NW CHD ODN Board Meeting Minutes
15th June 2026

Chair: Carolyn Cowperthwaite

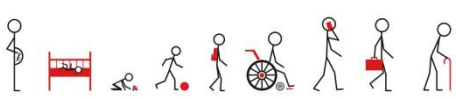


Table of Contents

Item 1 – Welcome, Introductions & 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 / 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
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
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
Michelle McLaren (MMc)	Lead Nurse	NW CHD Network
Nicola Marpole (NM)	Network Manager	NW CHD Network
Paulo Santos Eden (PSE)	Paediatric Cardiologist Consultant & Clinical Lead	Manchester University NHS FT
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Sarah Picken (SP)	Operational Manager	Manchester University NHS FT
Reza Ashrafi (RA)	Consultant Adult Congenital Cardiologist	Liverpool Heart & Chest Hospitals NHS FT

Apologies:

Alfie Bass (AB)	Medical Director	Alder Hey Children's Hospital NHS FT
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)
Chloe Lee (CL)	Associate Chief Operating Officer	Alder Hey Children's Hospital NHS FT
Christopher Dewhurst (CH)	Consultant Neonatologist and Deputy Medical Director	Liverpool Women's NHS FT
Cordelia Lieb-Corkish (CL-C)	Operational Manager	Alder Hey Children's Hospital
Harriet Riggs (HR)	Co-Chair PECs Group & Consultant Paediatric Consultant	Northern Care Alliance - Oldham
Joe Downie (JD)	Director of Operations	Liverpool Women's Hospital
John Brennan (JB)	Deputy Chief Medical Officer	Liverpool University Hospitals NHS FT
Josh Bainbridge (JBa)	Divisional Director, Division of Medicine	Manchester University NHS FT - Royal Manchester Children's Hospital
Manoj Kuduvalli (MK)	Divisional Medical Director for Surgery/Consultant Cardiac & Aortic Surgeon	Liverpool Heart & Chest Hospital NHS FT
Nicky Povey (NP)	Business Manager - Medicine	Liverpool Heart & Chest Hospitals NHS FT
Ram Dhannapuneni (RD)	Consultant Cardiac Surgeon	Alder Hey Children's Hospital 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

Kyrstie Crompton, patient and member of the PPV Group.

The board were shown a video recording from Kyrstie which is summarised below:

- Born with a complex congenital single-ventricle heart condition Kyrstie underwent open-heart surgery at 3 months old.
- Early treatment allowed her to have a relatively normal childhood.
- As an adult, she faced emotional challenges coming to terms with her lifelong condition.
- Following a cardiac arrest, she received a pacemaker, improving her safety but limiting her daily activities.
- Kyrstie is grateful for the excellent care and support from Liverpool Heart and Chest Hospital and her family.
- Sadly, Kyrstie experienced significant trauma following three miscarriages, including the loss of her son, and felt unsupported during her care at Saint Mary's Hospital, Manchester. Highlighting the contrast between compassionate cardiac care and poor communication during other healthcare experiences.
- Kyrstie's key message is that compassionate, honest communication and treating patients as individuals are essential to safe, high-quality healthcare, and she hopes her experiences will help improve both the clinical and emotional care future patients receive.

Item 3 – Network Update/Finance

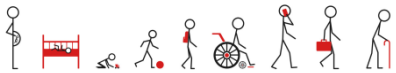
Nicola Marpole, Network Manager, NW CHD Network

Finance – CHD Network Financial Position FY 2026/27

- The network is currently in a recurrent deficit of approximately £4,500, despite reducing staffing following Linda Griffith's retirement.
- The deficit is caused by funding uplifts not keeping pace with national pay awards, making the gap unsustainable and likely to increase each year.
- This year, the network received a £67 funding uplift, while pay awards are expected to cost around £6,000, with additional medical pay rises still to be funded.
- A temporary in-year surplus of just under £30,000 is due to short-term staffing arrangements and is not a sustainable solution.
- Reduced lead nurse capacity (0.4 WTE) is limiting clinical leadership and increasing risks to governance, assurance, and delivery of national CHD standards.
- A quality impact assessment has been completed, and the impact is being monitored.
- An options appraisal has been submitted to NHS England, with the preferred option being reinstatement of the lead nurse to 1.0 WTE, requiring a recurrent £50,000 funding uplift.
- The network has also requested permission to carry forward savings from the network manager salary to provide short-term financial stability.

Discussion:

- Concerns were raised that the network's funding appears lower than in other regions. It was explained that other regions have different operating models, allowing greater resource sharing, making direct comparisons difficult.
- The host organisation supported raising the financial risks with NHS England. NHS England confirmed there is no additional funding available this year and acknowledged that pay costs are outstripping funding uplifts.
- Future changes from April 2027 may provide opportunities for greater collaboration and shared resources.



- It was recognised that the financial pressures are affecting many networks, with no immediate solution available, although concerns remain that the current funding model does not adequately reflect population size, service demand or cross-border responsibilities, including services provided to Wales.

Database

- Successful data uploads are now being received from Liverpool Heart and Chest Hospital and Alder Hey, establishing a regular data flow.
- Progress has been delayed by external factors, including outstanding analyst access to the database.
- Ongoing technical challenges at MFT have been escalated, with initial data uploads currently expected in October.
- Some key technical requirements at MFT remain unresolved and may affect implementation.
- Overall, good progress is being made, but external dependencies continue to impact the project timeline.

General Updates

- **Team capacity** - has been adjusted by increasing analytical and support officer time to maintain delivery while the Network Manager covers two network roles.
- **Reports** - the Annual Report has been published and the Assurance Report submitted to NHS England, with feedback expected in the coming month.
- **NHS England** - following Marion Eaves' departure, Lydia Ball has been appointed as the new Lead National Commissioner. A meeting is scheduled for 7th July to discuss key national priorities, including peer review, service standards, and recognition of congenital heart disease (CHD) as a lifelong condition. A letter from the Parliamentary Under-Secretary of State confirmed that while CHD meets the criteria for a lifelong condition, it is not currently recognised as such in NHS policy. This will be discussed with the new commissioner.
- **Patient videos** - two new patient videos have been published to support people with learning disabilities preparing for and undergoing an MRI scan.
- **Slides for professional staff** - new patient-centred approach slides have been added to the network website to help healthcare staff improve communication, empathy and patient experience.

Item 4 – NHSE Update

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

Database

- Delivery of the CHD database remains a key priority for the year. NHS England has been working with MFT to emphasise the importance of progressing the database, recognising the need to include MFT's patient cohort in the regional dataset.
- NHS England will continue to monitor progress closely and offered ongoing support, including attending meetings if required, to help resolve any further delays.
- HC noted that contractual data-sharing requirements (Schedule 2F) could be used if necessary to support progress and ensure the project remains on track.

Discussion

Update from MFT: RB confirmed that MFT remains committed to implementing the database by September. The main challenge is the technical interface with the Epic electronic patient record system, making the required build more complex. The Network are now engaging with the appropriate technical teams and reassured the group that MFT is prioritising the work.

The Chair welcomed the assurance and emphasised the importance of maintaining focus to ensure the project stays on track.

Item 5 – Education Update & Feedback from PPV Patient Information Day

Michelle McLaren, Lead Nurse, NW CHD Network

- Two network education events are planned:
  Neonatal Cardiac Study Day – 2nd October, which will be delivered in collaboration with the North West Neonatal Network.
  GP/Emergency Department webinar – 3rd November – which will focus on recognising cardiac red flags and improving referral pathways.
- **Patient Information Day** held on 7th March 2026:
  - Organised by the Patient and Public Voice (PPV) Group with network support. The event covered congenital heart disease across the lifespan, mental wellbeing, surgery, family planning, learning disability, and included lived experience presentations.
  - Around 97 people attended, including patients, families, healthcare professionals, PPV representatives and partner charities.
  - Feedback was overwhelmingly positive, with attendees praising the organisation, the lived experience sessions, the dedicated paediatric sessions and the opportunity to engage with support organisations.
  - Suggestions for future events included: sibling support, bereavement services, and fitness and nutrition. A key theme from the feedback was that the event helped patients and families feel less isolated in their congenital heart disease journey.
  - Board Chair, CC, welcomed the education update and praised the success of the Patient Information Day, recognising the significant contribution of the Patient and Public Voice (PPV) Group in delivering a valuable event for patients and families.

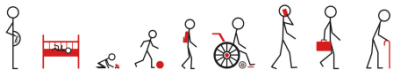
Item 6 – Provider Risk Register Update

Alder Hey – presented by Caroline Jones, Clinical Lead & Consultant Fetal & Paediatric Cardiologist Paediatrics on behalf of Cordelia Lieb-Corkish, Operational Manager, Alder Hey Children's Hospital

- No changes were reported to the provider risk register since the previous meeting.
- Workforce shortages remain a key risk, with staffing levels below expected standards. A business case to increase staffing is due to be considered by executives.
- Limited access to CT and MRI remains a concern, and a collaborative working group is proposed to improve cross-sectional imaging across the network.
- Progress on developing a single service model remains limited due to wider NHS financial pressures, and a different approach may be needed.
- Bed capacity continues to be a risk but is also being addressed through the current business case. Overall, several initiatives are underway, although no immediate changes have been achieved.

Discussion: about the risk of staff burnout and whether it was reflected in sickness absence?

- Staff burnout remains a concern following sustained workforce pressures and prolonged consultant absences.
- A business case proposes a two-consultant on-call rota to improve resilience and workload.
- Additional investment in high dependency nursing is also planned to better meet patient demand and support staff.



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

- Work is underway to increase ACHD surgical capacity, including expanding surgery from two to three days per week to help meet growing demand.
- The demand for ACHD surgery is increasing due to a growing and more complex adult congenital heart disease population, suggesting current capacity projections may underestimate future need.
- The risk relating to ACHD interventional cardiology has improved following the appointment of a new interventional consultant, strengthening the service and potentially allowing this risk to be downgraded.

Royal Manchester Children's Hospital NHS FT – presented by Cathryn Winchcombe, General Manager, Division of Medicine

- RMCH has reviewed its longstanding risks and removed three risks after resolving the underlying issues.
- The remaining key risks relate to:
  - Insufficient paediatric cardiac physiology workforce, leading to consultants undertaking echocardiograms.
  - Outpatient capacity, where demand exceeds available clinic capacity.
  - Space and equipment have been secured at the Gorton Diagnostic Hub, and an internal business case will explore expanding the physiology workforce to increase outpatient capacity.

Manchester Royal Infirmary NHS FT – presented by Sarah Picken, Operational Manager, Manchester University Hospitals NHS FT

- No risks are currently rated above 12.
- A risk rated 10 relating to the backlog of overdue outpatient appointments is being reviewed, as recent improvement has stalled.
- A workforce business case has been developed but is awaiting approval through the organisational prioritisation process.

Item 7 – Documents for Ratification

The following documents were approved and signed off:

NWCHDN_62	**DBS Check SOP**
NWCHDN_67	**Congenital Heart Disease Operational Delivery Network Strategy**
NWCHDN_68	**Congenital Heart Disease Operational Delivery Network Volunteer Agreement**
NWCHDN_69	**Congenital Heart Disease Operational Delivery Network Volunteer Role Description**

No further feedback received, Board approved the documents for publication.

Item 8 – Patient Representatives – PPV Group

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

- JR again thanked PPV representative Kyrstie for sharing her patient story and acknowledged her bravery.
- The Patient Information day held at the beginning of March, was highlighted as a significant achievement with increased involvement from PPV representatives in organising the event and sharing lived experiences, demonstrating the group's growing maturity and capacity.
- The PPV group also contributed to the National CHD Networks' meeting at the end of March and hopes to continue supporting future national work.
- Working in collaboration with the Network's Lead Nurse, work will continue to make the PPV group more self-sufficient. A new structure is being developed, with two vice-chairs now being appointed.
- Work continues to seek national recognition of congenital heart disease (CHD) as a lifelong condition, with plans to work alongside other networks to progress this nationally following changes in national leadership.

Discussion

- The group discussed ongoing work to have CHD recognised as a lifelong condition and the plans to link in with the national lead commissioner for CHD to arrange a separate meeting to maintain momentum and plan next steps.
- Strengthening links with primary care was identified as a key PPV priority to support this work.
- Plans continue for awareness activities during World Heart Day and Congenital Heart Week
- Patient engagement remains a focus, with drop-in sessions and Patient Information Days helping to recruit new PPV representatives and improve awareness.

Item 9 – Current Research Activity

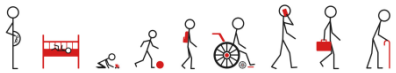
Reza Ashrafi, ACHD Consultant, Liverpool Heart & Chest Hospital NHS FT

RA presented an overview of recent research activity, highlighting a growing number of department-led publications, particularly in exercise, electrophysiology (EP), and pacing.

- Current research strengths include established EP and exercise testing infrastructure, strong industry and research collaborations, and valuable support from patients in shaping research projects.
- Ongoing studies include research into bicuspid aortic valve genetics, anomalous coronary arteries, pacing, heart failure, and exercise, with further trials planned.
- The department has secured over £75,000 in research grant funding, marking a significant milestone for the ACHD service.
- Challenges include limited research funding, a lack of dedicated research fellows and trainees, increasing regulatory and governance requirements, and financial pressures affecting research capacity.
- Despite these challenges, the team remains committed to expanding ACHD research and acknowledged the support of patients, collaborators, and academic partners.

Comments/Discussion

- The Chair welcomed the update on ACHD research and recognised both the team's achievements and the financial and operational challenges they face.
- Concerns were raised about delays in information governance approvals following centralisation of the service. It was confirmed that the issue has been escalated, and the Board requested an update at the next meeting while offering support if needed.



- The research team was commended for delivering significant research activity alongside NHS clinical work, much of it without dedicated research time.
- Discussion highlighted the difficulty of securing major research grants without initial funding, emphasising the importance of a little funding and institutional support to help develop future research bids. The recent grant success was recognised as an important step towards securing further funding.

Item 10 – Regional Updates including data

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

CJ presented AH's data on service performance, noting that the new data dashboard is still being refined.

Key points:

- MDT performance has improved, with more efficient case discussions and reduced waiting times for new appointments, which are now around six weeks.
- Referral numbers remain stable, DNA rates remain low (around 6%), and the new patient waiting list has reduced significantly, supported by Advanced Nurse Practitioners.
- Work continues to reduce the follow-up backlog, particularly for patients overdue appointments, and to review the transition service to better meet patient needs.
- The paediatric surgical programme continues to perform well, with timely access to surgery, very few cancellations, and capacity to support other centres.
- The main operational challenge remains access to dental services, which is delaying some patients from proceeding to surgery.
- Interventional cardiology waiting times remain healthy, with plans to strengthen the workforce over the next 12–24 months.
- Electrophysiology (EP) waiting lists remain a concern, with additional lab capacity required to reduce delays.

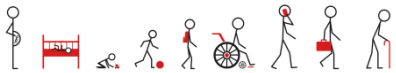
Discussion/Comments:

- Discussed the ongoing impact of dental service delays on patients awaiting cardiac procedures. It was reported that the dental team is now working closely with the cardiac service, with patients being assessed earlier and dedicated appointment slots helping to expedite treatment before surgery.
- While challenges remain, particularly where extensive dental treatment is needed close to the surgery date, members agreed that there has been noticeable improvement.
- PPV group members commented that dental capacity has been a longstanding concern, including limitations around clinical space, and welcomed the progress being made.

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

Key points:

- An increase in new referrals was reported, reflecting improved awareness following the dissemination of the network's referral guidelines. Work is underway with GPs to encourage appropriate referrals and to audit triage processes for consistency.
- Waiting times and DNA rates have improved, with a significant reduction in patients waiting over six and 12 months, supported by additional clinics.
- Further improvements are limited by clinic space, despite good staffing levels, and this remains on the risk register.



- Work continues to validate and reduce the follow-up backlog, and the transition service is under review to ensure patients receive the most appropriate care.
- The Board welcomed the positive progress while recognising that further work is needed to sustain these improvements.

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

Liverpool Heart & Chest Hospital NHS FT

Key points:

- Outpatient backlog is growing, with waiting lists increasing due to rising demand. Current capacity is unlikely to meet future demand, and additional consultant capacity is likely to be required.
- Whilst a business case could be developed, securing funding remains challenging due to wider financial pressures. The importance of demonstrating the risk to patients was highlighted.
- CHD surgical waiting lists remain among the longest nationally, although interventional services are improving following recent recruitment. Electrophysiology and diagnostic catheter services are performing well.
- MDT waiting times remain a concern, with only one MDT meeting per week resulting in delays to case discussions.
- DNA rates have improved through better communication with patients, and plans are in place to update patients about waiting times and the work being undertaken to address backlogs.
- Although some patients experience long waits for surgery, this is not always due to service capacity, as factors such as dental treatment and other clinical needs can also contribute. Overall, surgical cancellations remain low and other procedural waiting lists are well managed.

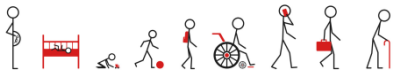
Manchester Royal Infirmary

Key points:

- Patient demand continues to rise, particularly due to increasing numbers transitioning from paediatric to adult services.
- Follow-up backlogs are growing again after previous improvements, mainly because of reduced clinic capacity and fewer registrar staff.
- New patient waiting lists are not a significant issue; the main challenge is follow-up appointments.
- The reported 43-week median follow-up wait is considered misleading, as it does not show how overdue patients are from their planned review date. The new regional database should help to provide more meaningful reporting.
- WNB (was not brought) rates have improved significantly, largely due to better patient communication through the My MFT app and are thought to be below the national average.
- Additional staffing is needed to meet increasing demand and improve follow-up capacity.

Comments/Discussion:

- Highlighted the need to understand what the backlog data means and its impact on patient care.
- Some backlog is expected in the NHS, but increasing backlogs are a concern.
- Current data does not identify which overdue patients are at highest clinical risk, making prioritisation difficult.
- Consultants currently review overdue patient lists manually to identify those needing urgent appointments. Although labour-intensive, this provides an important patient safety net.



Item 11 – Paediatric Single Service

- No substantive update was available
- It was agreed to review whether the single service proposal is still progressing and whether it remains fit for purpose given the changes since the original business case.
- An updated position will be brought to the next meeting and the item will remain on the agenda.

Item 12 – Celebrating Success

This item was raised for inclusion at the next meeting.

Item 13 – Any Other Business

None.

Closing remarks from the Chair

Carolyn Cowperthwaite, Board Chair, NW CHD Network

- Members were asked to bring a brief example of a success or achievement to future meetings to recognise and share good practice across the network.
- The meeting highlighted the importance of compassion and keeping patients and families at the centre of decision-making.
- Positive progress was recognised in patient and public involvement, patient education, staff education, and research.
- Financial pressures remain a concern, but there was confidence that resources are being managed appropriately.
- Board oversight of provider risks has improved, with better visibility of issues and support where needed.
- Thanks were given to all contributors, with encouragement for members to continue sharing their views openly at future meetings.

Date of Next Meetings

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