

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

Date: Tuesday 19 December 2017, 10:00 – 13:10

Venue: Reed Hall, University of Exeter, Streatham Drive, Exeter, EX4 4QR

Chair: Dr David Mabin

Minutes

Item	Notes and Actions
1.	<p>Welcome, Introductions & Apologies (see appendix). DM welcomed and introduced the attendees and noted apologies.</p>
2.	<p>Approval of Minutes</p> <p>The minutes of the Network Board meeting on 28 September 2017 were agreed as an accurate reflection of the meeting.</p>
3.	<p>Patient Story</p> <p>The Board was shown a video of the patient experience of “Frankie” which had been provided by BS.</p> <p>The video raised important issues such as the impact of surgical cancellations on patients, and the need for trust/rapport to be developed with the patients.</p> <p>SC indicated that it was not routine to contact the referring hospitals if operations were cancelled. It was agreed by all that good communications with the patients was vital.</p> <p>Action – SC to ensure that the Bristol adult team emails the ACHD CNS in Cardiff if surgery is cancelled. Action – SV to arrange for video to be shown at Senior Nurses Meeting.</p>
4.	<p>Actions</p> <p>The actions log was updated as appended. Notable comments:</p> <p><u>Action number 1 – Yeovil and Plymouth Network Pathways</u></p> <p>The Network Team met with NHS England on 4 December 2017 and discussed both of these regions and discussions being taken forward. AT and SV will meet with Meredith Kane in the New Year.</p> <p>ACTION – CLOSED.</p> <p><u>Action number 11 – Use of Skype/Videoconferencing for joint calls between patients</u></p> <p>AT confirmed by way of slide presentation the Skype/Videoconferencing which is currently available. For those centres who do not have equipment, AT suggests they nominate an IT champion to determine what equipment they have, the model location and the connectivity. (See appendix for detail.) AT confirmed there is funding available to centres to support the roll-out due to a legacy inheritance.</p> <p>Action – Centres to identify a clinical champion to drive progress locally. AT to email IP address to all the centres.</p>

	<p><u>Action number 21 – Website</u></p> <p>Website work is underway. Some patient representatives have given feedback and NM is involved in developing the patient/family FAQs. ACTION – CLOSED.</p> <p><u>Action number 28 – Access to UHW Systems through Cardiobase</u></p> <p>Work is underway on this, but not yet completed.</p> <p><u>Action number 35 – Paediatric protocols</u></p> <p>5 protocols will be presented at today's meeting. This action will be closed on the tracker but remains in the work plan as an ongoing piece of work. ACTION – CLOSED.</p> <p><u>Action number 44 – Identification of Opportunities for Improved PIC Transfers between UHB and UHW</u></p> <p>CM met with Dr J Fraser (PICU Lead) who confirmed there is increased activity going to Cardiff, which echoed DW's comments at the previous Board meeting. ACTION – CLOSED.</p> <p><u>Action number 46 – Pregnancy and Obstetric Care Protocols</u></p> <p>SC confirmed that she sent these to HW in November and that she is still waiting for HW to confirm if they are in line with Welsh practice.</p> <p><u>Action number 47 – Development of a Patient Folder with Key Information</u></p> <p>This is being developed as part of the Network Website. ACTION – CLOSED.</p> <p><u>Action number 49 – Welsh Standards</u></p> <p>CM confirmed that AR will give an update on this action on item 11 of the agenda. ACTION – CLOSED.</p> <p><u>Action number 50 – Specialist Nursing Provision</u></p> <p>CM confirmed that this is a continuing area of work. This action will be closed on the action tracker but will remain in the work plan. ACTION – CLOSED.</p> <p><u>Action number 52 – Fetal Out of Hours Rota</u></p> <p>AT confirmed that it is not feasible to develop an out of hours rota. He confirmed that the on call paediatric cardiologists in Cardiff/Bristol need to take the calls and ring whoever they need to. ACTION - CLOSED.</p>
5.	<p>Items arising</p>
	<p><u>1. Network Palliative Care Toolkit</u></p> <p>FE presented the Network Palliative Care Toolkit to the Board and asked members to give feedback by e-mailing him or SV with any comments. Action for all board members to review and comment.</p>

	<p>The Toolkit will be circulated to the whole Network once feedback has been received.</p> <p>2. PICU at the BRHC</p> <p>CM presented her paper on the Paediatric Intensive Care Unit at the BRHC to the Board. VM confirmed that a business case for the expansion of PICU is being prepared to increase capacity from 18 flexible beds to 24 beds. The recommendations in the paper were supported:-</p> <ol style="list-style-type: none"> 1. To add PICU capacity to the Network Risk Register 2. To support the case for PICU expansion
6.	Level 3 Centres Update
	<p>DM presented this update to the Board, referring to the paper 'Centres Exception report narrative'.</p> <p>DM brought to the attention of the Board the risk (Taunton adult service) which has been escalated to the Network of David MacIver retiring in February 2018. The Network Team had worked with NHS England and sought assurance from the Trust regarding its ongoing commitment to providing an ACHD service.</p> <p>RL says that she has been informed that the Trust will do what is needed to adhere to the CHD standards and that there has been agreement to recruit to the post. The concern is if it will be possible to fill the post and support may be needed from Bristol. It was agreed that SC and CM will meet in the New Year to feed-back to Vaughan Lewis and Stuart Walker (Medical Director of the Trust).</p> <p>Action – CM to arrange discussions between BHI and Network Team in January about the succession issue in Taunton.</p> <p>DM finally brought the attention of the Board to the risks in the centres as follows:-</p> <ul style="list-style-type: none"> • The lack of specialist Cardiac nurses: the role of the specialist cardiac nurses is essential to fulfil so many of the Network standards • PEC cover in Taunton and Torbay
7.	Performance dashboards
	<p>CM presented the Network dashboard and summary of exception reports for December 2017 (see report for full details). Follow-up backlogs are an area of particular concern, with numbers growing in several centres and almost 4000 patients being overdue across the centres that had responded to the request for data. AT suggested mapping the hotspots where there are large backlogs. Action – CM to request further information from centres regarding their plans and clinical risk assessments of backlogs.</p>
8.	Level 2 centres update
	<p>BS and DW provided updates to the Board via VC. Please see Centres Exception Report (Paper 8) for detail.</p>
9.	Level 1 centres update and psychology service update
	<p>SC provided the following update to the Board on behalf of the adults service:-</p> <ul style="list-style-type: none"> • New psychologist now fully embedded in service and busy • The service has successfully appointed a locum consultant who is due to start in January 2017. This is a 6

	<p>month post which will focus on outpatient activity and reduction of backlogs. Report to follow at upcoming Network meeting.</p> <p>VM provided the following update to the Board on behalf of the paediatric service:-</p> <ul style="list-style-type: none"> • Successful reduction in surgical waiting list. • Weston and Nuffield clinics planned to start January to support reduction in follow up backlogs/ new patient waits. • Plan to refresh capacity and demand modelling in new year • New Assistant General Manager starting 8th Jan • Catherine Armstrong (Consultant) now in post • Mark Walsh is leaving and hoping to appoint a replacement for EP in the next few months <p>As Vanessa Garratt was not able to attend the meeting VM and CM presented the Level 1 Cardiac Psychology Service Update and confirmed that the psychology team will present at the next Board meeting on 22 March 2018. The Psychology team will write to centres with details of the service and referral guidance in the new year.</p>
10.	Network update
	<p>Twitter – CM confirmed that the Team is now on Twitter (@CHDNetworkSWSW)</p> <p>Audit programme – CM highlighted that the standards require at least one significant audit per year from each centre.</p> <p>Action: Centres to consider audit opportunities.</p> <p>Updated work plan –CM invited the Board members to hold the Network Team to account. Are the Network Team doing the right things and what is going well?</p> <p>Discharge communications – CM confirmed that she is aiming to draft a SOP and asked the members of the Board the best way for electronic communications to be received at centres.</p> <p>AC said that in Taunton they have a generic e-mail for consultants and CNS which works well (example of message - if you are replying in regard to oncology issues please add tauntonpaedonc@tst.nhs.uk to the message so all the local team can read it). SC said that they have a team email at the BHI. CA said that BRHC has a paediatric cardiology account and a group NHS net email account. This works well with Truro.</p> <p>Medical workforce issues – CM noted progress in working with Health Education England to highlight our workforce risk in the region. Work ongoing.</p> <p>Paediatric Protocols – SG explained that five protocols have been sent out with the Board papers for today’s meeting and five will be sent out for the next Board meeting. She asked the Board members to consider the protocols and e-mail any comments to her or SV.</p> <p>Action: Board members to send any feedback on these to Sheena Vernon and Susie Gage by the end of January.</p> <p>After receiving any feedback from board, the protocols would then pass through the UHB and UHW governance and then be sent out to the Network. The first five protocols sent out with the papers for the December Board could be signed off at the Board meeting in March.</p>

	<p>Education/Training – SV confirmed that there is a PEC Training Day on 8 February 2018. There are 50 places and 20 clinicians have already signed up for the Day. There is a Network Day for Level 1 and Level 2 nurses on 30 January 2018.</p> <p>Network risks – CM summarised these as: link nurses, funding for Network team, PEC recruitment/gaps, medical workforce (succession plans) and PICU capacity pressures.</p> <p>Network incidents – AT summarised these as paediatric patient having to be transferred to Southampton, 5 post-natal diagnoses where an antenatal suspicion/diagnosis may have been possible and a 16-year old patient presenting at A & E in Wales and being refused care by local adult/paediatric hospitals who then had to be transferred to the Level 2 centre.</p> <p>Primary Care – AT confirmed that General Practitioner Louise Paterson is now a member of the Board and should be in attendance at the March Board meeting. He said that it would be helpful to have guidelines for GPs and online training on the Network website.</p> <p>CRG update – AT gave details of the Specialised Services Quality Dashboards for paediatric/adults which are now live and report monthly. These show where each Level 1 centre sits within certain parameters, for example, the number of last minute cancellations. AT noted he can only show data for Bristol.</p> <p>A call to action for 2018 – CM asked the Board members how they saw their role and asked whether individuals could work with the Network Team on driving progress. Areas where input would be welcomed include: audit, research, governance, palliative care, incidents, GP training, returning clinician profiles, forming sub-groups to focus on different areas of work or any other suggestions</p>
<p>11. Commissioner Update</p>	<p>AR explained the new arrangements at WHSCC. She confirmed that there is now a planner in each portfolio. They are now in teams commissioning rather than working as individual planners, and working more on the quality aspects of commissioning. In the cardiac team there is an Associate Medical Director for cardiac services (Paul Flynn), she is the Specialised Services Planning Manager and Susan Kedward is the Assistant Planning Manager. Paediatric cardiology used to sit in Women’s and Children and is now the Cardiac team.</p> <p>AR confirmed that they have drafted a set of standards (a service specification) for adult CHD. For fetal and paediatric CHD there is a draft but this has not been shared with anyone and will not be released until a review has been done. This will be a huge piece of work going forward.</p> <p>AR confirmed that WHSCC has invested in ACHD service of which there are 2 stages. Stage 1 is fully committed and all posts have been filled. They are still waiting for the feedback/data sets. Stage 2 has not been started as they are waiting to review stage 1 first. There is no new funding – a risk management frame-work has been introduced. The work is being prioritised with health boards. All new work needs to go through a prioritisation process.</p> <p>DW confirmed via VC that he has a meeting with AR soon.</p> <p>RW made the following points:-</p> <p>There is a recognition that the national team is looking at funding of Network teams. RW will feedback</p>

	<p>to Network team re details of this when known.</p> <p>They will now focus/capitalise on Network arrangements. How the Networks arrange themselves across units. How/if they can work with adjacent Networks to make things easier. Work towards a standardised approach – on same pathways. Emphasis around standards in more local units – an audit.</p>
12.	Any Other Business
	<p>The next Board meeting is Tuesday 22 March 2018 in Wales.</p> <p>CM indicated that the Network Team would like the patient story to be a standing item on the agenda and therefore welcomed these via the Board members.</p>

Attendees

Name	Inits.	Job Title
Amiri, Hussein	HA	Patient Representative (via VC)
Armstrong, Catherine	CA	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB (via VC)
Benefield, Rachel	RMB	Administrator – CHD Network Team
Blakemore, Catherine	CB	Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust
Cathy Carey	CC	Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust
Clinchant, Andre	AC	Lead Nurse and Paediatric Oncology Outreach Nurse, Children's Community Nursing Service, Taunton & Somerset NHS Foundation Trust
Curtis, Stephanie	SC	Consultant Cardiologist and ACHD lead, University Hospitals of Bristol NHS Foundation Trust
Edwards, Francis	FE	Paediatric Palliative Care Clinical Nurse Specialist, University Hospitals of Bristol NHS Foundation Trust
Finch, Sarah	SF	ACHD CNS, University Hospital of Wales, Cardiff (via VC)
Gage, Susie	SG	Paediatric Cardiology and Surgical Pharmacist, University Hospitals of Bristol NHS Foundation Trust
Hulbert-Powell, Emma	EHP	Consultant Paediatrician, Plymouth Hospitals NHS Trust
Kedward, Susan	SK	Assistant Planning Manager, WHSCC
Lambert, Rebecca	RL	Staff Nurse (ACHD) Clinic, Taunton & Somerset NHS Foundation Trust
Liversedge, Helen	HL	Associate Specialist Obstetric and Gynaecological Ultrasound, Royal Devon & Exeter NHS Foundation Trust
Mabin, David	DM	Chair of CHD Network and PEC, Royal Devon & Exeter NHS Foundation Trust
Macfarlane, Victoria	VM	Deputy Divisonal Director, Women's and Children's Division, University Hospitals of Bristol NHS Foundation Trust
Maddicks, Hilary	HM	PEC, Royal United Hospitals Bath NHS Foundation Trust
Moss (nee Marnell), Caitlin	CM	Manager – CHD Network Team
Osborne, Nigel	NO	PEC, Royal Devon and Exeter Foundation Trust
Padmanabhan, Sam	SP	PECSIG, Royal Cornwall Hospital NHS Trust, Truro
Patten, Lisa	LP	Paediatric CNS, University Hospitals of Bristol NHS Foundation Trust
Richards, Andrea	AR	Specialised Services Planning Manager, WHSCC
Sheehan, Karen	KS	Cardiac Research Sister, University Hospitals of Bristol NHS Foundation Trust
Shiers, Bethan	BS	ACHD CNS, University Hospital of Wales, Cardiff (via VC)
Tometzki, Andrew	AT	Clinical Director – CHD Network Team and Consultant Paediatrician, University Hospitals of Bristol NHS Foundation Trust
Vernon, Sheena	SV	Lead Nurse - CHD Network Team

Name	Inits.	Job Title
Walsh, Rod	RW	Senior Service Specialist, NHS England
Wilson, Dirk	DW	Consultant Paediatric Consultant, University Hospital of Wales, Cardiff (via VC)

Apologies

Name	Inits.	Job Title
Baulch, Mary	MB	Matron/Children's Lead, Royal Cornwall Hospital NHS Trust, Truro
Bedair, Radwa	RB	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Bowen, Samantha	SB	Technical Head of Echocardiography, University Hospital of Wales, Cardiff
Elbehery, Soha	SE	Consultant Paediatrician, Aneurin Bevan UHB (Nevil Hall)
Elmasry, Ola	OE	PEC, Royal Cornwall Hospital NHS Trust, Truro
Flynn, Paul	PF	Associate Medical Director for cardiac services, WHSSC
Gandhi, Manish	MG	Consultant Cardiologist, Royal Devon & Exeter NHS Foundation Trust
Gilbert, Melanie	MG	Matron, Child Health and NNU, Royal Cornwall Hospital NHS Trust, Truro
Hawker, Corrina	CH	Patient Representative
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Gloucester
Lewis, Vaughan	VL	Clinical Director, Specialised Commissioning NHS South, NHS England
Marriage, Will	WM	Paediatric Intensivist and Lead, WATCH
Mashford, Kevin	KM	Patient Representative
Morris, Nicola	NM	Parent/Support Group, Heart Families South West
Nash, Becky	RN	Patient Representative
Packer, Liza	LP	Patient Representative
Parry, Andrew	AP	Consultant Paediatric Surgeon, University Hospitals of Bristol NHS Foundation Trust
Parker, Sally	SP	Heart Families South West
Paterson, Louise	LP	GP, Bradford on Avon and Melksham Health Partnership
Skipwith, Gina	GS	Women's and Children's Operational Manager, Torbay and South Devon NHS Foundation Trust
Stuart, Graham	AGS	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Tidcombe, Rachel	RT	Patient Representative
Tulloh, Rob	RMT	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB