

CHD Board Notes

28th September 2020

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



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Item 1 – Welcome & Apologies Network Board

Present:

Abby Peters (AP)	Associate Director of Strategy and Partnerships	Alder Hey Children's Hospital NHS Foundation Trust
Andrea Richards	Specialised Planner – Cardiac Services	Welsh Health Specialised Services Committee
Anthony Smith (AS)	PPV Representative	NW CHD Network
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
Denise Szpunar (DS)	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
Jill Moran (JM)	Network Support Officer	NW CHD Network
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
Mike Bowes MB)	Consultant Paediatric Cardiologist	Alder Hey Children's Hospital NHS FT
Nayyar Naqvi OBE (Chair) (NN)	Consultant Cardiologist & Responsible Officer	Wrightington, Wigan & Leigh NHS FT
Phil Rigby (PR)	Service Specialist (Specialised Commissioning Team)	NHS England and NHS Improvement – North West Region
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Sarah Vause (SV)	Consultant Obstetrician in Fetal & Maternal Medicine	Manchester University Hospitals NHS FT

Item 1 – Welcome & Apologies

Apologies: Claire Noctor, Helen Sanderson

Declarations of Interest: None



Item 2 – Introductions

Introductions were made and welcome extended to new members:

- Abby Peters, Associate Director of Strategy and Partnerships, AHCH
- Andrea Richards, Specialised Planner – Cardiac Services, Welsh Health Specialised Services Committee, Service Specialist (Specialised Commissioning Team)
- Phil Rigby, Service Specialist (Specialised Commissioning Team), NHS England and NHS Improvement – North West Region

Item 3 – Board Notes, Matters Arising & Action Tracker

Meeting notes from NWCHD Network Board meeting on 19/06/2020 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:

No.4 – Network Database – Other Networks - Action to be closed

No.5 – Network Database – Set up Task & Finish Group – Action to be closed

No.6 – Network Database – Invite LHCH to Task & Finish Group initial meeting – Action to be closed

No.7 – Document Management – Network Documents Reviewed & Signed Off – Action to be closed

No.8 – KPI – Finalised – To be signed off at today's Board meeting

No.9 – NWCHD Risk Register – In progress - Risk to be formally reviewed, scored and the presented at Board in December

No.10 – Remote MDTs and Image Sharing – Action to be closed

No.12 – Ratification Policy – In Progress

No.22 – Network Database – Letter to Kate Warriner, CIO AH – Action to be closed

Item 4 – Regional Covid Updates

ACHD at LHCH: No real change. The number of operations per week has increased with an additional day on alternate Wednesdays. There is a lot of uncertainty with the second wave of Covid on the horizon and how we are able to contain this in the winter months. From an interventional perspective the service remains about two thirds down on the normal activity due to PPE requirements. Outpatient activity varies depending on how many patients can be seen per day subject to the number of sonographers available. There is a contraction on the number of patients who can be seen face to face however patient lists are being triaged to prioritise patients. Recent outbreak of COVID-19 at LHCH was managed effectively.



Paediatric CHD at Alder Hey: Patient activity is back to full capacity in terms of the surgical list, with waiting lists reduced. Cath lab is at 80%-90% activity. Normal bed capacity issues as per pre-COVID. Clinics have now returned to eight patients per clinic which is making an impact on the back logs. Weekend clinics have commenced with four to six patients being seen per weekend.

MFT adults: Inpatient activity being managed very well. Outpatients have been triaged and re-triaged to establish diagnostics for either a telephone conversation or face to face appointment. The MFT tactical rota was stood down at the end of July and preparations are in progress to prepare for a second wave of the pandemic. The pressures appear to be on inpatient beds rather than critical care at the moment.

MFT Obstetrics: update on pregnancy & maternity services. Face to face, pre-conceptual and post-natal appointments have been re-instated. Still doing telephone appointments which is saving patients needing to travel long distances. Contraception is now being offered on the post-natal wards and this approach will continue post pandemic. Shielding list is being updated in preparation of the second wave. There has been a reduction in pre-term births noted nationally. Not clear why this has happened although it is a possibility that mothers have had more opportunity to rest during lockdown whilst being pregnant.

Item 5 – Patient Back-Log

Background and Context:

The Network has been collecting data since May 2020 from L1 & L2 centres for Paediatrics and Adults. This has been in response to COVID-19 and the need for both regional and national commissioners to understand the impact of the pandemic on CHD services. The request has been collated into one spreadsheet for providers and the Network has been responsible for collecting the data and updating commissioners on a monthly basis.

Data being requested (NW Commissioners):

- Total cohort of patients (new and follow up)
- Total number of patients overdue an appointment (New and Follow up)
- New patients
 - > 3months
 - > 6 months
 - > 12 months
- Follow up patients
 - > 3months
 - > 6 months
 - > 12 months
- Patients waiting for discussion at MDT
 - Total number waiting
 - >breaching 6 weeks



Data requested (National SCT)

- Patients waiting for surgery
- Patients waiting for an intervention

Patients waiting for an EP procedure

The quality of the data being received has been highlighted. The backlogs and data have been discussed at the North West Paediatric Partnership Board on 21/09/20. Meetings have also been held with paediatric leads and managers from Alder Hey Children's Hospital & Manchester Children's Hospital who have been asked to develop action plans to tackle the backlogs. These have been shared with commissioners and the Network continues to support providers where possible. Plan to meet regularly to review progress against the action plans. Local Paediatricians with Expertise in Cardiology (PEC's) have offered their support. Despite the data being returned there is an expectation that the backlogs are significant especially at Manchester Children's Hospital. Therefore the problem needs to be seen as North West problem that will require a North West response. The same process will be applied to the ACHD Service and the Network will share the data and draw up action plans as soon as possible. The Network plans to meet with commissioners every two weeks to also review progress against action plans. The backlogs were being discussed this morning with the Senior Leadership Team (SLT) at Commissioning level and this has now been escalated and will result in increased scrutiny of the data moving forward. Therefore assurance around the quality of the data is vital.

Some of the backlogs are historical from over a ten year period and whilst not wholly COVID related have been compounded by the pandemic. Concern raised that this isn't just seen as a COVID related problem but there is an acknowledgment that the backlogs are long standing. There is concern that whilst there are backlogs across the Network, that Manchester Children's Hospital has a big backlog of new patients as well. It is felt that they must also have a large historical backlog of patients waiting to be seen that must have been made worse by COVID-19. This is despite the data returns that suggest otherwise. Not only does there need to be an operational approach to the backlogs there also needs to be high level discussion as to the best way to deliver CHD services moving forward in order to deal with the problem.

There is an expectation from commissioners that an exceptional MOU needs to be agreed that will facilitate staff moving around the Network to support services. This would not only be for patient backlogs but also assist with winter pressures. It is something that has been piloted in London. NHS England are also working on a digital passport, which would facilitate the movement of staff and will be available soon.

Concern raised that the backlog numbers were not actually presented at the Board today. The reason for this is due to the poor quality of the data which has been received so far. This is now a priority to address in order to understand backlogs more clearly. The CHD Board should also have a role in monitoring progress against those action plans and tracking the backlogs to ensure there is oversight and progress and being made. Agreement that the quality of data submitted to the commissioners is not of a high enough standard despite constant validating. IT and PAS systems are not adequate and is not reflective of real life of services and patient activity. Clean data is vital.



The situation has definitely been made worse by COVID. Message needs to go back to the Commissioners and NHS England how clinicians are competing with everyone else during COVID. Clinicians have dedicated many hours in triaging patients. Triaging has proved beneficial to ensure the right patients are being offered face to face appointments in a limited environment.

The Network has produced a short video for parents from a patient perspective, Caroline Jones and Linda Griffiths produced a short video about appointments. This was to address some of the concerns expressed and noted on social media by parents and patients. There does not appear to have been any official communication strategy for patients and families about the current backlog situation. The Network here has been no official communication sent out to families at present and as discussed at the PPV (Patient & Public Voice) Grep group, parents and patients are very anxious to have information regarding the backlogs and to understand what action is being taken.

ACTION:

- 1. Backlog Data to be presented at Next CHD Board on 27th January 2021**
- 2. Backlog data to be shared with Network PPV Group**
- 3. Network to meet with ACHD service at LHCH and MFT to agree action plans etc.**

Item 6 – Update – Data Manager & Project Managers x2, Expressions of Interest for 1PA

Data Manager post has been advertised and two applications received. Interviews will take place this week. The Network has received a tremendous amount of support from Jemma Blake, Cardiac & Clinical Information Data Manager at AH. Thanks expressed on behalf of the Network to Jemma for her valid input.

Two, Band 6, Project Manager posts are due to be advertised today. These posts will support all aspects of the Network. These are anticipated to be in post by the end of October. The positions are flexible regarding clinical/management backgrounds and experience bit will include Project Management skills to be able to lead on some of these complicated projects on the horizon.

‘Expressions of Interest’ are to be sent out shortly for a 1PA post to support the Network’s clinical governance needs. If anyone is interested please contact northwestchdnetwork@alderhey.nhs.uk.

Item 7 – Lost to Follow Up

The Network has re-commissioned the ‘Lost to Follow Up’ project and funding has been made available for Sarah Ellison to lead this project for one day a week. Sarah has applied to Liverpool John Moore’s University to do a PhD to do this project as a piece of research.



A 'Lost to Follow-Up' presentation was made recently to Michael Wilson at NHS England. Most Networks around the country have reported similar issues. The challenges of how we find patients who may have been lost to follow up exists everywhere. Engaging with primary care and GP's is a vital part of the patient journey.

A small project group will be formed to progress the project forward over the next year. Question raised about requiring PPV representation for this project? Thought to be good suggestion and that it should be taken back to the PPV group to ask for support.

ACTION: PPV Group to be approached for a patient/parent to support the work

Item 8 – Network Database

The Task & Finish group reports back to the Network on the Network Database development. It was agreed at the last CHD Board meeting to commission someone to carry out an options appraisal. It is important to understand whether the clinical repository that has been developed at LHCH has the capacity to deal with all of the demands of the Network. Kath McEvoy was commissioned and has now completed a small options appraisal. This appraisal will be discussed at the next Task & Finish group in October to review the recommendations. The suggestion of a joint database is also being discussed at this meeting.

It is important to carry out a formal request of all clinicians in all of the sub-speciality areas of CHD in order to understand what the database needs to be able to do. It is not currently clear what is to be collected from a regional perspective. Kath has liaised with a number of different colleagues regarding the type of data to be collected, however, the decision for the LHCH clinical repository to be developed into a Network database is still to be agreed. Kath recommends in her appraisal that this might not be the best solution. Part of the new Project Manager's role will be to collate the information/requirements from regional Clinicians.

ACTION: further work to be undertaken to undertake stakeholder and clinical engagement across the CHD network area to understand more about the full requirements for a database

Item 9 – Network KPIs / Dashboard

Network plan for KPI's shared.



KPI development
CHD Board 28-09-20



Item 10 – Network Oversight Board – Governance Structure. Feedback from Paediatric/ACHD Partnership Board

The Network was criticised at the Peer Review last year regarding the Governance structure was too complex with too many Committees & Boards. Agreement has subsequently been reached as to how both the North West Paediatric Partnership Board (NWPPB) and the new adult Partnership Board relate to the Network and commissioners.



final CHD North
West Governance Stru

Moving forward the regional ACHD Partnership Board will have good representation from around the region, similar to that of the NWPPB. Concern raised that the NWPPB is not exclusively about CHD services and does not represent level 3 centres. The role of the CHD Network will become more influential and necessary moving forward.

The Network is also facilitating the PECSIG group on a monthly meeting. Feedback from that group to the Network CHD Board would be appropriate.

Item 11 – Patient Representative Feedback to the Board

Acknowledgment that is really valuable having PPV Representatives attend this CHD Board. Introductions and welcome made to PPV partners attending today.

Communications Audit Update

- Registered the Audit with AH Audit Department
- £5K funding approved
- Support from Consultant, Mike Bowes, Paediatric Cardiology Consultant, AH
- Focus Group with families set up for 21st October to listen to families experiences of communication.
- Once questionnaire prepared, this will be sent to every patient at AH. RMCH has been approached for involvement.



Other projects

- Streamlined the process of how to apply to become a PPV partner. Aim to create easy read versions of documents to facilitate people with learning disabilities getting involved in PPV work
- Redesign of the Network website
 - New logo
 - Fetal Pathway
 - Re-design of the site map
- Patient information leaflets
 - How to make the most of remote appointments
 - Adult + Paediatric (to include transition)
- **Task and Finish Groups. PPV Partners involved in**
 - **Database**
 - **Website**

Question raised regarding the provision of ECMO particularly in response to COVID-19. ECMO is a nationally commissioned service. During COVID-19 the small numbers of services that offer it were asked to increase their capacity at the height of the pandemic. For the Manchester region Wythenshawe hospital that offers this service for adults. Alder Hey offers a full ECMO service and will continue to do so over the winter. The number of patients with CHD expected to require this treatment in our region is extremely small.

Patient reps fed back that they enjoy this role and feel it's important to try and help the Network improve services for patients. Specials thanks were extended to Damien Cullington and Linda Griffiths for their support and information provided to patients during the pandemic via face book live events via the NWACH Support Group.

Item 12 – Outstanding MOUs

The majority of MOUs sent out have been signed and returned. IOM and Wales are still outstanding, mainly because of the differing Governance processes. The Network will continue to liaise and support to get these signed off.

Item 13 – Ratification of Documents

Documents have been circulated prior to the meeting and require agreement and sign off at the CHD Board today:

1. NWCHDN PPV Representative documents
2. NWCHDN Risk Management Procedure

All agreed to ratify these documents.



Item 14 – Network Risk Register & Clinical Governance

The Network now has an active Risk Register. These are due to be uploaded on to the Alder Hey Ulysses system. This will enable the Network to produce electronic reports for future Board meetings. The Network SLT and Clinical Leads will be meeting on 5th October to review the risks. Risks have been shared from ACHD services but as yet no risks have been identified or shared from the level 3 providers. Moving forward we are due to agree process for Incident reporting and mortality reviews.

Ratification Task & Finish Groups for Paediatrics and Adults have been set up. They are responsible for signing off documents on behalf of the Board. Any documents that are Network based will come to the Board for ratification.

Request that an email be sent out particularly to L1, L2 & L3 ACHD & Paediatric providers. It would be help to be aware of any significant risks on their registers that the Network is not aware of, especially any major items.

ACTION: LG to send risk request to L1, L2 & L3 centres

Item 15 – Any Other Business / Feedback from All

Shielding

Has other regions experienced patients unnecessarily shielding? A recent list issued by GP's in Wales revealed a shocking number of young people that did not need to shield during height of the pandemic. With the second wave upon us, asked if a statement could be issued to Primary Care from the Network emphasising the children that do need to be shielded unnecessarily. The general advice is that virtually no CHD patients should have been shielding. The Network has been following the BCCA (British Congenital Cardiac Association) guidelines.

The UK MCS (Internal Cardiac Society) have released a list of conditions were pregnant women should shield

The guidance on the CHD Network's website is currently up to date and follows the BCCA and Government guidance. This also includes up to date pregnancy information. The Network information has been shared with every GP and DGH Hospital in the North West. It has not been shared with Welsh providers or The Isle of Man. The Information is easily available for patients on the websites at LHCH, Alder Hey and The Network. We have not been able to get the link onto the MFT website. BC offered to take this forward.

ACTION: LG to investigate how to share the NW Network COVID-19 advice in Wales and the Isle of Man

ACTION: BC to liaise with MFT's Communications/Website Team



Wythenshawe Clinic:

There is a new planned outreach clinic to be held every month at Wythenshawe Hospital. This will operate as a level 3 outreach clinic with joint support from the ACHD service at LHCH. Clinic will be run jointly between Dr Anita McNabb and Dr Reza Ashrafi. The Network is pleased to be able to offer this support to the team at Wythenshawe.

Chair thanked all Board members for their time and contribution to the meeting.

Date of Next Meeting

Wednesday 27th January 2021 10.00-12noon

