

# NW CHD Board Notes

## 27<sup>th</sup> January 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
Damien Cullington (DC)	Consultant Adult Congenital Cardiologist / ACHD Clinical Lead	Liverpool Heart & Chest Hospital NHS FT
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
Jill Moran (JM)	Network Support Officer	NW CHD Network
Joe Downie (JD)	Service Specialist - CHD	NHS England
Linda Griffiths (LG)	Lead Nurse	NW CHD Network
Lowri Smith (LS)	PPV Representative	NW CHD Network
Matt Sandman (MS)	Consultant Paediatrician	Ysbyty Glan Clwyd Hospital
Nayyar Naqvi OBE <i>(Chair)</i> (NN)	Consultant Cardiologist & Responsible Officer	Wrightington, Wigan & Leigh NHS FT
Reza Ashrafi (RA)	ACHD Consultant Cardiologist	Liverpool Heart & Chest 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
Vasileious Papaioannou (VP)	Consultant in Neonatology & Paediatrics	Liverpool Heart & Chest Hospital NHS FT
Jemma Blake (JB)	Cardiac and Clinical Information Data Manager	Alder Hey Children's Hospitals NHS FT NW CHD Network
Kenny Ward (KW)	Project Manager	NW CHD Network

## Apologies

Andrea Richards (AR)	Specialised Planner – Cardiac Services	Welsh Health Specialised Services Committee
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Clair Noctor (CN)	Cardiac Specialist Nurse	Manchester University Hospitals NHS FT
Mike Bowes (MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Rafael Guerreo (RG)	Consultant Congenital Cardiac Surgeon	Alder Hey Children's Hospitals NHS FT
Denise Szpunar (DS)	Network Manager	NW CHD Network
Anthony Smith (AS)	PPV Representative	NW CHD Network

**Declarations of Interest:** None

## Item 2 – Introductions

Introductions were made and welcome extended to new members:

- Kenny Ward, Project Manager, NW CHD Network

## Item 3 – Board Notes, Matters Arising & Action Tracker

Meeting notes from NWCHD Network Board meeting on 28<sup>th</sup> September 2020 were circulated prior to the meeting. No comments or amendments to record and all agreed accurate record.

Action Tracker available but not reviewed during the meeting.

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

### Paediatric CHD at Alder Hey:

Extreme pressure continues during the second lockdown. Outpatients services continuing with 75-89% capacity (8 patients per clinic). Looking to increase to 10 in the next two weeks which will see a significant decrease in the backlog.

Data Manager providing a monthly report for overdue patients, which is allowing clinicians to validate patients who are overdue. Telephone clinics have continued but are limited when ECGs, ECHO etc are required.

Still have a few patients that are six months overdue, but majority are three/six months over their planned appointment.



All peripheral clinics are being run in a similar way with eight to ten patients per clinic. This includes the IOM and Barrow.

AH agreed to accept adult COVID-19 patients again. Currently have nine adult patients in self-contained ICU pods. This has had a small impact on Alder Hey's ability to provide surgery and interventions, predominately due to the loss of anaesthetic cover. Surgical capacity has reduced to 80%. However, still able to deliver emergency cover and most of the elective work. Cath lab is at 80% activity.

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

Wales a little behind everywhere else in terms of COVID-19. There is a significant waiting list throughout the region, but this is variable. The threat of losing outpatient services due to areas being taken over for COVID related activity is still there and needs to be monitored.

### **ACHD (LHCH):**

Out-patient services now fully restored with eight face to face clinics. Fewer DNA's recorded than during the first lockdown, so patients appear to feel safe to attend. There are no significant backlogs building up.

All elective surgical and interventional cases have been cancelled. Twenty-four ICU beds and a medical ward have been allocated to COVID-19 patients.

Awaiting confirmation regarding mutual aid of clinicians from LHCH supporting Alder Hey to manage their adult COVID patients and to support the chest physicians there.

### **ACHD (MFT)**

Currently have some limitations on out-patient numbers due to number of scans allowed, currently 50% capacity. Saturday clinics are being run to clear backlogs of patients that have been waiting a long time or are lost to follow up. These will continue to the end of March.

The 10 hospitals in Manchester area are currently dealing with 400 in patients with Covid-19 and approximately 50 patients are still in ITU. Surgery is being cut back in general as the numbers haven't started to recede yet in the North like it has in the south.

### **ACHD (Level 3)**

The Wrexham satellite out-patient clinic is continuing once a month. Blackpool now seeing twelve patients (usually sixteen). A monthly satellite clinic has also been set up at Wythenshawe.

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

Maintaining a normal service as possible. Telephone and video link appointments working very well. Main concern has been contraceptive services have not been offered by GP's during the pandemic.



## ACHD Nurse Specialists (MRI and LHCH)

Several the nurse specialists have been helping on the wards and ITU. This could impact their ability to support the help line at LHCH although being maintained currently.

## Item 5 – Clinical Governance Update

- Risk Register now fully functional on Ulysses system at AH
- Clinical Effectiveness – Rob Johnson (Paediatrics) and Vas Papaioannou (ACHD) have now been appointed and will be sharing 1 PA Consultant post with the Network.
- Plan to host two Study Days and two Clinical Effectiveness meetings a year alternating every 3 months.
- Clinical effectiveness to focus on mortality and incidents across the Network. Will report on learning outcomes, identify any improvements identified and ensure that information is shared across the Network.
- A new Project Manager, Dan Short, will be coming into post in February. Dan has been appointed to assist with the Clinical Effectiveness work for the Network.

## Item 6 – Risk Register

Network risks presented and summarised highlighting high scoring risks in particular. If anyone has any further risks they wish to raise, please contact the Network.

CHD Network Risk Register Summary (26.01.2021)

(2332) Ongoing difficulties with respect to agreeing best way forward for providing co-operative/combined provision of paediatric cardiology services by AHCH and MCH. (20)
(2284) Inability to store and share images digitally in a suitable format that facilitates timely transfer of images across the Network as required. Unable to meet NHS England Congenital Heart Disease Standard (D8) (12)
(2285) COVID-19 Pandemic and its impact on CHD Services. (12).
(2331) No Cardiac Foetal Nurse offering support at St Mary's Hospital in Manchester (12).
(2276) No database available across the Network to capture robust data (9)
(2281) No formal arrangements in place to review, update and the ratify documents as being "fit for purpose" on behalf of the NW CHD Network (9)
(2333) List of patients on PAS at MFT following collapse of Level 1 services in 2017 and new list of patient found on Cardex in 2020 (9).
(2336) Lack of consistent Paediatrician with Expertise in Cardiology (PEC) support at some level 3 centres (9).
(2339) Patient Backlogs in Blackpool could result in risk of delayed treatment resulting in potential harm to patients. (9).
(2337) The Network does not have Link Nurses established consistently at Level 1, 2 + 3 hospitals across the Network. (8).
(2280) There is no robust Network structure in place for reporting significant clinical incidents (6).
(2282) No robust audit process for measuring services against the NHS England Congenital Heart Disease Standard (CHD) Specification 2016 (6)

### Comments

**(Risk 2331)** Discussions are on-going. It is difficult to get business cases through for service development. However, there is commitment from Manchester to develop the



role of the Fetal Nurse role and there is a lot of work being done informally. Some pressure from the Network may help to formalise and progress this.

**(Risk 2332)** This is being addressed by Chief Executives and Managing Directors from both AH and RMCH. Agreed that there is real commitment from the senior leadership teams across both sites to develop a single partnership service.

All Network risks are recorded on the Ulysses system at AH. Any organisation flagging a high score will be contacted by the Network Clinical Director to ensure this is also entered on their local register and appropriate measures are being taken to address it. If risks aren't being dealt with the Network can escalate to the partnership boards (either Paediatric and ACHD) and can escalate to commissioners where appropriate.

## Item 7 – Backlog Data

The Network has been monitoring backlogs since May 2020 following a request from regional commissioners and Central NHS England to monitor the impact of the pandemic on CHD services. Data collected is around surgical and interventional waiting lists and patient cohorts and back log data from clinics.

### Discussion:

The quality of the data being returned is improving and confidence is now assured that the paediatric data from Alder Hey is a true reflection of the backlogs there. Clarification of the need to understand backlogs and not just numbers of patients on waiting lists remains challenging. The Network needs to work with Operational Leads and Commissioners to ensure that the data is a true reflection, is realistic and that the right questions are being asked. Request made from patient representatives that this is seen as a priority for the network to resolve.

### LHCH

- MDT waiting list is increasing. Meetings are held weekly and there has been a recent increase in the length of the meetings. Patients are also reviewed and prioritised to ensure that they are discussed in order of clinical priority.
- LHCH is currently not able to submit data on their overall numbers and backlogs. They have been sending exemption reports and have discussed this with commissioners. They are working to find solutions.
- They have been focussing on working with MFT on the historical PTL from Manchester. Urgent cases have mostly been seen now with >800 patients been given an appointment. They are now working on the rest of the backlog with good progress being made.

### MFT

- Monthly data returns to Network do not reflect what is happening in real life and agreement that the figures are not accurate.
- Network to work with MFT to look at supporting them with data returns.



## RMCH

- New patient backlogs are improving
- They don't appear to have any significant f/u backlogs according to the data being sent. This is due to the governance process in place that results in patients being issued a new follow up appointment following clinical validation from Consultant.

## Alder Hey

- Apologies given that data for October did not reflect the accurate figures clarified at the time.
- Data Manager has been involved in providing backlog figures to clinicians and Network and confident data is accurate.
- Backlogs manageable and reflect impact of COVID-19.

## Level 3 Centres

- Level 3 data is not currently collected. However, there is a KPI plan in place that will look at what data is to be collected and how this will be done.

**ACTION: Network to meet regularly with providers to review data being sent and to try and find further solutions to the problems identified.**

## Item 8 – CHD Network Governance

Explanation of current Network Governance: -

- Management not fully represented on the Board.
- Hard to access data, work force planning and influence management of providers.
- Providers have raised concerns around representation/access to the Board.

Following discussions with the Network's Senior Management Team and commissioner, Joe Downie, the Network would like to put forward the following proposal: -

- With the Board's approval the SMT would like to look at options for putting in an Operational Group below the Board.
- The main function of this group would be to operationalise the strategy from the Board.
- The Operational Group would theoretically reduce the number of meetings, such as data and backlog meetings.
- The Operational Group would aim to bring operational management across the network together.
- The Board would maintain oversight of all groups in the Network.





### Discussions/Questions:

- Who will be the members of this group? How often will they meet?
  - Operational managers, Data Network managers and representatives attending depending on the topics of discussion including clinician representation.
- Aim to meet monthly but will be discussed and tailored to what the Network needs once the full proposal has been written.
- Concerns about the scope and who should be invited?
  - The Network understands the need not to add additional pressure to workloads. This group would aim to be the delivery arm of the Network to deliver and resolve key issues swiftly.
- Concerns about duplicating issues with other working groups being formed.
- A delivery group would release the board to concentrate on strategy and able to push down issues to action to the delivery arm.

**ACTION:** All agreed for the proposal to be written and brought back to the next meeting for discussion.

## Item 9 – Network Database – Task & Finish Group Update

Update from the last Database Task & Finish Group held on 13<sup>th</sup> January 2021: -

- Adult/Paediatrics teams have different requirements although both are important.
- NICOR remains key for Alder Hey who need to update their current system. Adult services are concerned that focussing on NICOR may be at the expense of other priorities identified by NHSE.
- Adult services need to focus on patient numbers and backlogs rather than NICOR.
- NHS England CQUIN was awarded to LHCH in 2019/2020 to develop a database.
- Database was intended to be something that the Network could build on further. They have now delivered on this and are wanting to roll this out across the adult providers.
- NHS England requirements for the database are: -
  - A common database for the Network.
  - To report on high quality outcomes.
  - Patient and family experiences to be recorded.
  - Clinical audit reporting. To identify sub optimal outcomes and experiences so that plans can be put in place to remedy this.
  - Map out the flow of a patient.
  - Management capacity.
  - Improve resilience and safety of care delivered.
  - Workforce planning capabilities.
- A repeat All-Age MOSCOW survey was carried out in December 2020 across the Network with an excellent response



- A Project Group has been formed and will be led by the Network's new Project Manager, Kenny Ward, and Ian Gilbertson, Associate Director – Digital Transformation working across Alder Hey and LHCH. They will be working with the Innovation Team at AH, to discuss the options available to develop things further.

## Item 10 – Patient Representative Feedback to the Board

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- The PPV Group are planning more on-line patient events for the coming months
- Facebook Live events are going well
- Children's Heart Association hosted a Zoom session for parents across the North West (COVID focused).
- The PPV Group have helped create patient information leaflets to help parents and adult patient make the most of their hospital appointments
- They have been involved in the communication Audit
- Working on improving communication across the PPV group. So far, they have only met remotely.
- The Network has kept the group up to date with the data issues and backlogs and the group have written to RMCH regarding concerns that they have. A response has been received which the group are currently replying to.

The importance of the patient group and how the Network want to hear their voice was emphasised They were formally thanked for their commitment and focus.

## Item 11 – Network Documents for Signing Off

The Network has a process for ratification and management of Network documents. Currently there is a paediatric and ACHD Ratification Task and Finish Group (RT&FG). These groups are currently being operated via email whilst we are in the middle of a pandemic.

The following documents have been through the Network RT&FG's and have been signed off on behalf of the Board: -

- Kawasaki Guidelines
- Acute Post Natal Cardiac Pathway
- Urgent referral for the Management of PDA in the Premature Baby
- Clinical Urgency Update Form
- Network Document Management Policy
- Ratification Task and Finish Terms of Reference
- Guideline for the Management of PDA (from the NW Neonatal Network)

**Comment:** Request that consideration of the mother and what will happen to her and whether she will be able to be transferred with the baby should be included. A general point that parents need to be considered as an integral part of the baby's care and considered when determining where the baby is transferred to.



The acute post-natal document is a pathway to signpost transport team as to the most appropriate hospital to take the baby to and is a simple flow diagram to aid decisions around this. These decisions are made on the clinical condition of the baby. It's not intended to be a detailed pathway in terms of care given or plans around mother & baby. The Network is required to look at this.

## Item 12 – Any Other Business

None recorded.

## Date of Next Meeting

Wednesday 26<sup>th</sup> March 2021 10.00-12noon

