

Congenital Heart Disease Network South Wales and South West Network Board Meeting

Date: Thursday 29th September 2016 14:00 – 16:00

Venue: Heart and Lung Conference Room – Torbay Hospital

Chair: Andy Tometzki

Minutes (Draft)

Item	Notes and Actions
1.	<p><u>Welcome, Introductions & Apologies</u> (see appendix). AT welcomed and introduced the attendees.</p>
2.	<p>Patient story / context of network</p> <p>AT presented a brief background and update of the Network and introduced the members of the network team: the Network was set up to implement the new standards of care following the NHS England review which reported in July 2015; at present UHB is hosting and funding the Network, with a view to this being centrally funded by commissioners from next year; and AT explained the definition of the centres – Levels 1, 2 and 3.</p> <p>This Network has unique challenges as it bridges 2 sets of commissioners across England and Wales with different governance regimes, and because distances between the centres in the Network are large going from the Isles of Scilly to West Wales.</p> <p>AT re-iterated that although hosted and funded by UHB the Network was independent. The initial priorities of the network are to establish the governance structures, visit centres, and evaluate self-assessments against the NHS E standards.</p> <p>Plymouth and Yeovil are unique hospitals in the network as they refer patients to Southampton as well as UHB. Swindon has some referrals pathways to Oxford as well as Bristol. This will be explored with those centres alongside commissioner support to ensure patients can have choice of provider, and that commissioning intentions can be met.</p> <p>ACTION: JD/AT to continue discussions with NHS England about commissioning decisions for network providers</p> <p>It was felt a patient story / feedback from patient reps should feature in future meetings</p> <p>Action: JD to request input for this ahead of the next meeting</p>
3.	<p>Terms of Reference for Network Board</p> <p>JD sought comment and approval on the Terms of Reference. Broadly the TORs were approved, subject to the following comments:</p> <p><u>2.5 Education, Training and Workforce</u> AT asked if any of the centres were doing any educational events or study days, they should let the Network Team know and they would record this.</p> <p>RB questioned whether requiring the Network Board to develop a programme of research across the Network was going too far; rather the focus should be to support a programme of work.</p> <p><u>3. Accountability</u></p>

JD explained that the aim is for the Network to be fully accountable to NHS England and NHS Wales, separate to UHB as host. Other networks, for example, the neonatal and burns networks have direct accountability and this is the aim for the CHD Network. The Board members agreed with this.

The process to ratify this is to agree at a meeting with commissioners from NHS England and NHS Wales on 18th November, before the commissioners approve the process through their respective Boards. CC agreed that the approach suggested by JD appeared sensible and that he could not see why this could not be adopted in Wales; however this would be agreed at the meeting on the 18th.

It was noted that there was no representative from NHS England at the meeting; it was felt important that NHS E are represented.

2.7 Demonstrate Value Adding

Demonstrating additional value is essential to the success of the network. This will be done through delivery of the annual work plan, and evidence through an annual report and an annual open meeting.

4. Board Membership

4.2 Quorum

JD sought the views of the attendees as to whether they felt Option A or Option B was more appropriate.

The summary of views was:

- Members should commit to attend or send deputies
- With the challenge of geography, it would be unwise to be too prescriptive on quorum, but there should be a range of representatives across L1,2,3; between Wales and England; and to ensure patient and commissioner representation.
- Video conference facilities would be key to ensure attendance
- The membership should not be Bristol-centric

4.4 Reporting

There was general agreement that the minutes should go to Medical Directors or CEOs to ensure that there was weight to the work of the network.

NK felt that the CEOs should formally sign up to the Network and that membership should potentially go into performance frameworks as happens with the Diabetes Network.

DW questioned whether the Medical Directors were aware of the Network. He said that his directors in Cardiff ask him what they should do.

There was discussion around the commissioning arrangements in Wales and discussion as to how the Network can influence in the absence of commissioners for some CHD services. CC raised that there is a Heart Disease Delivery Plan in Wales that is currently under review that could potentially include a section on CHD. CC believes that the Chair of this group is Judith Paget.

ACTION: ALL attendees to e-mail JD re possible quorum.

ACTION: JD to re-draft and re-circulate the Terms of Reference after the Meeting with NHS England and Wales on 18 November 2016 for comment and approval.

ACTION: JD and CC to consider the appropriate mechanisms to implement the standards in Wales and to contact the leads for the Heart Disease Delivery Plan as appropriate.

ACTION: JD/AT to consider how minutes are disseminated to Medical Directors and to ensuring that all Trusts have recognised or formally signed up to Network

4.	<p>Network Governance Structure, Roles & Responsibilities</p>
	<p>The roles and responsibilities documented was presented for approval. There was broad agreement of the document. This will be finalised and circulated after the meeting with NHS England and NHS Wales. Sub-groups may be semi-permanent (e.g. for governance), or may be task and finish groups focused around a particular challenge (e.g. image sharing). Members of these groups may not necessarily be Board members. The roles and responsibilities of these groups can be established as they are formed. He confirmed that the members of the sub-group would not necessarily be members of the Network Board.</p> <p>ACTION: JD – to update after meeting with NHS England and NHS Wales and circulate for comment and approval</p>
5.	<p>Annual work plan</p>
	<p>JD asked the attendees to look at the work plan and to provide their views on it. It will be circulated for comments on anything to add or for areas Board Members feel are a priority.</p> <p>AT said that the Team had come a long way already. SV starting with the Team soon and JD has taken over as Manager from Caitlin Marnell. The Team are talking to those centres who have not completed the self-assessments. The Team will look in depth at reds and ambers in self-assessments and will ask centres how they are going to meet the standards. The Team may challenge centres on the greens in their self-assessments.</p> <p>ACTION: All– to review the Work Plan and give feedback to JD</p>
6.	<p>Self-assessment gap analysis – linking to priorities for network</p>
	<p>JD explained that there were 200 standards for Level 3 Centres. The Team asked each to self-assess. 5 out of the 12 adult centres replied and 61% of the standards were green. 11 out of the 14 paediatric centres replied and 35% of the standards were green. JD explained the results and said that the Team were looking at themes rather than individual hospitals.</p> <p>It was recognised that the answers and RAG rating are subjective, so there will need to be some validation by the network team.</p> <p>There was a question as to whether Wales and England had been looked at separately. They had not, and the themes in general were similar. There may need to be different approaches to tackling some of the issues due to commissioning difference, but in general the challenges will be matched.</p> <p>The themes from the self-assessments were reviewed to identify initial actions / priorities.</p> <p><u>Themes from self-assessments</u></p> <p><u>Technical/practical links between centres</u></p> <p>Data and image transfer (of echos, MRIs and CTs) was recognised as being a significant challenge for all centres. Patients and their representatives also felt that this was an issue in terms of having confidence that clinicians have access to all the relevant information and not needing to repeat their story. It was agreed that any solution would need to have feedback from patient reps to ensure it met their needs.</p> <p>There are a number of options at present, but none currently solve the problem: KM explained “My Heart” which is a patient-held App. The patient holds their records on the App which can be uploaded on to a portal. The consultant can then see the patients’ ECG, X-ray, recent letters and notes. The system could connect through a Trust server onto PACs and image exchange.</p>

The company developing My Heart has charitable funds from BHI. Southampton has something similar to My Heart. It was that patient portals are worth thinking about and asked if a group could look at My Heart.

The EVOLVE system of electronic patient records at UHB; PECs / Adult Cardiologists from across the region can have remote access to this via honorary contracts allowing them to view the full UHB patient record. NB – historical notes are only scanned when patients attend for outpatients or a procedure

ACTION: JD to established working group to resolve the issue between UHB & Cardiff with a view to implementing something across the network. To include consideration of patient portals.

ACTION: All to contact RB if they want an honorary contract at UHB for access to Evolve and to notify if the process was cumbersome

Data input

There will be development of a network dashboard to show key metrics such as total number of patients in each unit, delays to follow up.

It was recognised this may be difficult in level 3 centres as cardiac episodes and waiting lists are not always coded in a distinguishable way

Non-face to face contact with patients

There are some models (such as Skype and similar) for level 1 & 2 consultants to consult with patients alongside their level 3 consultants without the need travel to other centres. This is operating in pockets across the region but needs clinical champions to take forwards

ACTION: AT and JD to provide document describing how this is done as an example for other centres to develop their own services

Facilities

Access to CT and MRI is an issue across the network. In Wales there are commissioning decisions that need to be made around this, which will be discussed at the meeting on 18/11/16

ACTION: JD to ensure that MRI is on the agenda for the meeting with NHS Wales

Family accommodation for two members is not necessarily achievable without additional investment. NM added that the care was more important than the environment and this view was agreed by all the attendees.

AT said that for pre-op assessment and planning there was a finite number of beds as hospitals become more acute-focused with a contraction of beds. Tests could potentially be done locally, but that there were difficulties with image-transfer and video-conferencing.

ACTION: JD / AT consider in work plan a focus around pre-op assessment clinics closer to home

It was agreed that many protocols are service-specific and that it is not possible to have a region-wide protocols for everything. Each unit will need to develop their own as required, but there may be some useful examples in centres. SA has an example protocol of patients to be managed by PEC vs general paediatrician. UHB has produced some ACHD protocols.

ACTION: SA to share protocol as network example

ACTION: JD to share ACHD protocols and put on website once constructed

Job planning and medical staffing

AT said that it should be put in consultants' appraisals – in PDPs – how they are going to comply with the standards. It was felt it would be useful for the network to state the minimum mandatory requirements for job planning and write to the relevant Medical Directors to support local consultants in the job planning process.

ACTION: JD / AT to summarise consultant job planning requirements in a letter to Trust Management (clinical directors or medical directors)

It was felt getting attendance at MDT would be a huge challenge in terms of timetabling. Tele-conference would help. There will need to be consideration of timings of MDTs to enable people to conference in for specific sections

ACTION: JD to consider MDT attendance as part of work plan

Nursing, AHP, physiology, psychology

It was recognised that some areas (such as Taunton) had good models for link nurse support but further work was needed to support link nurses and provide education.

NM said that from a patient perspective, there was a lack of support – a shortage of liaison nurses. Cardiff and Bristol were good. But at other L3 centres parents could feel isolated. There were community nurses, but that was not the same. The psychologists, CNS and physiologists from Bristol were trying to cover too large an area.

ACTION: JD/SV – to map current provision and put together an action plan for training, support and where required propose cases for additional investment.

KM said that there should be funding for psychological training for nurses, rather than necessarily needing additional psychologists. Nurses should be able to sign-post patients that need care. He had no psychological care after 40 years with CHD.

ACTION: JD/SV to consider if this is a model that could be considered and what competencies could be built in to training

HM said they do not have physiologists with CHD experience. They do not have sufficient practice to keep up their skills. JD said the Team could go back to NHS England to ask whether this is a realistic standard.

Governance, Audit and Research

There was agreement that the network needs to be aware of relevant incidents and risks, but these need to be defined, with a simple system for sharing and logging. There are certain key issues that the network team should know about for example deaths of patients, improper patient transfers. Clinicians should continue to report incidents locally (not least where these support the case for further investment) until network systems are established

NO said that with the Neonatal Network, every incident is investigated by the hospital. If the incident is medium/high and meets the required threshold, for example, bed-capacity or transport, then it is referred to the Network. The thresholds are a mechanism.

	<p>ACTION: JD/AT/ST to develop definition of network risks and incidents and a method for sharing these</p> <p><u>Patient information and communications</u> It was agreed that shared access to information through a website is essential.</p> <p>ACTION: JD to begin work on a network website. To involve patient representatives in design and content</p> <p><u>Transition, Dental, Foetal, Pregnancy and contraception and Palliative care and bereavement</u> JD said that we need sub-groups to determine best practice around these areas and we need to agree how to disseminate this information.</p>
7.	Prioritisation from gap analysis
	<p>There was not enough time to discuss this in the meeting so members are asked to consider the gap analysis in line with the work plan, and whether there are any areas that are missing from the work plan or that need priority focus</p>
8.	Feedback on meeting
	<p>It was agreed by all the attendees that 2 hours was not long enough for the meeting and that the next meeting should be scheduled from 10.30am – 3.00pm.</p>
9.	Any Other Business
	<p>There were suggestions to have sub-group work alongside board meetings. It was agreed that there should be a patient story and to get feed-back from the patients. NM said the Board meeting could be part listening event, if timed well and this would allow the Board to get good feed-back. NO said it would be good to have a listening event in Musgrove.</p> <p>NO asked how the Network Team was going to engage Yeovil and Plymouth. AT said that at present Yeovil have not formally joined the network, but have been working with Southampton in their network approach. There will be discussion with commissioners and with the Southampton network to ensure that patients have the choice of which pathway to follow.</p> <p>RKL says that some Plymouth patients (particularly female patients) come to Torquay and she generally offers them referral to Bristol. There will be further discussion with commissioners about these pathways.</p>
<p><u>Date, time and location of next meeting</u> The next meeting is Tuesday 6 December 2016, 10:00 – 16:00 in Cardiff. Venue details to follow.</p>	

Attendees

Name	Inits.	Job Title
Amiri, Hussein	AM	Patient Representative
Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB
Baulch, Mary	MB	Matron/Children's Lead, Royal Cornwall Hospital NHS Trust, Truro
Bedair Radwa	RB	Consultant Cardiologist, UHB
Benefield, Rachel	RMB	Administrator – CHD Network and Note-Taker
Coslett, Christopher	CC	Specialised Services Planning Manager Cwm Taf LHB - Welsh Health Specialised Services Committee
Dunn, James	JD	Manager – CHD Network
Kelly, Nicola	NK	Service Manager - Paediatrics, Royal Gwent Hospital
Kerr-Liddell, Rowan	RKL	PEC, Torbay and South Devon NHS Foundation Trust
Lambert, Rebecca	RL	Staff Nurse (ACHD) Clinic, Taunton & Somerset NHS Foundation Trust
Maddicks, Hilary	HM	PEC, RUH, Bath
Mashford, Kevin	KM	Patient Representative
Morris, Nicola	NM	Heart Families South West
Osborne, Nigel	NO	PEC, Royal Devon and Exeter Foundation Trust
Packer, Liza	LP	Adult Representative
Tometzki, Andrew	AT	Clinical lead – CHD Network
Vernon, Sheena	SV	Nurse lead – CHD Network
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB
Wilson, Dirk	DW	Consultant Paediatric Consultant, University Hospital of Wales

Apologies

Name	Inits.	Job Title
Clinchant, Andre	AC	Lead Nurse and Paediatric Oncology Outreach Nurse, Children's Community Nursing Service, Taunton and Somerset NHS Foundation Trust
Curtis, Stephanie	SC	ACHD lead, UHB
Edwards, Francis	FE	Paediatric Palliative Care, UHB
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Cheltenham
Lewis, Vaughan	VL	Clinical Director Specialised Commissioning NHS South
Mabin, David	DM	Consultant Cardiologist, Royal Devon & Exeter NHS Foundation Trust
Parker, Sally	SP	Heart Families South West
Shiers, Bethan	BS	ACHD CNS, University Hospital of Wales
Stuart, Graham	GS	Consultant Cardiologist, UHB
Walsh, Rod	RW	Senior Service Specialist, NHS England