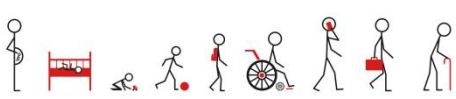
NW CHD ODN Board Meeting Minutes
9th February 2026

Chair: Carolyn Cowperthwaite



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Item 1 – Welcome, Introductions & Apologies

Present:

Abby Prendergast (AP)	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
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist / Joint Clinical Director NW CHD ODN	Alder Hey Children's Hospital NHS FT
Carolyn Cowperthwaite (CC)	Chair – NW CHD Board	NW CHD Network
Catherine Winchcombe (CW)	General Manager, Division of Medicine	Royal Manchester Children's Hospital NHS FT
Chloe Lee (CL)	Associate Chief Operating Officer	Alder Hey Children's Hospital NHS FT
Cordelia Lieb-Corkish (CL-C)	Operational Manager	Alder Hey Children's Hospital
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead / Joint Clinical Director NW CHD ODN	Liverpool Heart & Chest Hospital NHS FT
Dan Grimes (DG)	Director of Operations	Liverpool Heart & Chest Hospital NHS FT
Harriet Riggs (HR)	Co-Chair PECs Group & Consultant Paediatric Consultant	Northern Care Alliance - Oldham
Helen Chadwick (HC)	Service Specialist (Specialised Commissioning Team	NHS England & NHS Improvement
Janet Lamb (JL)	PPV Representative	NW CHD Network
Janet Rathburn (JR)	PPV Representative	NW CHD Network
Jill Moran (JM)	Network Support Officer	NW CHD Network
Josh Bainbridge (JBa)	Divisional Director, Division of Medicine	Manchester University NHS FT - Royal Manchester Children's Hospital
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Michelle McLaren (MMc)	Lead Nurse	NW CHD Network
Nicola Marpole (NM)	Network Manager	NW CHD Network
Nicky Povey (NP)	Business Manager - Medicine	Liverpool Heart & Chest Hospitals NHS FT
Paulo Santos Eden (PSE)	Paediatric Cardiologist Consultant & Clinical Lead	Manchester University NHS FT
Ram Dhannapuneni (RD)	Consultant Cardiac Surgeon	Alder Hey Children's Hospital NHS FT
Sarah Picken (SP)	Operational Manager	Manchester University NHS FT
Reza Ashrafi (RA)	Consultant Adult Congenital Cardiologist	Liverpool Heart & Chest Hospitals NHS FT
Sophia Khan (SK) *Guest*	Consultant Paediatric Cardiologist	Royal Manchester Children's Hospital NHS FT

Apologies:

Amy Lewis (AMe)	Senior Planning Manager - Paediatrics	NHS Wales – Joint Commissioning Committee (JCC)
Andrea Myerscough (AM)	Director of Operations	Manchester University NHS FT
Angharad Boundford (AB)	Assistant Director of Commissioning	NHS Wales – Joint Commissioning Committee (JCC)
Christopher Dewhurst (CH)	Consultant Neonatologist and Deputy Medical Director	Liverpool Women's NHS FT
Joe Downie (JD)	Director of Operations	Liverpool Women's Hospital
John Brennan (JB)	Deputy Chief Medical Officer	Liverpool University Hospitals NHS FT
Manoj Kuduvalli (MK)	Divisional Medical Director for Surgery/Consultant Cardiac & Aortic Surgeon	Liverpool Heart & Chest Hospital NHS FT
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Yahya Najjar (YN)	Consultant Cardiologist & Clinical Head of Cardiac Services	Manchester University NHS FT

Declarations of Interest: None

Welcome & Introductions

Carolyn opened the meeting and welcomed everyone, including guests attending on behalf of board members.

Item 2 – Patient Story

Janet Rathburn, Chair, Patient & Public Voice (PPV) Group on behalf of patient

Gill describes her experience of living on lifelong warfarin after her third open-heart surgery in 2016. For nine years she struggled to access self-testing for her blood clotting levels despite repeatedly asking about it. Regular blood tests were stressful and difficult to arrange, with frequent appointment shortages, cancelled visits, and problems obtaining blood samples due to difficult veins. The closure of her local anticoagulation clinic during the COVID-19 pandemic and lack of transport made access even harder.

These ongoing challenges significantly affected her life as a mother in her early 40s, preventing her from returning to regular work and disrupting time with her young son. She often felt dismissed by GP staff and was repeatedly passed between services, with no team taking responsibility for helping her access self-testing.

In October 2024, after contacting the Somerville Heart Foundation, Gill finally received advocacy and was referred to specialist congenital heart disease nurses in Manchester and Liverpool. With their support, she was eventually approved for a home monitoring machine in June 2025, which she had to pay for herself.

Her experience highlights major gaps in care for patients on warfarin, including poor coordination between services, unclear pathways to self-testing, and the impact of frequent blood tests on patients' work, wellbeing, and family life. She argues that better communication, clearer responsibility between services, and wider access to self-testing could reduce stress for patients and potentially lower costs for the NHS.

Item 3 – Network Update/Finance

Nicola Marpole, Network Manager, NW CHD Network

Network funding/staffing issues

- NHS England has confirmed that the network budget will be £231,000, which is significantly lower than the amount previously used for recruitment and financial planning. To stay within budget for 2026–27, the senior leadership team has decided not to replace a retiring 0.6 full-time equivalent lead nurse, leaving 0.4 FTE lead nurse capacity going forward.

- With this reduction and an assumed 3% annual pay rise, the network expects to cover pay costs and still have around £5,000–£7,000 of discretionary funding in the next financial year. However, future budget increases are expected to be minimal (around 0.03%), creating longer-term financial pressure.

- Financial modelling shows that by 2027–28, staff pay will consume the entire network budget, and by 2028–29 the network may no longer be able to fully cover pay costs, even with the reduced lead nurse role. This represents a structural funding risk that could affect the network's ability to meet the service specification and may require reconsideration of the network's future operating model if funding is reduced further.

- Next steps include coordinated action across hosted networks in the North West, including exploring a joint letter to NHS England requesting removal of the 2% efficiency deduction, continuing discussions about the long-term funding model, and conducting internal scenario planning for future years to assess service impacts and identify potential risks and mitigations.

Discussion:

Concerns were raised that the network's reduced funding will make it difficult to maintain current nursing support and service delivery. It was noted that many other networks across the UK appear to have more extensive staffing structures, often including a full lead nurse, additional education nurses, and sometimes other roles such as echocardiographers, suggesting the North West network may be funded at a comparatively lower level.

In response, it was confirmed that Marion Eaves, Lead Commissioner for CHD, NHS England, has circulated a benchmarking survey to all networks, and responses have now been received. The results should soon provide a clearer picture of baseline funding levels and team structures across networks. This information will help determine whether there are funding discrepancies affecting the North West and support discussions with NHS England or alternatively inform whether the network may need to review its own structure.

Networks are funded based on population size, but different regions may organise their networks differently. In the North West, networks are separately structured rather than centrally grouped, which may limit resource sharing and lead to smaller teams operating with tighter budgets. Other networks in the region face similar issues, meaning a collective response to NHS England may strengthen the position.

Key programmes

- **Database** - the project has experienced delays due to inconsistent and late engagement from providers, which has required reworking previously completed elements and extended the timeline. The main outstanding issue is lack of engagement from MFT. MFT's current position is that the project did not follow the correct internal processes and attempts to contact the relevant lead have not yet received a response.

  As a result, the matter has been escalated through NHS England. Andrew Bibi, Regional Director of Specialised Commissioning, has sent a letter to the Joint Chief Medical Officer at MFT requesting urgent assurance that the issue is being addressed and asking for a timeline for resolution. Dr. Munshi has acknowledged receipt of the letter and confirmed the matter will be reviewed urgently.

  The project team is now awaiting further updates on next steps. Despite the delays, progress continues, and a revised go-live timeline will be produced once MFT engagement is secured, which remains the top priority.

- **Annual report** - is now in production and a full draught will be circulated for board feedback and approval prior to publication.

- **Network website** - the network website is now live. Promotion will occur this week via social media to align with CHD Awareness Week, along with an email update to all network colleagues. Team members are encouraged to share the website within their own teams and organisations to maximise reach.

- **Patient Information Day** - planning is in progress for a patient information day on 7th March at Alder Hey. The event will feature sessions on CHD surgery for all ages and a "Beyond the Heart" session covering wider wellbeing and lived experiences. The team hopes for a strong turnout from patients and families.

- **National CHD Networks meeting -** Preparations are underway for the national CHD networks meeting on 26th March in Liverpool, which will initiate the review and update of the national CHD standards.

- **Neonatal/CHD Joint Study Day** - the team is collaborating with the neonatal network to co-produce a study day for neonatal colleagues, covering the full patient journey from fetal life through to adulthood. The event is expected to take place around September/October this year.

- **PEC Co-Chair** - Sameer Misra is stepping down as co-chair of the PEC group. Expressions of interest are open until 13th February. The group is highly engaged and adds significant

value to the network. Colleagues are encouraged to put themselves forward, as no applications have been received yet.

Item 4 – Liverpool Partnership

Dan Grimes, Director of Operations, Liverpool Heart & Chest Hospital NHS Foundation Trust

The following is an update on the Liverpool adult acute and specialist services integration:

- In 2023, the ICB commissioned a Clinical Services Review for Liverpool, which identified duplication, inefficiency, and the need for clinical and corporate integration across the city.
- This led to the formation of the LASP Joint Committee (Liverpool Adult Acute and Specialist Providers) to drive clinical and corporate integration.
- In the same year, Liverpool University Hospitals (LUH) and Liverpool Women's Hospital merged under a single board, forming the UHL group. In September 2024, Liverpool Heart and Chest Hospital joined the group, consolidating governance under one board.
- A case for change was submitted to the ICB board and NHS England, including commitment to a shared EPR and development of the UHL 2030 strategy, focusing on clinical reference groups and corporate service integration.

Clinical reference groups currently focus on:

- Cardiology services – improving secondary-tertiary interface and cardiac outcomes.
- Respiratory medicine – reducing duplication in pathways for lung and sleep conditions.
- Spinal services – improving urgent care and tertiary pathway integration.
- Pain services – addressing fragmentation between LUH and Walton Centre.
- Stroke services – increasing thrombectomy rates.
- Women's services – improving care and reducing inequalities, aligned with existing ICB work.

UHL 2030 strategy priorities:

- Optimise hospital pathways across organisations.
- Enhance diagnosis and treatment planning in community settings to reduce late presentations.
- Work with neighbourhoods and primary care to keep people well, maintain independence, and focus on strengths-based care.

The strategy also aims to improve patient experience, reduce waiting times, streamline care transitions, utilise digital capabilities, enhance career development for staff, and deliver better value for money.

The case for change is currently under review by NHS England, with key lines of inquiry to be addressed by providers. Following satisfactory responses, the strategic business case for citywide organisational change will be submitted.
Liverpool is moving toward integrated, citywide clinical and corporate structures to streamline services, improve patient care, and maximise resources.

Discussion

The question was raised whether congenital heart disease (CHD) services have been included in the Cardiology clinical reference group and its impact on CHD services.

Dan responded that CHD likely hasn't been a focus so far, as the group has mainly concentrated on acute coronary syndrome pathways, but he will check with the lead for the group, John Morris, about CHD involvement going forward.

LG commented that CHD is often excluded from major decisions, leaving the service to adapt afterward, and suggested it would be valuable for CHD to be included from the outset.

DC reassured the board that he regularly engages with John Morris and has advocated for CHD, highlighting its importance and acknowledged there are some concerns about maintaining CHD's specialist identity within the broader cardiology programme, but stated these are being addressed.

Efforts are being made to ensure CHD services are represented in the Cardiology clinical reference group, with recognition of the need to maintain their specialist identity within the programme.

Item 5 – Provider Risk Register Update

Provider Risk Reporting

- Engagement in the risk reporting process dropped in the latter half of 2025, but a revised approach improved responses previously, though current engagement is slightly lower.
- Providers report high-level risks (score above 12) via a structured slide to minimise workload while ensuring the board sees key issues.
- The network risk register currently highlights two main risks:
    1. Finance risk – score increased to 20, with controls reducing it to 16.
    2. Database risk – previously reported.

Cordelia Lieb-Corkish, Operational Manager, Alder Hey Children's Hospital

Risk scores of 12 and above:

- Few changes have occurred since the last board report.
- The main update is the reduction of the single service risk shared with Manchester: initially 20, reduced to 16, and with controls, further reduced to 12.
- No other risks have changed.

Sarah Picken, Operational Manager, Manchester University NHS FT

- No current risks score above 12.
- A previous risk of 12 was rescored down to 8 following board recommendations.
- Another risk, clinician provision, currently scores 10, with a statement of case awaiting review.

Nick Povey, Business Manager – Medicine, Liverpool Heart & Chest Hospital NHS Foundation Trust

There is currently one remaining high-risk item on the risk register (score 12) related to patient safety due to limited capacity in the interventional team and resulting waiting times. This was discussed at the previous meeting.

Updates:

- A new intervention list member is expected to join the team around April.
- An interventional nurse post is expected to be advertised this week.
- A visiting consultant has been arranged to run lists at LHCH in March, which should help reduce the waiting list.

Overall, although waiting times have been significant in recent months, these actions should increase capacity and help reduce the backlog, suggesting improvement ahead.

Joshua Bainbridge, Divisional Director, Division of Medicine, Royal Manchester Children's Hospital

The service is currently going through a period of transition in relation to risk management. An updated, comprehensive review of risks across the service is being prepared and will be discussed at the Clinical Group Risk Committee next week, after which a clearer and updated risk position will be available.

Workforce improvements are progressing, including Dr Khan joining as a consultant in January, completing consultant recruitment, and a locum is expected to start next month.

However, there is ongoing residual risk related to physiology capacity and waiting times in some parts of the service. Following the internal review, the team expects to present updated risks to the Network Board going forward.

Comments/Discussion:

A comment was raised questioning the scoring of the network budget risk, which had been flagged as 20, as this seemed disproportionately high compared with risks reported by providers. A request was made for the host organisation to review the scoring to ensure it aligns with the standard risk scoring matrix used across the network. It was clarified that the raw risk score is 20, but with controls in place the current score is 16. The risk had previously been scored at 12, but was escalated due to recent significant changes and challenges affecting the network.

LG responded providers are being asked to carefully review their risk scoring to ensure it accurately reflects the situation. If the risk score does not decrease after controls are applied, it may suggest that the controls are inadequate. Therefore, providers should check that their scores genuinely represent the effectiveness of their controls.

LG further highlighted that current ICC risk scores (12, reducing to 10 with controls) are too low to trigger board-level reporting, despite the inherently catastrophic nature of ICC risks. In August 2023, it was agreed that the risk score should reflect high impact score of 5, with controls reducing it to a possible 3, resulting in a score of 15—high enough to be reported. The discussion is whether these risks should remain under board oversight, given that ICC services in the NW are currently poorly set up.

CJ suggested meeting with the RMCH team, to review and strengthen the ICC service across both paediatric centres. It is not a fair statement to label all risks as catastrophic, noting that while sudden death risk exists in all patient groups (similar to congenital heart disease), not every service risk should be classified at that level. The meeting would help align risk assessments between Level 1 and Level 2 services.

Item 6 – Documents for Ratification

Linda Griffiths, Lead Nurse, NW CHD Network on behalf of Michelle McLaren, Lead Nurse, Education, NW CHD Network

The following documents were approved and signed off:

NWCHDN_20	**ACHD Referral Pathway**
NWCHDN_30	**Paediatric Cardiac Catheter & Intervention SOP**
NWCHDN_64	**Patient Stories**
NWCHDN_64.1	**Patient Stories: Form for reading out at the Board**
NWCHDN_63	**Letters to Patients – Good Practice Guidelines**
NWCHDN_65	**Cardiac Assessment in ADHD**
NWCHDN_48	**Referral Proforma for Urgent Advice**
NWCHDN_52	**ICC Transition SOP**
NWCHDN_52.1	**ICC Late-Stage Transition – Documentation**
NWCHDN_52.3	**Adult ICC Documentation**
NWCHDN_52.2.1	**ICC Early-Stage Transition Questionnaire**
NWCHDN_52.2.2	**ICC Mid-Stage Transition Questionnaire**
NWCHDN_52.2.3	**ICC Late-Stage Transition Questionnaire**

CC praised the work, noting it will support clinical teams, and invited any suggestions for improving the documents to ensure they remain live and up to date.

Item 7 – Patient Representatives – PPV Group

Janet Rathburn, Chair, and Janet Lamb, member, PPV Group

- Continued engagement with Marion Eaves regarding funding, though no new funds are available.
- Working to have CHD recognised as a lifelong condition, collaborating with the NW network, NHSE and national groups like Children's Heart Federation.
- Exploring the creation of an all-party parliamentary group for CHD, including engagement with MPs.
- Activities for CHD Awareness Week, including press releases, media interviews, hospital visits, and raising the PPV group's profile.
- Development of patient perspective slides to be shared with professionals, especially in education.
- Planning for Patient Information Day with strong attendance and active PPV member involvement.
- Updating standards and documents, with new members contributing actively.
- Preparing for life after Linda, with volunteers helping manage secretarial and social media tasks to reduce workload for Michelle.

Overall, the group is highly active and focused on advocacy, patient engagement, and organisational continuity.

Item 8 – Surgical Update

Ram Dhannapuneni, Consultant Cardiac Surgeon, Alder Hey Children's Hospital

RD gave an overview of surgical activity, drawing on the latest national cardiac audit data from NICOR. Nationally, 12,225 procedures were performed across adult and paediatric services, exceeding pre-COVID levels, though still below the peak seen in 2016–17. Growth is largely driven by adult activity (up 14%), particularly in adult congenital heart disease (ACHD), alongside increases in interventional (+10%) and electrophysiology procedures (+15%). In contrast, paediatric surgical volumes remain static, and neonatal cases have declined by 6%, possibly reflecting lower birth rates and a shift toward earlier or interventional treatments.

Despite these changes, outcomes remain consistently strong across all centres, with survival rates of approximately 98.7% in paediatric and 98.3% in ACHD patients. Mortality and complication rates remain low and in line with national benchmarks, even with relatively high case complexity at centres such as Alder Hey.

Locally, Alder Hey has recovered well following a post-COVID dip in activity and has now exceeded the key benchmark of 400 surgical cases per year. With approximately 404–450 procedures, it is now the second-largest paediatric cardiac surgical centre in the UK, overtaking Birmingham, though still behind Great Ormond Street. Over the past decade, activity has steadily increased again, with both surgical and interventional volumes rising.

Across the Northwest, combined paediatric and adult congenital activity continues to grow. When considering adult congenital procedures delivered in partnership with Liverpool Heart and Chest Hospital (LHCH), the region is approaching the position of the largest national centre. However, reporting differences mean some adult cases (particularly over-16s) are not always fully captured in paediatric datasets.

Performance indicators show that survival rates at Alder Hey and LHCH are in line with or better than predicted outcomes. Complication rates - including ECMO use, renal support, and pacemaker requirement, are comparable to other major centres, with slightly higher ECMO rates reflecting commissioned specialist services.

In terms of current operational position, Alder Hey has completed over 260 cases so far this year and is on track to exceed 400, with waiting lists reduced from a peak of 110 to around 75 patients. At LHCH, ACHD surgical activity has reached its highest level since the programme began in 2018, with over 100 cases completed; however, waiting lists remain a significant challenge at around 120 patients.

To address this, measures include utilising additional operating capacity when available, limited weekend operating, and a proposed business case for a third dedicated operating day at LHCH. Overall, activity, outcomes, and regional positioning remain strong, though managing demand and waiting times continues to be a key focus.

CC thanked Ram for a comprehensive and reassuring update, highlighting strong outcomes and expressing confidence in the safety and quality of care.

Comments/Discussion

- Increasing complexity in case mix, particularly in adult congenital heart disease (ACHD).
- More complex and unplanned cases, including infective endocarditis, repeat surgeries, and combined procedures, which are not fully reflected in current reimbursement models and create challenges for service planning.
- Congenital heart disease (CHD) must be considered within wider regional transformation planning, given the clear trajectory of growth.
- Challenges with commissioning were raised, particularly reliance on historical activity data, which may not adequately reflect future demand. There was agreement on the need to project and plan for continued growth in ACHD services.

Item 9 – Regional Updates including data

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

CJ presented a revised data reporting format focused on exception reporting, comparing current performance with the previous quarter and the same period last year. Work is ongoing to introduce a red/amber/green (RAG) rating system to better indicate performance against expected standards.

- For Alder Hey, overall waiting lists and referrals remain stable. Significant improvement has been achieved in new patient pathways, with advanced nurse practitioners now reviewing many cases. This has enabled new patients to be seen within six weeks consistently over the past year, freeing up consultant time for more complex cases.
- The main challenge remains the follow-up backlog, particularly among long-waiting patients and within the ICC service. Plans to address this include further recruitment of advanced nurse practitioners as part of the service transformation.
- Surgical waiting lists were not discussed in detail, as they were covered earlier.
- Interventional services have faced staffing pressures, operating with reduced consultant capacity, but performance has been maintained, supported by recent recruitment and a new lead starting soon.
- Electrophysiology (EP) is identified as a key growth area, currently limited by having a single consultant. While some additional activity has been introduced, increasing planned capacity will be a priority over the next year to reduce waiting times.

Overall, performance is stable with notable improvements in new patient access, but ongoing pressures remain in follow-up and specialised services, requiring workforce expansion and service development.

Paulo Eden Santos, Paediatric Cardiologist Consultant & Clinical Lead, Royal Manchester Children's Hospital, Manchester University NHS FT

The update focused on interpreting referral and waiting list data, emphasising the need to understand what the numbers truly represent rather than simply tracking increases or decreases.

Key points included:

- Referrals are down slightly from last quarter (likely seasonal) but remain significantly higher than the same period last year, indicating sustained structural pressure.
- Total patient numbers continue to rise, reflecting accumulation rather than acute surges. WNB rates remain broadly stable.
- Backlogs show a reduction in patients waiting over three months, but an increase in those waiting over six months; 12-month waits are stable. Follow-up pressures are most notable in the three-to-six-month window.
- Transition activity is returning to baseline with the return of two consultants, with plans to expand transition clinics further.
- It is important to validate waiting lists to ensure accuracy. Early review of 200 patients from RMCH showed 66 could potentially be discharged after simple tests (ECG, ECHO, telephone clinic), as they do not have congenital heart disease. This highlights the need for careful triage and referral auditing.
- Current referral guidelines exist but may not be fully disseminated or utilised by GPs and community paediatricians. Many referrals could be managed locally, for example through community diagnostic centres offering first-line ECGs or Holter monitoring before referral to specialist cardiology.

Overall, current clinical models could be optimised to make better use of existing capacity. While no immediate solution to reduce numbers exists, focused validation, auditing, and better triage could improve efficiency, with outcomes to be reviewed in six months to a year.

Comments/Discussion:

- Are there specific concerns or areas where support from the board was needed, including if these concerns aligned with the risk register?
  While the Senior Leadership Team (SLT) has been involved in the risk register, clinicians and clinical groups will now have greater involvement. The initiative is just starting, its impact on the risk register will become clearer over time and will seek network support if needed.
- NM acknowledged that referral guidelines exist but may not reach everyone who needs them, assuring that better communication with ICB distribution groups is improving guideline dissemination, and a primary care study day later in the year should further raise awareness. These efforts should positively affect referrals, ensuring only appropriate cases reach specialised services and help manage capacity more effectively.
- JB noted that referral protocol adherence is limited by diagnostic capacity in Greater Manchester, particularly ECHO scans, which are only available at RMCH. Expanding diagnostics, potentially via community centres, is essential to reducing referral demand.
- CJ highlighted a large BHF grant supporting community hubs for diagnostics via the physiology team and suggested exploring how this could link across the network. There is a need for streamlined pathways and collaboration to build a robust congenital heart physiology workforce in the Northwest, covering both paediatrics and adults, as current services are fragile and vulnerable to staffing gaps.

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

Manchester Royal Infirmary

- Appointment wait times and the PTL in Manchester have been well controlled for over 12 months.
- The longest-wait patients (over 12 months) have dropped significantly from 171 to 97 in the last quarter.
- Clinic capacity is largely stable with five ACHD cardiologists, though on-call and leave variations exist.
- Some redistribution of consultant staff across the Northwest may be needed as demand grows at LHCH, focusing on booking long-wait patients efficiently and described historical triaging and validation work as important but not something to repeat regularly.

Liverpool Heart & Chest Hospital

- The adult congenital patient population is growing. The PTL increased by about 200 patients in the last quarter and roughly 1,000 compared to a year ago. It could double over the next 5–10 years.
- The growth is driven by successful paediatric interventions, earlier and more effective patient transitions from Alder Hey, and improved long-term outcomes.
- Despite the increasing numbers, backlogs remain manageable, and the goal is to keep patient wait times under six months.
- Electrophysiology (EP) services are stable.
- Surgical services have increased activity to meet demand, with further improvements expected once the new congenital interventional lead starts.

Comments/Discussion:

- The ongoing growth in patient numbers is significant and should be reflected in service development and workforce planning. DC added that referral thresholds are lower than in the past, as clinicians increasingly seek reassurance for even straightforward cases, leading to higher referral rates. Sometimes seeing the patient directly is the simplest way to provide reassurance.

Item 10 – Current Research Activity

Sophia Khan, Consultant Paediatric Cardiologist, Royal Manchester Children's Hospital NHS FT

SK outlined cardiology research activity in the Northwest, covering local, multi-centre, and national priorities. Highlighting the new British Congenital Cardiac Association (BCCA) research hub emphasising patient-centred outcomes, professional development, and better life-course health.

At Alder Hey, key studies include:

- **CHADWICK** – testing oral dispersible formulations to improve medication administration in infants.
- **Nadal study** – personalised 3D-printed medication for teenagers with arrhythmias, aiming to improve compliance and quality of life.
- **Empower study** – exercise prescription for children with hypertrophic cardiomyopathy, addressing physical and mental health.

At RMCH, the cardioactive study combined exercise, lifestyle, and mental health support for congenital heart patients, showing high retention and strong engagement from staff.

Highlighted multi-centre and international studies:

- **Refine study** – large registry data collection to improve understanding of poorly understood conditions like neonatal pulmonary hypertension.
- **Nurture AKI** – examining kidney injury after bypass surgery and long-term effects on child health.
- **Industry-led trials** – e.g. myosin inhibitor trials (maficantine/enaficantine) for hypertrophic cardiomyopathy, offering potential life-changing outcomes.

The team are highly dedicated, often contributing time voluntarily, and are making significant progress in integrating research with clinical care, improving patient outcomes, and professional development.

The Chair thanked Sophia for her presentation and acknowledged time constraints of the meeting and invited Reza Ashrafi to defer his update to the next board meeting in June, RA agreed.

Item 11 – Paediatric Cardiology Single Service

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

There is no major update on the paediatric cardiology single service. Engagement with Alder Hey's senior leadership continues, but commissioning currently does not prioritise this, and responses from commissioners are still pending.

Next steps will involve discussions between organisations to determine a way forward. NM agreed that the Network will follow up with providers and commissioners to clarify next steps.

Item 12 – Any Other Business

None.

Closing Remarks from the Chair

Summary

The Chair thanked all participants for their valuable contributions and closed the meeting by highlighting key points:

- Launch of the new website and plans for engagement across services.
- National CHD meeting in Liverpool, supporting visibility and profile.
- Positive collaboration with the neonatal partnership and smaller groups.
- Financial challenges and the impact of losing the lead nurse
- Progress on the city-wide integrated adult care pathway.
- Thanks to Ram Dhannapuneni for the surgery update, Sophia Khan for the research update, and acknowledgment that Reza Ashrafi's update will be covered next time.
- Appreciation for the PPV group's work raising awareness and influencing care.
- Special thanks to Linda Griffiths, marking her last board meeting, for her leadership, compassion, and lasting impact working for the NW CHD Network, with an invitation for colleagues to send personal messages.

Date of Next Meetings

Monday 15th June 2026 10.00am-12.00noon via MS Teams
Monday 12th October 2026 10.00am-12.00noon via MS Teams