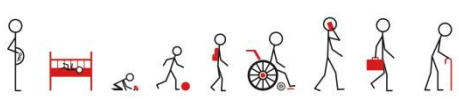
# NW CHD ODN Board Meeting Summary Notes 26th February 2024

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist





# Table of Contents

# Item 1 – Welcome, Introductions & Apologies

## Present:

| | | |
|---|---|---|
| Alfie Bass (AB) | Medical Director | Alder Hey Children's Hospitals NHS FT |
| Caroline Jones (CJ) | Clinical Lead & Consultant Fetal & Paediatric Cardiologist / Joint Clinical Director NW CHD ODN | Alder Hey Children's Hospitals NHS FT |
| Elliot Shuttleworth (ES) | Divisional Director for Cardiac Services | Manchester University NHS FT |
| Helen Chadwick (HC) | Service Specialist (Specialised Commissioning Team | NHS England & NHS Improvement |
| Janet Lamb (JL) | PPR Representative | NW CHD Network |
| Janet Rathburn (JR) | PPV Representative | NW CHD Network |
| Jill Moran (JM) | Network Support Officer | NW CHD Network |
| Jonathan Mathews (JMa) | Chief Operating Officer | Liverpool Heart & Chest Hospitals NHS FT |
| Joshua Bainbridge (JBa) | Divisional Director, Division of Medicine | Manchester University NHS FT |
| Manoj Kuduvalli (MK) | Divisional Medical Director for Surgery/Consultant Cardiac & Aortic Surgeon | Liverpool Heart & Chest Hospital NHS FT |
| Linda Griffiths (LG) | Lead Nurse | NW CHD Network |
| Nayyar Naqvi OBE ***(Chair)*** (NN) | Emeritus Consultant Cardiologist | Wrightington, Wigan & Leigh NHS FT |
| Richard Palmer (RP) | Senior Planning Manager - Adults | Welsh Health Specialised Services Committee |
| Sameer Misra (SM) | PECSIG Chair & Director of Medical Education<br>Consultant Paediatrician and Lead for Cardiology | Bolton NHS FT |
| Sanjay Sastry (SS) | Consultant Cardiologist | Manchester University NHS FT |
| Sarah Bowman-Jones (SBJ) ***on behalf of Chloe Lee*** | Service Manager, Division of Surgery | Alder Hey Children's Hospitals NHS FT |

## Apologies:

| | | |
|---|---|---|
| Abby Prendergast (AP) | Associate Director of Strategy and Partnerships | Alder Hey Children's Hospital NHS Foundation Trust |
| Andrea Myerscough (AM) | Director of Operations | Manchester University NHS FT |
| Beth Weston (BW) | Chief Operating Officer | Liverpool University Hospitals NHS FT |
| Chloe Lee (CL) ***Sarah Bowman-Jones in attendance*** | Associate Chief Operating Officer | Alder Hey Children's Hospitals NHS FT |
| Damien Cullington (DC) | Consultant Adult Congenital Cardiologist / ACHD Clinical Lead / Joint Clinical Director NW CHD ODN | Liverpool Heart & Chest Hospital NHS FT |
| Elizabeth Shackley (ESh) | PECSIG Chair | Stockport Hospital NHS FT |
| Gary Price (GP) | Chief Operating Officer | Liverpool Women's Hospital NHS FT |
| John Brennan (JB) | Deputy Chief Medical Officer | Liverpool University Hospitals NHS FT |
| Kimberley Meringolo (KM) | Specialised Planner, Cardiac Services | CTM UHB - Welsh Health Specialised Services Committee |
| Lynn Greenhalgh (LGr) | Medical Director | Liverpool Women's Hospitals NHS FT |
| Rachael Barber (RB) ***Joshua Bainbridge in attendance*** | Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead | Manchester University NHS FT |
| Raphael Perry (RP) | Medical Director | Liverpool Heart and Chest Hospital NHS FT |
| Sally Briggs (SB) | Medical Director | Manchester University 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 |

**Declarations of Interest:** None

# Item 2 – Network Update & Finance Workplan

Nicola Marpole (NM) reported the following network updates:

**Finance**

- Budget for 24/25 has been confirmed as £216k, with top up to cover annual and incremental pay increases.
- Underspend has been allocated as follows:
    - £100k investment in the all-age regional database development (in addition to the £96k from NHS England)
    - £24k hosting fee for the database (3 years)
    - £53k redundancy pay for outgoing network manager.
    - Remaining £40k used to support:
        - clinical training and education
        - network training and education
        - patient experience improvement
        - patient education and information materials

**Hosting Fee**

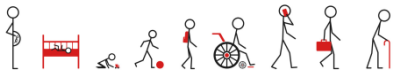
- Alder Hey have requested a 3% fee to support services provided to hosted ODNs.
- ODNs have raised the impact this will have on limited budgets with Alder Hey and NHS England regional spec comm.
- Pending response from NHSE.  HC confirmed discussions are ongoing with the commissioning senior leadership team as this affects a number of networks and will feedback as soon as a response is known.

**ODN Workplan**

The work plan outlines the ODN's priority work streams and objectives for 2024-25, which broadly fall into the following categories:-

- Draft overview of the workplan was included with papers.
    - Network arrangements including our engagement with three regional ICBs and establishing governance arrangements.
    - Recruiting a new board Chair as it's Nayyar's last meeting today.
    - Clinical pathways policies & protocols.
    - Development and launch of patient experience surveys specifically for young people and patients with learning disabilities. Which in turn will enable us to establish a patient experience forum which will run twice a year alternating with and complementing the network clinical governance meetings. This group will comprise representatives from providers, PPV





group and ODN and will review the results from the patient experience surveys, identify areas for improvement and oversee workstreams.
    - Training & education – continue to work with providers to identify our requirements for different staff groups involved across the network and review any current provision, identify gaps and develop network wide education and training.
    - Due to limited budget and resource our main goal for research this year will be to agree and outline the first steps of a research strategy which can be built upon in the future.
    - This will mainly focus on support with promoting research participation generally by highlighting the benefits to patients and staff and more specifically by sharing information about ongoing and upcoming opportunities for patients to participate in research.
    - Service improvement – focusing on supporting providers to collect and submit accurate and timely data for reginal and national review.
    - External relationships – continue to work and collaborate with relevant groups, i.e. fetal and maternity services.
- Detailed workplan to be developed over the next two months. This will require approval by:
    - ODN Senior Leadership Team
    - CHD ODN Board
    - Regional Specialised Commissioning
    - ICBs
- The final version will form part of the ODN assurance report to NHSE in June

Once the high level objectives have been agreed they will be shared with the network's senior leadership team, the NW CHD ODN board, Specialised Commissioning and ICBs for final sign off. The final version will form part of the ODN Assurance Package Report to NHS England in June.

NM asked the group for approval and if there were any questions/comments on the above? No questions/comments raised. **Agreed approval of the draught objectives.**

**Database**

- Confirmation of support for the CHD all-age regional database has now been received from Alder Hey, LHCH and MFT.
- MFT to come on board April/May with Alder Hey and LHCH hopefully to follow in June/July.
- Regional NHS England Specialised Commissioning to approve timeline or advise regarding escalation. HC updated that a response from NHS England imminent within the next couple of weeks.

**Specialised Commissioning National Transformation Proposal**

- To use a comprehensive evidence-based approach to accurately identify areas within the CHD service that require transformation or improvement to be safe and resilient to the global challenges facing the NHS.

- The national CHD Clinical Reference Group (CRG) has “respond and advise” status, if the transformation proposal is accepted it would move to “transform”.
- A draft has been developed by the national CRG, including patient. representatives, and is currently with regional ODN teams for review and comment.
- The key areas put forward for transformation are workforce, health inequalities, patient flow, integration and partnership working and data and research challenges.
- This is a competitive process, so if the proposal progresses to the next round the group will seek to undertake a comprehensive programme of engagement ahead of final proposal submission.
- If successful in the first round, then a programme of engagement will be commenced for wider input and development. The board will be kept up to date of any progress.

HC acknowledges the challenges faced by the team and the wider network, particularly regarding the pressures seen in cases handled by paediatric teams. HC emphasized the importance of investment and funding to support the transformational work required, noting that such initiatives are typically driven by those already engaged in the work. HC expressed the need for resources to facilitate the proposed changes and mentioned raising the issue with Marion, the head of the national program for women's and children's health. HC emphasises the importance of realistic expectations regarding resource allocation to support the network and providers across England in achieving the desired goals.

# Item 3 – Regional Updates including Data

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

**Waiting Lists**

- There continues to be a rise in surgical list, approximately 63, however, our post COVID waiting list was very low allowing room to cope with the post pandemic influx. It is starting to reduce.
- Staffing issues have been a contribution to loss of lists, but this is improving.
- The programme should be back up to full capacity by May.
- Intervention list is slightly up and down, however, no reported issues.
- Surgical wait times – patients categorised according to the national P1 P2 & P3. No issues with PICU beds. Cancellations have been mainly due to lack of theatre staff.
- Winter pressure issues have been minimal, no issues to report.

**New Patients**

- Outpatient waiting lists have reached extremely high levels and work continues to increase availability of appointments.

CJ highlights efforts to increase appointment availability while managing competing priorities between new patient referrals with low pathology yield and follow-up appointments for complex congenital heart conditions. CJ acknowledged the current struggle with backlogs and expressed the need to address this issue by creating more job plans and business cases for new consultants. Additionally, CJ mentioned utilising advanced nurse practitioners (ANPs) to conduct more clinics in order to alleviate the backlog, especially for new patients.

**Follow Up Appointments**

- The back-log data is significantly high, there has been an increase of over 1000 patients, mainly over the transition period, which needs investigating. CJ is concerned about the reliability of the data since the new EPR system go-live and will discuss further at the upcoming meeting with the Data Manager.
- CJ discussed the challenges posed by the current funding model for congenital heart disease and outpatient services, particularly in terms of making business plans. CJ explained that current funding is based on a block contract for follow-up patients, which does not generate income to create new consultant positions. CJ highlighted the limited income generated from seeing new patients, the majority of whom are assessed and discharged without needing further follow-up. Despite some patients having severe, life-limiting conditions, there is no additional funding or business model to support their care. CJ expressed uncertainty about how to address this problem effectively.

**Transition**

- Transition service is steady, though there are some remaining issues with the equity of service, particularly for our patients who are predominantly seen in Level 3 centres.

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

- DNA rates remain reasonable between 5 & 7%.
- New patients' referrals per month are approx. 200-250 per month.

**Joshua Bainbridge, Divisional Director, Division of Medicine, Manchester University NHS FT (on behalf of Rachael Barber)**

**New Patients**

- Overall numbers of waiting times are slowly decreasing.
- New patient referrals are approx. 800-900 per month.
- Now have an additional visiting Consultant supporting from Alder Hey and another appointment in process.
- Paediatricians with an interest in cardiology (PEC) now in place at Royal Oldham and North Manchester General Hospitals.
- The additional clinics will assist in reducing wait times as they become established and bring us on track with national guidance waiting times at the end of the current financial year.

**Follow Up Appointments Backlog**

- Similar issues to Alder Hey.
- Work continues into clinical review and prioritisation of the backlog and most clinically urgent patients.

**Transition**

- Service working well, no issues to report.
- Continue to have excellent engagement with our adult transition colleagues.

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

- Slight reduction in new patient referrals
- JB discussed the variability in paediatric services and notes that while their performance has improved compared to the previous year, there is still room for further improvement to reach historical benchmarks of around seven to eight percent. JB mentioned a slight drop in new patient referrals in recent months, with December typically being quieter.

**Jonathan Mathews, Chief Operating Officer, Liverpool Heart & Chest NHS Foundation (on behalf of Damien Cullington)**

**Liverpool Heart & Chest Hospital NHS FT**

**Updates**

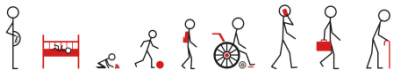
- Key areas in surgery wait times and intervention.
- Continue to manage and clinically prioritise national targets of 65 and 78 weeks.
- Some issues with surgical wait times but no areas of concern.
- Out-patients – no issues to report.
- Follow-up backlogs – remain area of concern on our risk register.

**Elliot Shuttleworth, Divisional Director for Cardiac Services, Manchester Royal Infirmary (on behalf of Damien Cullington)**

**Updates**

- New appointment backlog has reduced from over 300 to 88.
- ES discussed a significant reduction in the new appointment backlog, decreasing from over 300 to 88. ES attributed much of this reduction to data quality validation and the addition of extra appointments in the system. ES believes that the current number better reflects the expected level of backlog. ES reflected on previous discussions about data sets, acknowledging the inclusion of transition patients, which affected the accuracy of the data. Despite starting in a challenging position, ES was pleased to note progress and further efforts to improve. Over the past 12 months, ES estimated a reduction in the overall backlog to around 200, with an improvement in follow-ups within 12 months. ES expressed disappointment that data for January was not available, but mentioned seeing positive trends, such as fewer follow-ups within 12 months. ES praised Damien and colleagues for their work with the OPS teams, noting that





the current position is the best in a couple of years in terms of management and support. ES highlighted the benefits observed, particularly in terms of overall size. ES attributed the progress made to the hard work of everyone involved, demonstrating a commitment to ensuring alignment with objectives set about two years ago. ES acknowledged progress in reducing previous problems but notes the possibility of double counting in some areas with colleagues across the Northwest. ES emphasized a focus on long-term patient cohorts, highlighting that although the number of follow-ups is below 1000, there are still 960 from January, indicating more work is needed. ES expressed encouragement that progress is heading in the right direction but emphasized the need for further efforts to address issues related to staff and requirements.

# Item 4 – Cardiac Maternity Update

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

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

# Item 5 – Level 3 Centres Update

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

- SM acknowledged the challenges faced by others and mentioned similar challenges on the registrar side. SM highlighted the financial constraints in Greater Manchester (GM), where budgets are being reduced, making it challenging to accommodate extra activity requests due to increased financial pressure.
- SM suggested approaching the situation from a mathematical perspective, focusing on three key questions: Can referrals be reduced? Can capacity be increased? Can referrals be redirected to more appropriate locations, freeing up resources for other needs? SM emphasized the importance of optimising resource allocation and efficiency in managing the workload effectively.
- SM expressed the need for more detailed information regarding the nature of the referrals received, whether the referrals primarily consist of undifferentiated innocent murmurs, symptoms like chest pain or dizziness, or true pathological cases. There was an emphasis on the importance of critical input and triage in managing the workload effectively. SM noted similar challenges faced by the District General Hospitals (DGH) regarding increasing referrals and constrained capacity, as echoed in discussions following the November board meeting.

NM highlighted that phase one of the database concentrates on level one and two centres, recognizing the need for additional time to onboard level three centres. NM

mentioned the appointment of a network data analyst and outlined plans for collaboration with level three centres to consolidate data in the coming months. This proactive strategy aims to integrate data from all centres into the database effectively moving forward.

# Item 6 – Paediatric Cardiology Partnership Group Update

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

- Awaiting response of the business case from Commissioners.
- Concerns for resources to support the business case. The network does not have the resource capacity.
- A meeting is arranged with RMCH to discuss the next steps and what is achievable.
- CJ recalled that the network was approached over a year ago after the first business case to discuss how they could support the initiative. The network senior leadership team has repeatedly discussed the increasing demand year on year and the insufficient funding available, which only covers basic staff requirements.
- CJ explained that there isn't capacity in the work plan to take on a large transformational project involving level one and level two centres, described it as a significant task and expressed their view that it's challenging to undertake. CJ mentioned an upcoming meeting in a week or two with both the RMCH team and Alder Hey to discuss next steps, determine which data is feasible, and identify what may not be achievable.
- CJ invited JB to provide additional input on the current progress.
- CJ mentioned ongoing efforts to enhance clinical collaboration as part of the partnership journey, which has been beneficial for staff on both sides. However, it was noted a pause in activity following the response from the Commissioners, likely due to the transition to the Integrated Care Boards (ICBs), which will be a major focus in the coming months. It is anticipated that there will need to be similar conversations with new individuals in six months' time due to the changes in leadership and structure.
- JB announced the recent substantive appointments made to two vacant posts in RMCH, in partnership with Alder Hey. While this doesn't add capacity, it contributes to a more stable workforce, addressing a longstanding challenge. JB also mentioned ongoing discussions with Alder Hey regarding a joint post to address workforce challenges in echo physiology provision. Despite these efforts, JB highlighted the importance of continued collaboration with commissioners to address service improvements.

# Item 7 – Database Update

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

- Database update covered under item 2.

# Item 8 – Commissioner Update

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

- North west and national team working toward full delegation of our three Integrated Care Boards from April.
- Contract teams looking at 24-25 financial year contracts for all providers.
- Commissioners are going to be retaining accountabilities for all specialised services at NHS England but will be working closely with ICBs to embed and align with their aims and objectives.
- NW Specialised Commissioned Committee has now been set up which welcomes colleagues from all Integrated Care Boards.
- HC discussed the current status of commercial and funding approaches for high-cost drugs, which remain under specialised commissioning. Highlighting uncertainty regarding when or how this responsibility might be delegated and emphasised that this retention is not unique to the Northwest but is a national issue.
- HC announced that adult congenital heart disease (CHD) and paediatric cardiology have been deemed suitable and ready for delegation. Starting in April, ICBs will have full responsibility for decision-making. However, it was clarified that there will be alignment and collaboration with other stakeholders, ensuring a seat round the table for participation in the decision-making process.
- HC acknowledged the focus on prevention and early intervention in the pathway, recognising that it will take time to see the benefits of these changes. HC anticipates a busy period in the coming months as NHSE navigate these adjustments in preparation for April. However, there is an understanding that not everything will be ready by April, with the finance and contracts teams facing pressure to understand the implications of the changes. HC encouraged open communication and collaboration, offering to provide updates and receive feedback as needed. Despite the upcoming changes, HC expressed optimism that the transition will be manageable.

# Item 9 – Welsh Commissioners Update

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

- Welsh Health Specialised Service Committee will be merging into a new organisation from 1st April, called the Joint Commissioning Committee. This will comprise of all NHS Wales Commissioning including specialised. It is not envisaged to have any impact on the commissioning of CHD.
- WHSSC's recent focus has been on Wales's one Level 2 centre, in South Wales, currently in phase three of investment.
- Progress has continued in recent months, with a new consultant post undergoing scrutiny and a radiographer post being filled. Additionally, efforts are underway to explore ways of delivering a planned CMR uplift.
- Commissioning data has flagged pressures with cardiac surgery and interventional cardiology services at Liverpool Heart & Chest Hospital, mentioned above. This may have implications for HD patients and conversations are ongoing with the organisation.

# Item 12 – Patient Representatives

**Janet Rathburn, Chair, PPV Group and Janet Lamb, PPV Group Member**

JR gave the following PPV group update:

- Currently focusing on improving patient experience and how we can better support families, especially those struggling financially with rising food and transport costs.
- January's meeting welcomed Laura Allwood from Liverpool Heart & Chest Hospital, to talk about the PALS process.
- February meeting welcomed Michelle McLaren and Catherine Livingston from Alder Hey, to talk about the services and support that is available to families. The PPV group also welcomed Anna Harrison and Nick Povey to talk about concerns getting through to the helpline and cardiac secretaries as well as appointment letters arriving after the appointment date.
- Caroline Jones and Damien Cullington are attending March PPV meeting.
- Part of the PPV's role is to highlight why systems are not working efficiently and identify the gaps, and members of the group have been working hard to look at services and what support is available.

- The group have recently connected with Bristol PPV group to share experiences and some members will be attending the National PPV event in Leicester in March.
- Working with charities - Nathan Askew, Chief Nursing Officer, Alder Hey is to be invited to a future meeting to look at how Alder Hey work with other charities and how CHD families a can be supported.
- A number of PPV representatives will be coming to their end of office period later this summer and the group is looking at ways to recruit new members.

# Item 11 – Risk Register

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

**Lack of funding to support the transformational work that would be required to create a Single Paediatric Cardiology Service** (20) →
Agreed to remain at 20. Without the necessary funding then all of the other risks cannot be improved significantly and there is a large cummulative risk associated with not changing the current service model. still awaiting NHS England approval of the business case.

**Backlogs at RMCH and Alder Hey** (16) ↑
Recently increased to 16 due to the increase in backlogs at Alder Hey in particular. Clinicians and Operational managers aware and considering what options are available to them. Options limited within current service model.

**Backlogs at MRI** (12) →
Backlogs at MRI are slowly improving but remain high. It is agreed that everythign is being done to improve use of clinic capacaity with improved bookings and use of telephone clinics. The numbers are unlikely to come down significantly with the current respources.

**ICC Service North West** (15) →
No change to report. Work being done nationally to develop service specifications for paediatric ICC. Business Case in development at Alder Hey only. ICC specialist Nurse now appointed permanently at Alder Hey

**Cardiology Staffing at RMCH** (6) ↓
Reduce from 12 following the appointment of two Paediatric Consultant Cardiologists.

**Psychology Provision** (12) →
Remains the same

**Database** (12) →
Project continues to progress and on track

**Insufficient number of cardiac nurse specialists at RMCH** (12) →
No change. Banding remians different across level 1 + 2 centres. There is no dedicated fetal nurse or transition nurse at RMCH

**Paediatric Cardiac Physiologists** (12) →
Situation remains difficult with Alder Hey offering to support the situation at RMCH – although not sustainable in the long term

**Funding for Network** (12) →
Business case rejected by NHSE – therefore funding will not match work that is required by NHSE specification. Not able to continue with funding project manager after June 2024.

Note: Paediatric cardiology
It was agreed last year with managers from RMCH and Alder Hey, commissioners and Network staff that risk registers needed to be aligned. LG proposed to send out the updated risk scores to ensure that alignment can continue.

**ACTION:** LG to update Alder Hey, RMCH and Commissioners of current risk scores.

# Item 12 – Ratification of Network Documents

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

There are no documents to be signed off.

# Item 13 – Any Other Business

- Today's meeting is Chair, Nayyar Naqvi's last meeting. Nayyar thanked all members of the board for their support over the past four years and to the new members of the board that have joined today and contributed to the meeting.
- On behalf of the Network, Nicola Marpole thanked Nayyar for all his support, commitment, and leadership, not only to the Network but to all CHD services during his career. Nayyar will be very much missed, and all members present wished him all the very best for the future.
- Caroline Jones also thanked Nayyar on behalf of herself and Damien Cullington, as new Clinical Directors of the Network for his level of determination, commitment, positivity and enthusiasm for change, he will be very much missed.

# Date of Next Meetings

***Tuesday 21st May 2024 1.30pm-3.30pm via MS Teams***

***Monday 12th August 2024 2.00pm-4.00pm via MS Teams***