

# NW CHD Board Notes

## 26<sup>th</sup> March 2021

Chair: Nayyar Naqvi, Consultant Cardiologist, Wrightington Wigan & Leigh NHS Foundation Trust



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# Item 1 – Welcome & Apologies

## Present:

Abby Peters (AP)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Bernard Clarke (BC)	Consultant Cardiologist	Manchester University Hospitals NHS FT
Caroline Jones (CJ)	Clinical Lead & Consultant Fetal & Paediatric Cardiologist	Alder Hey Children's Hospitals NHS FT
Clair Noctor (CN)	Cardiac Specialist Nurse	Manchester University Hospitals NHS FT
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
Daniel Short	Project Manager	NW CHD Network
Helen Sanderson	Network Manager	NW CHD Network
Gopi Vemuri (GV)	Consultant in Neonatology & Paediatrics	Manchester University Hospitals NHS FT
Gordon Gladman (GG)	Network Clinical Director & Consultant Paediatric Cardiologist	NW CHD Network
Janet Rathburn (JR)	PPV Representative	NW CHD Network
Jemma Blake	Clinical Data Manager	NW CHD Network
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Nayyar Naqvi OBE <b>(Chair)</b> (NN)	Consultant Cardiologist & Responsible Officer	Wrightington, Wigan & Leigh NHS FT
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children's Hospitals 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 Hospitals NHS FT



## Apologies:

Andrea Richards (AR)	Specialised Planner – Cardiac Services	Welsh Health Specialised Services Committee
Jill Moran (JM)	Network Support Officer	NW CHD Network
Joe Downie (JD)	Service Specialist - CHD	NHS England
Lowri Smith (LS)	PPV Representative	NW CHD Network
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest NHS FT
Denise Szpunar (DS)	Network Manager	NW CHD Network
Vasileious Papaioannou (VP)	Consultant in Neonatology & Paediatrics	Liverpool Heart & Chest Hospital NHS FT

**Declarations of Interest:** None

## Item 2 – Board Notes

Meeting notes from NWCHD Network Board meeting on 27<sup>th</sup> January 2021 were circulated prior to the meeting. No comments or amendments to record and all agreed accurate record.

## Item 3 – Action Tracker

**Action 9** – Risk Register – All Network risks now registered on the Alder Hey Ulysses system **ACTION TO BE CLOSED.**

**Action 12** – Ratification Policy – signed off on at the 27<sup>th</sup> January meeting – **ACTION TO BE CLOSED.**

**Action 28** – Patient Backlog Data – presented at 27<sup>th</sup> January meeting. Data has been shared with PPV group. Network meeting regularly with paediatric and adult teams – **ACTION TO BE CLOSED.**

**Action 29** – Lost to Follow Up – a small project group now set up with PPV Representative identified – **ACTION TO BE CLOSED.**



**Action 30** – Network Database – MOSCOW survey now completed. Membership expanded to include the whole of the Network. Next steps being agreed at the Task & Finish Group with the Operational Sub-Group meeting fortnightly – **ACTION TO BE CLOSED.**

**Action 31** – COVID Advice – Welsh Healthcare service have been contacted re advice on sharing information on the website. Re the Isle of Man – a new PECSIG has been appointed and the Network will make contact. Working with MFT to share information on their website. Links on LHCH & Alder Hey website – **IN PROGRESS.**

**Action 32** – Network Risk Register – emails have been sent to Level 1, 2 & 3 paediatrics & adult centres requesting to share any CHD significant risks on their registers with the Network. As information is received it will be fed into the Risk Register – **ACTION TO BE CLOSED.**

**Action 33** – Network MOU – still awaiting MOUs from Isle of Man and Wales. The Network will continue to monitor progress of completed MOUs – **IN PROGRESS.**

**Action 34** – Patient Backlog Data – The Network continue to review the quality of the data although improving – **IN PROGRESS.**

**Action 35** – Network Delivery Group Proposal – proposal to be written and presented to the Board – to be discussed at agenda item No.5 – **IN PROGRESS.**

## Item 4 - Regional COVID-19 Updates & Impact on CHD Services

### Paediatric CHD at Alder Hey:

Increased clinic capacity to 10 patients per clinic. Managing back-logs closely using monthly data. Running network peripheral clinics as usual with slightly reduced numbers. Surgical and catheter lists running at full capacity with some recent lists being cancelled because of anaesthetic cover. Interventional and surgical waiting lists are very good with no backlogs reported. Increase in PIMS-TS patients in January/February has now resolved. Overall, it is 'business as usual'.

### ACHD (LHCH and MFT):

Out-patient services now fully restored. Increasing surgical numbers over the next couple of weeks and intervention back to normal.

Manchester still restricted in the numbers that can be seen face to face. This is counteracted by Saturday clinics which are helping to manage the backlogs. Hoping to see final 300 patients from the backlog and aiming to be at normal activity by the end of the summer. Overall feel the situation is continuing to improve. Confidence expressed that all previous patients from historical PTL at Manchester and the patients found



within the Cardex Database are now all known about. Working towards having one patient list for the whole of the North West. Urgent patients can easily be seen within 24-48hrs of contacting the team.

Cardex Update – There were 3000 individuals identified in the database. This data has gone to an independent review by colleagues in Leeds. The preliminary draft report suggests that there doesn't seem to have been a significant amount of harm caused, although the full report is still awaited

### **Paediatric CHD at RMCH**

Had over a thousand new patients waiting to be seen. Since October 2020 and with the assistance of cardiologists from Alder Hey have been running Saturday clinics. No patients are waiting over 12 months to be seen for a new appointment now which is an improvement. Transition activity has increased by 42%.

### **Maternity (St Mary's – Manchester)**

Maternity services not greatly affected by the pandemic. Services have improved with more choice for patients. Virtual appointments now being offered. Focus currently on the vaccination of pregnant women. Those meeting the NHS MCS criteria (prescribed by a doctor), have a BMI over 40 or have diabetes are offered a vaccination during pregnancy.

The Pregnancy Cardiac Guidelines is due for renewal and will be distributed across the obstetric Greater Manchester and Eastern Cheshire local maternity system. On completion of the renewal the guidelines will be brought to this board.

Nationally, maternal medicine networks are being set up. This will include the whole of the North West and patients with CHD will be part of the group that are covered by this network. Royal College Obstetricians – an extra £95 million for looking at safety in the follow on from COVID.

### **Paediatric Level 3 (Wales)**

Backlogs still the main issue. Despite additional clinics waiting lists remain high, currently approximately 125 patients. Working closely with administration and management to identify urgent patients. Alder Hey clinicians supporting where possible. The situation is similar across all peripheral clinics and is being monitored.



## Item 5 – Operational Group Proposal (Slides 9-19)



Board Agenda  
Presentation 26-03-2

A proposal was presented to the Board for an Operational Delivery Group to be added to the NW CHD Network structure. Please refer to slides 9-19 on attached Board Agenda Presentation.

### Board Feedback and discussion

- Concerns of wider membership resulting in busier meeting schedules and the quality of deliverables. Need to be cautious and mindful of busy clinical roles of members.
- The above concern acknowledged. The aim is for the Operational Delivery Group meeting to absorb many of the individual meetings that are currently happening and to focus them in one meeting a month instead. This should result in a reduction in the number of meetings overall.
- Request for the PPV group to be included within the new structure and to be clear about what is expected from the PPV group.
- MFT to be represented fully and to include Wythenshawe. Having the correct representation is important and recommend including deputy medical director of RMCH.
- Concerns developing this group this year is slightly ambitious given that clinical focus is currently to deal with the backlogs. Need to focus on the clinical time involved and what the current priorities and risks.
- How does the Network feed into the operational meetings looking at the service at RMCH? Everyone needs to prioritise improving and supporting the delivery of the service at RMCH.
- Identify who has the time to be involved in the first instance. Co-opting operational managers and other senior nursing roles would be vital.
- Split into Adults and Paediatric Operational Groups.
- Concerns equally expressed on behalf of peripheral clinics and the ability of PECSIG's to be involved

Board Agreed to look at setting up an operational delivery group for the Network with representation from operational managers and senior nurses as outlined. Dr Gordon Gladman to attend and represent clinical leads from paediatrics and adult services in the first instance.

**ACTION: Network to set up Operational Delivery Group and agree ToR. Plan to evaluate after 12 months and feedback to be sought from the Board as to relevance/effectiveness. If agreement that group is working well will then write into the operational framework for the Network**



## Item 6 – Governance Framework (slides 20-21)

The Network Governance Framework which was created in 2013 for ODNs (Operational Delivery Networks) to monitor progress against governance arrangements. The Network has adapted this model to monitor set criteria using a RAG rating system. This needs to be assessed and monitored on a yearly basis moving forward. (Please refer to slides 20-21)

Request for the PPV group to be included in the Framework. Additionally, for the PPV Group to have clarity regarding the workplan – what are the objectives of the PPV group from the Network?

Board agreed to sign-off of the Governance Framework.

**ACTION: Network to work with PPV Group to clarify workplan and what is expected from the PPV Group. HS asked the Board for agreeance and sign-off of this document?**

## Item 7 – Annual Work Plan (Slide 22)

Annual Work Plan shared with the additional papers to Board members prior to the meeting. It is based on the Network's strategic aims and every action or deliverable based on either a national standard, one of the four pillars of the ODN or the SCC 1888, which is a paper issued by the National Commissioning. Working closely with Commissioners to review progress.

The work plan details scheduled achievements for the next twelve months, with IT and the database expected to be longer.

Board's comments requested and approval sought. If all agree to sign off it will be forwarded to the Commissioners to incorporated in the contract in April. Some Board members don't appear to have received the papers prior to the meeting.

**ACTION: HS to circulate the Board papers again for review and comments to be sent back by Monday 26<sup>th</sup> April 2021**





## Item 8 – Risk Register (Risk Score >12) Slide 23

**(Risk 2332)** Remains top priority to develop a single partnership service for paediatric cardiology patients. Risk to patient safety and patient care paramount to keeping the momentum going to push for a single service.

### Further Comments

Risk register currently hosted on the Ulysses system at Alder Hey but is independent of Alder Hey risks and represents Network risks only.

Suggestion for the Network to review how the risks are presented to the Board i.e. clarity on the narrative, what actions are being taken and what the final risk is. The risk register should be driving the main priorities for the Network and is crucial. The Operational Group would be the ideal forum to review the full risks whilst the Board needs to consider those scoring > 12 and in order to put pressure on Trusts to resolve their risks within a certain time period.

**ACTION: The Board to receive full Risk Register document going forward for further clarity at least 2 weeks prior to each meeting.**

## Item 9 – Digital Solutions (slide 24)

The Network led a nationwide audit into nurse education in June/July last year. Abstract submitted to The ESC Euro Heart Care meeting in June. 30% of Band 5 nurses have not received any training in CHD in the past 2 years. Of those that have received some training a significant number have only engaged in self-directed learning. These band 5 nurses are the nurses delivering care at the bedside.

A communication audit is currently underway which also suggested that families also feel very anxious particularly in non-cardiac settings. Those families who had access to hand-held notes were at a clear advantage in terms of communication between level 1 centre and 3 centres.

Proposal to set up a small Task & Finish Group to discuss digital solutions and drive this forward.

### Feedback/Discussion

- Agreed webinars and technology a great source.
- MFT are to go live with a new EPR in 2022, EPIC. The idea raised for a patient portal.
- Not all organisations will have access to the EPIC system.
- PDF documents accessible on mobile devices is useful.
- Need to consider getting Trusts to use Share2Care which facilitates access to medical records for staff
- Contact the Alder Hey Innovation Hub for advice on solutions recommended.



The Board agreed for LG to set up a Task & Finish Group.

**ACTION: Task & Finish Group to be set up to consider options/solutions**

## Item 10 – Patient Representatives

- The PPV Group currently focusing on the concerns with MFT and their recent meeting with Medical Directors and Senior Clinical Leads. The team presented the group with very comprehensive answers to their questions: -
  - MFT reassured the PPV Group that no patients have been lost to follow up.
  - Prior to the pandemic waiting lists were working well within the 18-week pathway and they hoped to be back on track by June and they will let the group know if that is not going to happen.
  - MFT updated the group with the plans for the North West Children's Heart Partnership with Alder Hey, which is very encouraging. Concern raised by the PPV Group that this work moves at pace as the concerns are real and valid now. Also concern that change happens from the bottom up and not just at a strategic level.
  - Concerns about PAS were raised. Aware of new PAS/EPR EPIC system going live in 2022. Concern about delayed appointments and waiting times.
  - Group very concerned about the lack of admin support and would really urge that something is done to resolve this as quickly as possible.
  - Letters to parents – confusion regarding changes to appointments due to COVID and the PPV Group is working with MFT to follow this up.
  - MFT have asked for PPV reps to work with them on IT systems, possible patients lost to follow up and various other projects.
  - Follow up response to the MFT reply will be worked on at the next meeting.
- A 'house-keeping' meeting was held to address how the PPV group meetings are run.
- Agreed to have a chair – Janet Rathburn has been appointed.
- LG & AR to look at the structure of the meetings – currently meeting fortnightly and want to make sure that time and effort is maximised.
- Review of the Action Tracker on the agenda.
- To review and create a work plan for the PPV Group
- The PPV group did have concerns about the risk register and the report used previously. This has now been answered as part of this meeting.
- They welcomed two new members at the last meeting
- PPV group is very committed to helping the Network achieve its aim of delivering a high-quality service

**ACTION: Chair agreed for the Network to investigate further the lack of administrative resource at MFT and to encourage investment in that area.**



## Item 11 – Antenatal Detection – NCARDRS vs NICOR

Network standards state that we need to monitor regional antenatal detection rates of heart disease across the Network.

- The North West region is average compared to the UK.
- The National Institute of Cardiovascular Outcomes Research (NICOR) – documents antenatal detection of babies and children who have surgery or intervention only.
- NCARDRS (National Congenital Anomaly and Rare Diseases Registration Service) – Public Health England collect all antenatal detection including babies who haven't any surgery or intervention.
- NCARDRS data is more precise than NICOR data
- NICOR data is more accessible but is not as up to date
- The Network has been negotiating with NCARDRS to facilitate access to their data. Awaiting feedback from PHE as to whether this will be possible.
- Suggestion that both sets of data are useful
- Will assist for data for the annual report.
- Data will help focus training requirements where it is required.
- Fetal Anomaly Screening Programme (FASP) is only currently screening for 4 main cardiac anomalies.
- Role of fetal cardiac nurse specialist emphasised as being important and the current gap that exists at St Mary's in Manchester was raised by PPV Group
- Commissioners keen for the Board to decide what data set was to be used in the North West CHD Network to monitor.

**Decision:** NCARDRS data felt to be more up to date and reliable than NICOR. However, both sets of data can be useful.

**ACTION:** Network to continue to press NCARDRS to ensure that their data is easily accessible for the Network

## Item 12 – Annual Report

The Network's draft Annual Report for 2020 has been sent to all board members for review and comments. If no comments are received within a couple of weeks the report will be published on the Network website.



## Board Discussion

- PPV group – great that the report is very positive however a question raised that it also needs to reflect the issues raised regarding backlogs and the issues regarding data issues at MFT.
- Request for Obstetrics to be made more prominent within the report – SV has sent over comments.

**ACTION: PPV Group, SV & BS comments, together with any further comments received from other Board members in the next fortnight, to be incorporated into the final annual report document.**

## Item 13 – Annual Finances (Slide 28)

Update regarding the Annual Budget for the Network provided.

Current annual budget from NHSE is £200,000 per year. Last year all the annual budget was spent. This year we have > £2000 left for non-pay requirements which is not very much.

In 2019 we had an underspend budget which is being used to fund project managers and to spend on projects. Once this underspend has gone it will not be replaced. The Network is just about break-even paying salaries only. The Network will need to look at Board payments of £3000 per year which is costing the network £40,000 a year. This will need to be reviewed over the next year as this contribution cannot continue.

Will present the underspend budget to next Board.

## Item 14 – Data Update (Slides 29-39)

Plan to update the Board at each meeting about data submissions.

### Paediatric Data

#### Alder Hey Children's Hospital:

- Increase in the total number of new appointments in January. This has now come back down due to the increase in clinics being held. Patients waiting over 3 months has increased but there are no patients waiting over 12 months for a new appointment.
- Backlogs in follow up appointments have increased. This is mainly in patients overdue an appointment by 3-12 months with very few waiting more than 12 months.
- Total number of referrals and DNA rates also recorded more recently
- AHCH are happy and confident in the quality and accuracy of their data and the consultants can regularly review their own patients.
- 



## RMCH

- RMCH no longer cancelling and rebooking appointments.
- RMCH have been able to share referral rates per month. The Network is now looking at collecting this data for all paediatrics.
- Total number of new patients waiting to be seen is reducing and there are no longer any patients waiting more than 12 months for a new appointment.
- Number of follow up patients has risen sharply since change in practice from 49 patients overdue an appointment by > 3months in Oct 2020 to 817 patients > 3 months in Feb 2021. Patients overdue by >6-12months remains very low.

## Discussion:

- There are a large number of paediatric new referrals being received every month. Not all of these are appropriate to be seen at RMCH and AH.
- Paediatric Cardiology Outpatient Referral Guidelines have been written and shared with RMCH for comments.
- Highlighted the importance of Network pathways being used comprehensively by all providers.
- Network is going to start collecting DNA numbers for all paediatrics
- The Network will start looking into RTT figures and how they are collected for CHD.
- Concerns regarding data accuracy remain. Clearly need to keep monitoring this.
  - Backlogs at Alder Hey for f/u patients is accurate and a reflection of what would be expected post COVID. Extra clinics are once again being employed as part of their action plans to deal with this. This includes clinic capacity being increased back up to 10 patients with clinical validation occurring on a monthly basis on the backlog patients.
  - The RMCH numbers don't seem to add up. To have no one waiting for an outpatient appointment > 6 months can't be true. They had a total cohort of 5200 that now seems to have reduced to 3800.
  - It therefore doesn't make sense that clinicians from Alder Hey are going to Manchester to do extra clinics at the weekend when on paper the backlogs look worse at Alder Hey.
  - The capacity available at RMCH is much reduced compared to the capacity to deliver clinics at the Alder Hey site therefore these numbers do not make sense.
  - Acknowledgment that everyone is working together to find solutions to these issues, and everyone is working hard towards this aim.
- Saturday clinics helping to ease the backlogs at RMCH
- RMCH – new locum consultant in post from 1<sup>st</sup> April. RMCH remains very short staffed.



## Adult Data ACHD - LHCH Summary

- The historical PTL from Manchester including the extra patients who were lost from PAS but found within the Cardex Database has been the focus for adult services up until now. All the urgent patients have now been seen and most of the patients who needed to be seen within 6-12 months.
- Will be merging this data with real time monitoring of the PTL as per the paediatric services moving forward.
- Both LHCH and MRI are in the process of reviewing and improving the quality of their data and are in the process of undertaking a data cleanse. Hence no data received for February from LHCH or MRI but there is an expectation that this will resume from March 2021.
- Both centres noted high DNA rates, the Network would like to look at collecting this data in the future.
- Both centres noted that they didn't have the staffing to validate the lists on a regular basis.
- Concern that MFT don't seem able to identify backlogs in the same way as paediatric services. Therefore, a concern that the data being sent from adults is reflective of all patients waiting rather than backlogs alone.
- PPV Group concerned about the numbers of patients who still appear to be waiting a long time to be seen. Reassurance given that all adult patients are now known about and all patients have been clinically validated but undoubtedly has meant that some patients have waited a long time to be seen. This is gradually improving.
- It would be helpful to have IT systems that were willing to make the data work for clinicians and to create data that is meaningful and trustworthy.

**ACTION: HS to re-send data out to Board members**

## Item 14 – Ratification

A proposal was presented for the ratification of documents to be approved at Ratification Task & Finish Groups (Paediatrics & Adults) on behalf of the Board? This will allow updated information to be distributed in a timelier manner given that the Board only meets every three months.

**ACTION: Approved**

## Item 15 – Any Other Business

- Adult Congenital Echo Department have been certified by the British Society of Echo (BSE) congratulations for the hard work and effort from the Board for this achievement.
- Thinking about the effort being put into validation & revalidation across the network. Would it be helpful for the Network to provide guidelines around recommended follow up time frames to facilitate consistency?



- Notes of the Board to be shared with MD's from AH & RMCH. The notes from the Network Board are also available on the Network website.

**ACTION: Board notes to be shared with all Medical Directors from LHCH, MFT, RMCH and AH**

**Commissioning Update**

- ACHD reviews ongoing. Internal investigation report received, awaiting Mortality Review and Systems Audit. Spec Comm will be completing a Quality Review tabletop exercise of the reports on 4<sup>th</sup> May. This will review the findings of the reports where we will make their own findings and recommendations to be fed back to MFT and then subsequently to the Network. This may include some short and long term recommendations.
- Paediatric Partnership Group – Michael Gregory and Joe Downie will be joining the Joint Clinical Working Group that has been established.
- Network – Spec Comm continues to work with the Network and support. The Network Work Programme and Annual report, once approved by the Network Board will be reviewed and signed off by Spec Comm and will be included in the contract for 21/22. Once work programme has been agreed then a more detailed plan will be completed with action owners, project updates etc.
- ODN's will be required to do a maturity self-assessment. There will be small groups set up to work on this and that if the CHD Network would like to participate in this work, they can be sent further information.

## **Date of Next Meeting**

**Wednesday 28<sup>th</sup> June 2021 10.00-12noon**

