

NW CHD Board Meeting Summary Notes 24th January 2022

Chair: Nayyar Naqvi, Emeritus Consultant Cardiologist



Table of Contents

Item 1 - Welcome & Apologies	3
Item 2 - Board Notes & Action Tracker	4
Item 3 - Network Update	5
Item 4 - Paediatrics Partnership Update	5
Item 5 - Data & Regional Updates	6
Item 6 - Network Board Review	8
Item 7 - Risk Register	10
Item 8 - Database & Single ACHD PTL (Patient Treatment List)	10
Item 9 - Patient Representatives	11
Item 10 - Commissioner Update	11
Item 11 - Any Other Business	12
Date of Next Meeting: Wednesday 27th April 2022 10am-12noon	12



Item 1 – Welcome & Apologies

Present:

Abby Peters (AP)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Anna Harrison	Lead ACHD Nurse Specialist	Liverpool Heart & Chest Hospital NHS FT
Bernard Clarke (BC)	Consultant Cardiologist	Manchester University NHS FT
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Helen Sanderson	Network Manager	NW CHD Network
Gordon Gladman (GG)	Network Clinical Director & Consultant Paediatric Cardiologist	NW CHD Network
Janet Rathburn (JR)	PPV Representative	NW CHD Network
Jemma Blake (JB)	Clinical Data Manager	NW CHD Network
Jill Moran (JM)	Network Support Officer	NW CHD Network
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Nayyar Naqvi OBE (Chair) (NN)	Emeritus Consultant Cardiologist	Wrightington, Wigan & Leigh NHS FT
Rachael Barber (RB)	Consultant Paediatric Intensivist/Deputy Medical Director/RMCH Paediatric Clinical Lead	Manchester University NHS FT
Rob Johnson (RJ)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT
Sarah Vause (SV)	Consultant Obstetrician in Fetal & Maternal Medicine	Manchester University NHS FT
Paul Willgoss	PPV Representative	NW CHD Network



Apologies:

Andrea Richards (AR)	Specialised Planner – Cardiac Services	Welsh Health Specialised Services Committee
Clair Noctor (CN)	Cardiac Specialist Nurse	Manchester University NHS FT
Gopi Vemuri (GV)	Consultant in Neonatology & Paediatrics	Manchester University NHS FT
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children’s Hospitals NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest NHS FT
Phil Rigby (PR)	Service Specialist (Specialised Commissioning Team)	NHS England and NHS Improvement – North West Region
Vasileious Papaioannou (VP)	Consultant in Neonatology & Paediatrics	Liverpool Heart & Chest Hospital NHS FT

Declarations of Interest: None

Item 2 – Board Notes & Action Tracker

Meeting notes from NWCHD Network Board meeting on 28th June 2021 were circulated prior to the meeting. No comments or amendments to record and all agreed accurate record.

Action 33 – Network MOU – IoM and Wales still outstanding. Meeting in December with Andrea Richards – Welsh Commissioner was cancelled and to be rearranged. IoM meeting still to be arranged. HS to conclude before going on maternity leave - **IN PROGRESS.**

Action 36 – Network Operational Delivery Group – Terms of Reference for this group have now been shared with Board members. HS reported that due to staffing issues within the Network at present, the Operational Group meetings have been put on hold and will keep the Board updated of progress - **IN PROGRESS.**



Action 38 – RMCH Resources. **Admin Post** - (B4) has now been recruited to (hours TBC). **Locum Consultant** - An offer has been made to a candidate who has worked with us here as a trainee before – start date TBC pending recruitment checks etc – **ACTION TO BE CLOSED – to be reflected in the Risk Register.**

Action 39 – NCARDRS – Update received from Nicola Miller 02/08/21: Where there are MOU's in place between trusts data can be released to a named senior person. Request for data to be made. Newcastle CHDN agreed to share their knowledge and process for retrieving the data and a meeting to be arranged to discuss – **IN PROGRESS.**

Action 43 – Governance Structure – HS circulated to the Board, no comments received, for further agreement on today's agenda – **ACTION TO BE CLOSED.**

Item 3 – Network Update

Discussed in item 5 Network Board Review.

Item 4 – Paediatric Partnership Update

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

- A new Consultant started in post November 2021
- Cardiology MDT team participating in team development project with OD&T colleagues.
- Statement of case approved at RMCH Finance and Investment Committee, now moving to a full business case for additional workforce (consultant, clinical fellows, specialist nurses, sonographers and secretarial support).
- Partial booking has now commenced.
- Patient Initiated follow up – Further discussions underway before implementation
- Virtual triage, which includes Advice & Guidance has started for Paediatric Cardiology.
- Cardiology Improvement programme to begin in Jan 22
- Specialist nurses monitoring 'high risk' CHD patients & alerting consultants to ensure they are seen in a timely manner
- Continuation of Saturday clinics by RMCH and Alder Hey consultants
- Extended outreach clinics at Wythenshawe Starlight Unit to reduce variation between sites
- Establishment of a virtual MDT referral triage service with Oldham General Hospital



- Increasing strong links with NMGH and Oldham, General Hospitals to develop outreach clinics
- Procurement of three new Echo machines completed and in place
- Website update with all consultant and contact details for support continues

Item 5 - Data & Regional Updates

HS apologised to Board members that the data slides had not been circulated prior to today's meeting, this was due to staff sickness due to OMICRON and Christmas period leave.

Jemma Blake, Clinical Data Manager, NW CHD Network presented a summary of the data returns for paediatrics and ACHD for Alder Hey Children's Hospital, Liverpool Heart and Chest Hospital and Royal Manchester Children's hospital. **ACTION: Slide pack to be shared with board members.**

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

Paediatrics - Alder Hey Children's Hospital:

- Substantive recruitment of Dr Phuoc Duong, Consultant Cardiologist
- Upcoming retirement of Dr Ian Peart
- Workforce succession planning including full consultant job plan review
- Recruitment of a dedicated Clinical Fellow in Cardiac Anaesthetic team
- Internal development for Cardiac nurses with defined competency pathway
- Development of CardiCare internally to support with safe data storage
- Potential expansion of Ward 1C (Cardiac unit) due to new Neonatal build
- Development of digital catheter pathways
- Charity funding for purchase of new ECHO machine
- Development and growth on social media platform
- Improved relationships and development with All Age Network with LHCH and support of CHD Network
- Reverted back to all pre-COVID templates for outpatients
- Increased visits to peripheral sites to support with local backlogs
- Defined patient lists due to Trust wide validation project with support from new data assurance team
- Revised theatre schedule to support COVID surges and continued staff absence
- Increased theatre sessions at LHCH to support with high demand back logs



Paediatrics - Royal Manchester Children's Hospital:

- A new Consultant started in post November 2021
- Cardiology MDT team participating in team development project with OD&T colleagues.
- Statement of case approved at RMCH Finance and Investment Committee, now moving to a full business case for additional workforce (consultant, clinical fellows, specialist nurses, sonographers and secretarial support).
- Specialist nurses monitoring 'high risk' CHD patients & alerting consultants to ensure they are seen in a timely manner
- Group in place to implement: -
 - Partial booking has now commenced.
 - Patient Initiated follow up – Further discussions underway before implementation
 - Virtual triage, which includes Advice & Guidance has started for Paediatric Cardiology.
 - Cardiology Improvement programme to begin in Jan 22
- Specialist nurses monitoring 'high risk' CHD patients & alerting consultants to ensure they are seen in a timely manner
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- Website update with all consultant and contact details for support continues

ACHD - Liverpool Heart & Chest Hospital

- New Patients- Total cohort currently 494- these are a mixture of transition patients, patients referred from other cardiologists, pts who have moved in to the area etc.
- LHCH PAS system does not have the function to demonstrate if they have breached their expected contact date. All of the OWL of un-booked patients has been recently validated.



ACHD – Manchester Royal Infirmary

- We identified the PHT clinics had previously been excluded and these now appear in the figures. We also acknowledge PFO and ICC patients have been pulled through in the data. Validating underway.

Damien Cullington, Consultant Adult Congenital Cardiologist / ACHD Clinical Lead, Liverpool Heart & Chest Hospital, NHS FT:

- Over the Christmas period there were only three out of the six ACHD cardiologists covering the service and two members of staff returned to work following long term sick leave. Shortly to go out to advert for a locum consultant.
- Waiting list is reducing despite pressures that are being put upon the service in terms of GA and ODP availability.

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

- DNA rates for certain groups of patients – virtual appointments working well especially for genomic patients. Not suitable for all patients, some require face to face appointments for echos, ECGs etc.

Bernard Clarke, Consultant Cardiologist, Manchester University NHS FT:

- New system EPIC being implemented across the Trust in autumn 2022 which will assist with any conflicting data issues.

Item 6 – Network Board Review

HS updated the group on the Network's staffing situation changes. Linda Griffiths was taken ill in December and will be off for over six months. HS is also due to go on eighteen months maternity leave from the beginning of February, and Sarah Ellison, Primary Care Lead, resigned from the Network in December.

HS confirmed that her position has been sent out to advert but there will likely be a gap before they commence in post.

HS is awaiting to hear from Commissioners regarding funding to further cover remaining staff contracts and assist the continued work of the Network.



Nayyar spoke of his admiration for colleagues and members of the board and the hard work achieved by the Network to date and spoke of his concerns of challenges to come regarding the existence of the Network and the impact it will have on patients especially paediatrics.

Network achievements should be acknowledged including Data Collection. GM commented that the Network's Governance structures have improved immensely from the initial national peer review allowing the Network to be more influential in its decision making.

JR expressed concerns regarding the future of the PPV group (Patient Public Voice) with the current changes to the Network. The PPV are a very comprehensive group of representatives that have a lot to offer and JR is determined to do all she can to keep the group going.

HS reported that the Annual Report for 2021 is currently being written. HS commented that it will highlight the achievements of the Network from education and training, to clinical governance and data.

LG has championed a number of Network projects including a National Education survey for band 5 nurses to assess their feelings looking after CHD patients. This led to the concept of e-Health Learning modules, which with the help of funding from Health Education England, were able to be offered free to all nurses and Allied Health Professionals across the country.

AP reiterated the recognition of the Network's transformation from informal clinical network to a formal operational delivery network and the feedback being received nationally, is that the Network is playing a significant role in fulfilling its responsibilities. Feedback from Commissioners and nationally, are recognising how the Network has grown its role, responsibilities and confidence. It is unfortunate the Commissioners were unable to attend this meeting today and we await their decision.

AP is due to go on maternity leave also at the beginning of April and asked for her personal reflections to be noted; "it has been an absolute pleasure working with Helen and Linda over the past eighteen months and they have done a significant job."

AP informed the board that there have been a few requests to commissioners for support from across the system in CHD and that its helpful for the board to have awareness of that. CHD is at a bit of a crossroads, there is recognition nationally that that it's underfunded in certain areas and there are changes that need to happen. Within the North West things have come to a bit of a bottleneck in the last six months.

NN further commented that the Network is facing challenging times with the loss of valuable contributions from Helen and Linda and we await confirmation from Commissioners regarding additional funding to support the future of the Network and thanked Alder Hey for their support and input to the Network.



Item 7 - Risk Register (Risk Score >12)

Discussion of risks included:

CHD Network Risk Register Summary (24.01.2022)

(2332) Challenges to finding a solution to providing a "single service" model for paediatric cardiology may result in delays to patient treatment. This may result in potential harm due to inequitable service provision across the paediatric congenital heart disease operational delivery Network in the North West (18)
(2383) Psychology provision not meeting minimal NHSE Standards. Currently only able to focus on more severe presentations or crisis management for patients. Therefore, risk of negative impact on mental health of patients by not being able to provide timely care to avoid exacerbation or progression of presentation (16)
NEW (2536) The network does not have the financial resources to backfill senior leadership posts to the level needed. (16)
NEW (2535) The Network has no direct nursing input. the network SLT is reduced by one third. the lead nurse is a full-time post, therefore the work the network can produce will be reduced. (15)
(2339) Back logs in Blackpool could result in risk of delayed treatment resulting in potential harm to patients. (12).
(2284) Inability to store and share images in a suitable format may result in potential delays in clinical decisions and management plans being made for patients. (D8) (12)
(2331) Fetal Nurse provision is not equitable across the Network (12).
(2375) (NWTs) is not commissioned to transfer high dependency (non-ventilated) patients with complex heart failure who need to be assessed/treated in transplant centres across the UK. Potential delay or inability to transfer patients for transplant assessment in a timely manner. (10).
(2285) Impact of COVID-19 Pandemic on the ability of providers within the North West Congenital Heart Disease Network to continue to provide normal services and impact on the CHD ODN to monitor the situation operationally. (9).
(2276) No Network database therefore unable to collect data and therefore fails to meet NHS England Congenital Heart Disease (CHD) standard F10 (L1) (9)
NEW No access to dental treatment for patients with complex ACHD requiring GA risks causing delays in congenital heart surgery/intervention where dental treatment is required prior to their procedure. Patients will have an increased risk of developing endocarditis (9)
NEW Long-term sickness amongst ACHD Consultant Team risks creating further backlogs of patients waiting to be seen and the inherent risks that poses to patient care (9)

Item 8 – Database & Single ACHD PTL (Patient Treatment List)

Helen Sanderson, Network Manager, NW CHD Network.

- Work continues on the Network database.....
- Reviewing quotes from potential suppliers
- Funding – raised with Commissioners, awaiting response, however, staffing of the Network will take priority



Item 9 – Patient Representatives Update

Janet Rathburn, PPV Representative & Chair of PPV Group & Janet Lamb, PPV Representative.

The PPV Group have been discussing the following:

- Across the full age spectrum covered by the NW CHD Network there is considerable anxiety regarding the ongoing impact of the pandemic on services. The PPV have agreed that they are sufficiently concerned by continuing levels of anxiety that a follow up to the previous virtual meeting should be organised as soon as possible in Feb/March
- CHA is prepared to provide the online platform(Zoom) for this meeting but require Network and Clinical Support to address:
 - a. The overall situation of the services (paediatric, transition and adult)
 - b. Impact on timings of:
 1. Appointments
 2. Tests
 3. Interventions
 4. Surgeries
 - c. Current advice on vaccination, boosters, status regarding provision of anti-viral therapies etc
 - d. Mechanisms for contacting the service if they feel there is a worsening in condition
 - e. Mechanisms for contacting the service for issues where the heart condition impacts on other issues; schooling, Further and Higher education, employment, benefits etc.
 - f. Non-COVID issues impacting on the service
- Specific rules for the meeting will be agreed between the CHA team providing the moderation and speakers

Network will continue to distribute information regarding access of services via Twitter and the website and a newsletter will go out towards the end of February.

Item 10 – Commissioner Update

Apologies have been received from Phil Rigby, Service Specialist (Specialised Commissioning Team), NHS England & NHS Improvement – North West Region.



Item 11 – Any Other Business

Anna Harrison, Lead ACHD Nurse Specialist, Liverpool Heart & Chest Hospital NHS FT, commented that she is working with the ACHD nursing community in Linda's absence to ensure the service is supported and working with teams to ensure vacancies are filled.

Date of Next Meeting

Wednesday 27th April 10am-12noon

Friday 15th July 10am-12noon

Monday 17th October 10am-12noon

