their contributions and highlighting the importance of collaboration, data transparency, and patient-focused service improvement efforts.

Date of Next Meetings

Monday 11th November 2024 10.00am-12.00noon via MS Teams

