

CHD Board Notes

19th June 2020

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



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Item 1 – Welcome & Apologies Network Board

Present:

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
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
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
Helen Ashcroft (HA)	Locality Service Specialist	NHS England & NHS Improvement
Helen Sanderson (HS)	Network Manager	NW CHD Network
Jill Moran (JM)	Network Support Officer	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 (Chair) (NN)	Consultant Cardiologist & Responsible Officer	Wrightington, Wigan & Leigh NHS FT
Rengan Dinakaran (RK)	Consultant Paediatrician	Lancashire Teaching Hospitals NHS FT
Sara Naylor (SN)	Associate Director of Strategy & Partnerships	Alder Hey Children's Hospital NHS FT
Sarah Vause (SV)	Consultant Obstetrician in Fetal & Maternal Medicine	Manchester University Hospitals NHS FT

Apologies: Claire Cathcart (PPV Representative),

Declarations of Interest: None

Item 2 – Introductions, Network Chair, Lead Nurse & Support Officer

Dr Nayyar Naqvi introduced himself as new Chair of the Board and welcomed everyone. Introductions round the table were made.

Item 3 – Board Notes & Action Tracker

HS referred to the notes from the January Board meeting and asked if there were any comments/amendments. No comments or amendments to record.

HS referred to the Action Tracker and gave an update:

No.1 – COMPLETE - Chair now in post.

No.2 – COMPLETE - TOR agreed and sent out.

No.3 – COMPLETE - Manchester University Hospitals NHS FT use EPIC.

No.4 – Database - HS confirmed Bristol, Leeds and London Networks are still in the process of identifying functional databases – in progress.

No.8 – Quality dashboard for Paediatrics – still awaiting access.

No.9 – Local Risk Registers - in progress.

No.10 – Zoom access – in progress.

Item 4 – Regional Covid Updates

Paediatrics Service – Alder Hey Children’s Hospital NHS FT

CJ commented that restoration of services will commence from 6th July which will see the usual surgical service back to almost its usual operating schedule. Cath Lab activity at 75% of usual capacity.

Clinics are back running but at a reduced capacity to allow for social distancing, cleaning, PPE requirements etc.

Outpatients are being triaged by Consultants and only urgent cases being seen face to face. Some telephone clinics have been run but there are difficulties with not being able to view ECGs & ECHOs to make assessments.

CT and MRI service back up to a full two lists a week. Foetal service clinics have run as usual throughout the Covid-19 period with referrals criteria tailored.

Waiting Lists - there are currently 80 patients on the surgical waiting list with weekly planning meetings to triage and prioritise cases. Cath lab waiting list approximately 40. Outpatients is a slight concern with just over 1K patients behind on their appointment. Teams working closely on strategies and work around to address these issues.

ACHD – Liverpool Heart & Chest Hospital NHS FT

DC gave an update from LHCH commenting that the situation is very similar to that of Alder Hey.

Catheter lists returned to three days adhering to PPE requirements which has seen a reduction in the number of cases. Waiting lists are low which is partly reflected less patients being seen and referred to for procedures.

Surgery commenced five weeks ago. Now operating one day a week (only one case for now). This is due to the need for social distancing requirements etc having an impact on how many beds can be filled at any one time. There are plans to increase back up to two operations a day in August and eventually hopefully increasing to two days a week which will significantly increase capacity over time. LHCH have four patients with Covid-19 in the hospital at the moment.

Waiting List – 40-50 cases. Outpatients have been running four/five weeks with all Consultants validating their lists and selecting those patients to be seen face to face or a telephone call appointment.

Potentially from August hybrid appointments could be offered with four patients attending for ECHOs and then four face to face appointments.

ACHD - Manchester University Hospitals NHS FT

BC commented that similar to LHCH they have been triaging their services to indentify cases to be deferred and face to face clinics are scheduled to start week commencing 22nd June.

Royal Manchester Children's Hospital

CN commented their main issue is with paediatric cardiology outpatients with over 3K children waiting for appointments. With four consultants seeing only five patients per day with two Nurse clinics commencing next week.

NN enquired about the current situation in the peripheral clinics? CN replied they are unsure when the peripheral clinics will recommence and waiting lists continue to rise.

North Wales

MS added North Wales is still in stricter lock-down compared to England, however, clearance has been given to restart joint clinics in July. Waiting lists have been triaged and patients prioritised. As with other organisations, out-patients will be the most difficult to manage in the coming months.

Maternity Care – Manchester University Hospitals NHS FT

SV commented that during the pandemic preconceptual women have not been attending clinics and instead are triaged for face to face appointments. Virtual consultations will start with effect from next week.

Those patients shielding have been seen at the beginning of clinics. Postnatal appointments have been limited, with contraception advice now available on the ward prior to being discharged.

Item 5 - Network Work Plan

HS outlined the work done to date on the Network Work Plan. It has been produced working with Network colleagues and other Networks around the country, also looking at the National Standards and Peer Review for guidance. It includes the Network's aims, objectives, deliverables and actions for the next few years.

HS reported that the document was sent to NHS England for approval and feedback has been received which HS will incorporate into the plan and forward the updated version to members of the group.

SN commented that this work plan is currently still in draft format and would welcome any comments and feedback from the group. The Network does have funding to deliver the actions and will be monitored. SN thanked Denise, Helen and Linda for all the hard work they have done putting this plan together.

LG further commented that regular meetings will take place with Helen Ashcroft from NHS England to demonstrate that the Network are working towards meeting the deliverables.

ACTION: HS to share work plan on the Board Teams group, comments can be shared via email or Teams group.

Item 6 – Network Finances

HS confirmed finance reports will continue to be shared with future Board papers and uploaded on the Board Teams files.

NN agreed the finance report as acceptable and asked the group for formal acceptance.

HA commented she is awaiting confirmation from the Contracts Team if it is possible to carry the total forward into next year.

Item 7 – Network Database, IT & Digital Solutions

DS gave a brief background update on the Network Database and the work done so far with LHCH. A Task & Finish group has been formed led by Mr Rafael Guerreo,

Consultant Congenital Cardiac Surgeon at Alder Hey but due to the Covid-19 outbreak the group are yet to meet.

The Network have agreed to evaluate whether the LHCH database that is already in place can be built upon to provide a regional network database, however, there remains a lot of work to do. DS is to meet with Rafael and will report back to the next meeting. DS is also hoping to arrange a further demonstration to the Board of the current LHCH database.

DS further commented that one of the main priorities from the Network Work Plan is to recruit a Digital Manager with the expertise to develop the database. A job description is currently being agreed and will be sent to advert shortly.

DS asked the Board to push this forward through the Alder Hey recruitment processes.

HS commented that the LHCH demonstration was due to take place at the cancelled meeting before lock-down occurred. Would the Board like a virtual demonstration via an extraordinary meeting to view the database? All agreed yes and asked for the meeting to be recorded for those members not able to attend.

ACTION: HS will arrange virtual database demonstration extraordinary meeting.

DS asked would it be helpful to write a formal letter to Kate Warriner, Chief Digital & Information Officer at Alder Hey to ask for support to take the database forward. All & Chair agreed.

CJ commented it would be helpful to formalise exactly what we want the database to do. All agreed.

ACTION: DS to compose letter to Kate Warriner for NN & GG to sign and clarify the requirements of the database.

Item 8 – PPV Progress/Future Activity

LG gave an update from the PPV Representatives group.

Expressions of interest was sent out late 2019. 14 applications received. Excellent age range and geographical coverage from Liverpool, Manchester, Cumbria, Wales & Isle of Man.

A “Meet & Greet” event was held on 25th February where PPV reps that attended were introduced to the team and Caroline Jones gave an overview of the Network.

The first meeting of the PPV Reps was held on 25th May. This was a virtual meeting with eleven attendees with good engagement and a range of topics discussed. They agreed two patient reps to attend the Board meeting who will alternate attendances to aid with

continuity. The PPV Reps agreed that they are to represent the views of the group and not to bring individual items for discussion at the Board.

An additional informal meeting was held on 11th June to discuss issues being taken to the Board.

The next formal meeting is scheduled for 9th July to feedback information from the Board meeting back to the PPV group and as a group they requested for the Board minutes to be finalised and available for this meeting.

LG confirmed that Dr Emma Twigg, Consultant Clinical Psychologist at Alder Hey has kindly agreed to facilitate the PPV Meeting with LG going forward. There has been several requests from staff asking to attend the PPV's meetings. LG explained that the PPV meeting is not a support group and that if staff representatives are to attend we would need equity of attendance from across the network and this may mean more staff than PPV's present. LG reminded the Board that this PPV meeting belongs to the patients and they need to have the freedom to discuss matters that affect them. They also need to be able to invite staff members at times to discuss specific issues. The PPV Representatives agreed to only invite a professional if there is a specific topic to be discussed or likewise a professional has a specific issue to discuss with the PPV Representatives.

LG reported she is working to support families during the COVID-19 pandemic. She has been working with the Children's Heart Association and Team 1c to create two videos for families which will be uploaded on the Alder Hey YouTube channel. This has been a project with the clinical teams at Alder Hey and Manchester Children's Hospital and with Dr Emma Twigg (Clinical Psychologist). One video will cover all aspects about COVID-19 and CHD and the second will concentrate on managing anxiety.

LG reported that two of the PPV Representatives have volunteered to work with the Network on the development of the website.

LG commented that the current process to become a PPV Representative involves extensive paperwork. LG proposes working with a small group of the PPV Representatives to ensure the pathway and process is more efficient for future applicants. LG would also like to see further patient representatives from learning disability backgrounds and black & ethnic minorities.

NN agreed that it is important to have an active and committed patient group and thanked LG for her input with the PPV Representatives group so far.

Item 9 – Patient Representative Feedback to the Board

AS asked the following questions to the Board on behalf of the PPV Representatives group:

- **Database Task & Finish Group** – can a member of the PPV Representatives Group attend the Database Task & Finish Group?
- **Time Frame** – Can the Board give a realistic time frame as to how long it will take to get a database for the Network?

NN agreed a time frame on the database is important but it is also important that we get the database right. All agreed for a PPV Representative to join the Database Task & Finish Group.

GG agreed the importance of developing the database and moving it forward and is in complete support of the PPV Representatives aspirations.

LG clarified that some of PPV Representatives are frustrated with the progress of the database. There is also a genuine understanding from patients and parents that the database is how you monitor the service and know how well you are doing.

MB agreed there is a need to understand what is required. The first phase is about getting the basics right and understanding what the database needs to capture. MB also commented that if there are any members of the PPV Representative group that has a keen interest in developing Apps it would be really useful to get them involved.

DS asked AS to feedback to the PPV Representatives that the Network understands their frustrations regarding the database. Funding was only received earlier this year and capacity and resources have led to the delay in development. As discussed above we are working with our colleagues to progress and develop it as soon as possible.

AS agreed to feedback to PVV group there may be members with digital background to join the T&F group.

ACTION: PPV Representative to be invited to join the Database Task & Finish Group.

AS also reported on the communication issues that patients and parents are experiencing i.e. access to patient records/notes, clinical letters, diagnosis terminology. An index glossary explaining the acronyms and terminology would be helpful.

LG thanked AS for attending and presenting to the Board today. LG commented that Claire Cathcart, also a PPV Representative was unable to attend today but did send LG an email further highlighting the Communication issues – LG read Claire’s email to the Board.

Summary of Claire’s email:

- **Communication problems: Information not being fed back from the Level 1 & Level 2 centres and vice versa e.g. when a patient is discharged.** The group would welcome being involved in improving this and have suggested running a project:
 - to collate some parent stories to help identify the communication problems being experienced
 - Use these patient stories to create a questionnaire/audit to identify what the problems are and how wide spread they are

- Once the problems have been identified to work together at finding solutions

- **Communications:- Wider issues were also discussed:**

- > presenting at A&E – issues with notes
- > Confusion and anxiety around Covid-19
- > Clinic letters – issued to parents and simplified language

ACTION: Agreed LG + PPV group to set up a group working on communications to address issues raised

Item 10 – Ratification Policy moving forward

DS gave a background of the previous process for ratifying Network documents and asked the Board for clarity/suggestions going forward to simplify the process.

CJ suggested the Board think about the sort of policy/pathways being put forward and those that need Board approval. A robust digital system is required to bring documents to the Board for ratification. Suggested a key list of board members who are suitable for 60% or 80% ratification.

SV commented that the Board needs to decide the pathways that are required? Agreed with CJ's idea for a list of appropriate Board members to review documents with a sign off process at Board level.

All agreed.

ACTION: DS to progress with Ratification Policy procedure

Item 11 – Risk Register

LG shared on screen the governance structure for the North West Neonatal Network. LG commented that at the moment no such structure exists for the NW CHD Network and that we need to consider what this needs to look like for the CHD Network?

LG commented that the Memorandum of Understanding (MOU) is key to this process. Do we need create a Task & Finish Group to take this process forward and welcomed comments from the Board.

CJ recommended to do this correctly the Network needs a team of people dedicated to that role. Need to think about the clear trigger points i.e. communications between centres, issues in L3 centres and across the Network patch and communication between different providers.

GG agreed and supports the above comments. The Network does need a Governance person to filter the important issues. Regarding remuneration, there is a budget to support a Governance Lead.

LG asked if the Board agrees to progressing the work of the Risk Register or wait until a Governance Lead is in post?

DC commented that the Risk Register need to be discussed in more detail and suggested maybe a separate meeting?

LG agreed to organise a meeting with key people to take this forward and report back to the next Board. GG/DC/CN/CJ

DS commented that the Network will be appointing two Project Managers and one of the posts will support this piece of work moving forward.

ACTION: LG to arrange Risk Register Task & Finish group.

Item 12 – Website

LG gave an update on the website and shared a view on screen.

LG, HS and Jemma Blake have now been joined by two PPV Representatives with a background in communications and working for a digital company.

The group are working with a company called Studio Wide. The current website is a good platform on which to build but there are currently many gaps regarding content. The sitemap for the website has been updated and work is underway for a new Homepage. A process of prioritising the content to information that is important for patients first is underway starting with the foetal pathway first.

Logo – feedback from patients regarding the “wheelchair man” has been sought. Discussed at the PPV Representatives meeting and they agreed that the wheelchair is important and recommended it to be brought further down the line to represent normal life for some people with CHD.

COVID-19 Advice – Detailed information is now available on the NW CHD Website. This brings together a comprehensive set of advice with links to GOV.UK, NHS 111, BCCA, Obstetric and RCPCH guidelines. It is being kept up to date as advice changes. This has been distributed across the Network including to DGHs & GPs. Have not been able to get MFT to host the link on their website yet.

NN commented that the website is our showcase to rest of the country and the world and needs to be comprehensive. LG doing a great job. Thank you.

Item 13 – AOB

Oversight Board

GG described the current agreed reporting structure for the Network. At the outset it had been felt that an "Oversight Board" was required to ensure decisions were adopted and agreed by all providers. In time it was anticipated that the Network Board could act as both initiator and effector for regional development of CHD care and the oversight board might become superfluous. A meeting has been arranged for July to agree the structure, need and function of an 'all age CHD oversight board'.

ACTION: GG to report update of Oversight Board at the next meeting

Remuneration

Remuneration has been offered to members of the Board. The network has received some responses from members as to whether they prefer any remuneration to be paid directly to individuals or into training/network education funds. Funding for PPV Representatives is also being discussed as to how best we can support/remunerate them for their time and involvement.

Memorandum of Understanding (MOU)

DS feedback on the group set up at the last meeting to work on a Memorandum of Understanding for the Network, this included CJ & GV.

This has now been sent out to all Board members and DS asked for Board approval. Will contact all Trusts for who are required to subsequently sign it off.

All agreed.

Closing

NN thanked all members for their contributions to the Network.

Date of Next Meeting

Monday 28th September 10.00-12noon