

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

Date: Tuesday 13 June 2017, 10:00 – 12:30

Venue: Board-room 3, The Parkway Hotel, Cwmbran Drive, Cwmbran, NP44 3UW

Chair: David Mabin

Minutes (Draft)

Item	Notes and Actions
1.	<p><u>Welcome, Introductions & Apologies</u> (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 15 March 2017 were agreed as an accurate reflection of the meeting.</p>
3.	<p>Actions</p> <p>The actions log was updated as appended. Notable comments:</p> <p><u>Action number 1 – Yeovil and Network Pathways</u></p> <p>The network team are working to ensure that there are clear pathways with Plymouth and Yeovil for those patients who undergo treatment in Bristol. Visits have been arranged with both centres. There is no intention to change existing patient flows.</p> <p><u>Action number 11 – Use of Skype/Videoconferencing for joint calls between patients</u></p> <p>There is a new conference room in Bristol and the link has been tested with Cardiff. The quality of the pictures needs refining. Swindon wish to test the link to Bristol to engage in the JCCs.</p> <p>ACTION – JD to establish a roll-out plan for access to the JCC videoconference</p> <p><u>Action number 16 – Consultant Job Planning Requirements</u></p> <p>AT indicated that there is a variation in the job plans of the consultants. He stated that his main concern is succession planning which was an issue raised by clinicians, i.e., what is going to happen when the adult consultants retire. AT suggests doing a confidential Survey Monkey of the adult service.</p> <p>ACTION – JD – to undertake a survey of succession planning</p> <p><u>Action number 18 – Specialist Nursing Provision</u></p> <p>Nursing provision remains a challenge across the region with inequitable provision ranging from a few centres with consistent visiting CNS attendance, to others with no link nurse identified. It was proposed that the following actions be taken:</p> <ul style="list-style-type: none"> - Link nurse role description be identified (duties, education, support/training) - Learning to be shared from those centres that have begun to establish the roles (e.g. how it was funded / approved, practicalities, benefits / value-add to 'sell' the role) - The network team should support individual centres in progressing business cases for investment in link nurses

ACTION - SV to lead the above actions

Action number 21 – Website

AT confirmed that a supplier (WebBox) had been engaged. The company are starting work soon and there will be a launch date at the end of the Summer.

Action number 24 – NICU capacity / Out of Area Transfers

It was agreed that this action would be closed.

The incidence of this is relatively low, with an escalation process in place within UHB. This will continue to be reported as a clinical exception via the incident form.

Action number 28 – Access to UHW Systems through Cardiobase

DW confirmed that in theory this can be done.

Action number 34 – Clinical Protocols

Action closed. The ACHD Lesions Protocols have been adopted and circulated.

Action number 35 – Paediatric protocols

This work has not yet started.

ACTION: Demetris Taliotis has agreed to support Michael Yeong to produce the protocols. These should link to protocols already in existence (e.g. PEC handbook, UHW handbook)

Action number 37 – MRI Capacity Review for Wales

Cardiac MRI is not a specialised service in Wales (and therefore not a commissioning responsibility for WHSSC). However, WHSSC developed an all-Wales policy and service specification and are worked with Health Boards to develop local plans to meet capacity requirements. This is now complete.

Implementation of these plans will be the responsibility of the Health Boards. The Cardiac Network has agreed to support regional planning as required.

NEW ACTION – Clinicians to report if MRI access does not improve as a result of the new Health Board implementation plans

Action number 38 – Meeting with WATCH

Closed: A meeting has been arranged with the WATCH Team on Tuesday 27 June. Updates will be reported back to the Board.

Action number 39 – Formal Sign-off Process for Network Protocols which includes a Review against the NHS Standards

Closed: A process is now in place to ensure all protocols are reviewed against the CHD standards prior to adoption.

Action number 40 – Charity Partner Proposal

Above and Beyond will be the primary charity partner. This will be launched alongside the Website.

Action number 41 – Circulation of the Heading Titles for the Annual Report and Feed-Back from the Board Members

This action was discussed on item 5 of the Agenda.

Action number 42 – Contacting NHS Digital to improve Data Collection for Quarterly Dashboard

Closed: NHS Digital have been contacted, but the costs for data capture are prohibitive.

Action number 43 – Review of the UHB Surgical Capacity Plan

This action was discussed on item 6 of the Agenda.

Action number 44 – Identification of Opportunities for Improved PIC Transfers between UHB and UHW

This action is in progress. A meeting with WATCH has been arranged for Tuesday 27 June.

Action number 45 – Communication with Parents about Delays in Surgery

This action was discussed on item 6 of the Agenda.

Action number 46 – Pregnancy and Obstetric Care Protocols

SV and SC confirmed that these have gone to Helen Wallis for her to review if they are in line with Welsh practice. They need to hear back from Helen Wallis.

Action number 47 – Development of a Patient Folder with Key Information

It was proposed that this could perhaps be developed on the Network Website due to be launched in the Summer.

Action number 48 – Risks and Incidents

Closed: The risks and incidents will be resent quarterly and put on the Board Agenda. The CHD Network Team has developed a methodology and the information will go on to DATIX. The risk and Incident guidelines need to be split.

Action number 49 – Welsh Standards

CC will report back on the likely time-frame for Welsh standards after the NHS England consultation has closed in July 2017.

4. Items for Approval

	<p><u>Risks and Incidents</u></p> <p>SV outlined two papers entitled CHD Network Risk Management and Morbidity and Adverse Incident Reporting for approval and sought the views of the Board.</p> <p>OE enquired whether the risk is primarily with the Trust and therefore should be dealt with locally.</p> <p>AT confirmed that there was a parallel pathway – the management of the risk is with the Trust initially, but the Network Board should be aware of the risk as well. The Network would want to be alerted of the risk at the start of the process. AT confirmed that the method of escalation would be via a reporting form and e-mail address. The process is outlined in a flow chart in the document.</p> <p>Following comments from DW and CC it was agreed the papers should be redrafted and recirculated with the risks and incidents separated.</p> <p>AT agreed that JD needs to revisit both papers and separate out the risks and incidents.</p> <p>AT said that when redrafting the paper, the Risk Escalation Chart needs to show a parallel pathway in the Risk.</p> <p>[Following the meeting JD clarified through discussion with CC and DW and it was felt that the papers do not require further amendment and so can be tabled for approval at the next meeting.]</p> <p><u>Palliative Care Pathway</u></p> <p>SV presented the Pathway for the Board to discuss and asked for feed-back by e-mail.</p> <p>There was broad support for the Pathway presented. The following comments were made:-</p> <ul style="list-style-type: none"> • The document is long – DW indicated that he would like a document that was 4 pages long with supplementary appendices. <p>Key points were:</p> <ul style="list-style-type: none"> • Most children die in tertiary centres after exhaustive treatment in Level 1 centres. • Earlier end of life discussion is beneficial and consideration of referral to palliative care • Difficulties include parents not wanting clinicians to discuss this in front of their child. <p>ACTION – Board members to read paper and send comments to SV who will present a final draft of the paper at the September Board.</p>
5.	Network Update
	<p>AT and SV presented an update on the Network team’s activities, including:</p> <p><u>NHS England Consultation</u> – AT confirmed that purdah will cease after the government is formed.</p> <p><u>Upcoming education/training</u> – SV outlined, amongst other things, that there is an ACHD study day on 19 September and a paediatric study day the date of which is yet to be confirmed (now confirmed as 17 November 2017).</p>

	<p>Annual report - AT outlined the heading titles for the Annual report and asked the Board members for feed-back.</p>
6.	<p>Dashboard/Exception Reports from Units</p> <p>AT presented the Network dashboard and summary of exception reports for June 2017. He indicated that the report was correct as at Thursday 8 June, when JD went on annual leave.</p> <p><u>Children’s Services – Highlight areas</u></p> <p><u>UHB surgical waiting list:</u> - The paediatric surgical waiting list in Bristol has stabilised at approximately 90 patients. This is still considered to be too many patients. The clinical risk is being assessed weekly by the lead surgeon to prioritise the most urgent cases. The option of transferring patients to other surgical centres has been explored but on balance UHB do not think that it is in the patients’ best interests at present considering the waiting lists of other units and the delay in getting patients assessed in those units.</p> <p>Further work is needed to put in place a robust plan to meet current and future surgical demand</p> <p>ACTION: The network team will be supporting Bristol to develop this plan</p>
7.	<p>Commissioner Update</p> <p>RW explained that there has been a hiatus in the oversight group arrangements for 6 months or more. Because of purdah any progress has stalled for the last 6 weeks. He is meeting with Una Vajakovic, ODN Director, for Thames Valley and Wessex NHS England Specialised Commissioning South to try and make some progress with this. He will report back on this at the Board meeting in September.</p> <p>CC indicated that he had nothing specific to report regarding CHD. WHSSC are nearing completion of a 3-year integrated plan. There will be no new investment in specialised services. The focus will now be on risk management – identifying the risks and how to manage these.</p>
8.	<p>Patient/Support Group/ Charity Update</p> <p>DW expressed his view that there should be a patient story at the next Board meeting on 28 September.</p> <p>BS said that she has 7 patients interested in being active and they do not wish to attend the Board meetings. It would be better for these patients to attend workshops.</p> <p>RN agreed that attending the Board meetings can be overwhelming and that, even though she is a nurse the terminology is daunting.</p> <p>VG suggested using mentors for the Board meetings – she has video podcasts. She informed the Board that Sally Parker from Heart Families South West is stepping down in the next year. The organisation will look at its structure as 600 members is big. They are looking at charity status and may be splitting in to two groups – Exeter and Bristol.</p>

9.	Any Other Business
	<p>DW gave the following update regarding the Wales Heart Disease Delivery Group/Heart Conditions Implementation:-</p> <ul style="list-style-type: none"> • The fetal clinics have now increased to 3 per week with the 4th contingent on the recruitment of a new consultant. • An exercise overseen by Public Health Wales was carried out with support from paediatric and adult congenital cardiology to identify patients who might be at risk of <i>Mycobacterium chimaera</i> infection. As a result of the exercise, 9 patients were reviewed in the outpatient clinic and no chimaera infections have been identified. • Monies have been identified to allow the sending of echo images from Cardiff to Bristol and other English centres via the Image Exchange Portal – a procurement process is in place. • Dr Sandeep Ashtekar (PEC from Aneurin Bevan LOHB) is undertaking a 4-month sabbatical in paediatric cardiology. He will spend time in Cardiff and Bristol. • VC conference links have been tested between Cardiff and Bristol conference rooms. • NHS England consultation event – a small number of ACHD patients attended, all of whom expressed their support for the Royal Brompton Hospital. • Request for support from the network on how out-of-hours advice can be given for fetal emergencies. Algorithm to be developed and agreed. <p>(RMT suggested phoning the paediatric cardiologist on call. DW asked if it was possible to have a rota – of clinicians willing to provide expert advice of out hours in exceptional circumstances).</p> <p>ACTION – AT will speak to Patricia Caldas and Orhun Uzun to test willingness to be on a fetal out of hours rota</p> <p>SA said that the Wales Cardiac Network meetings are now formal. He will let JD and RB know the dates of these meetings. Last week there were 40 attendees. The Board was split between formal and education. Nurses and the PECs at the Level 3 centres were asking for help from Cardiff in upskilling. He would appreciate it if the Network could spread the word regarding the educational side of their Board meetings.</p>
10.	Date, time and location of next meeting
	<p>The next meeting is Thursday 28 September 2017, 10:00 – 16:00 in Exeter. Venue details to follow.</p> <p>Suggestions for the workshops that day were learning disabilities, transition, a patient story and M and M. 2 topics will be chosen for the afternoon workshops that day.</p>

Attendees

Name	Inits.	Job Title
Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB
Benefield, Rachel	RMB	Administrator – CHD Network Team
Coslett, Christopher	CC	Specialised Services Planning Manager Cwm Taf LHB - Welsh Health Specialised Services Committee
Curtis, Stephanie	SC	ACHD lead, University Hospitals of Bristol NHS Foundation Trust
Elbehery, Soha	SE	Consultant Paediatrician, Aneurin Bevan UHB (Nevil Hall)
Elmasry, Ola	OE	PEC, Royal Cornwall Hospital NHS Trust, Truro
Finch, Sarah	SF	ACHD CNS, University Hospital of Wales, Cardiff
Garratt, Vanessa	VG	Clinical Psychologist, University Hospitals of Bristol NHS Foundation Trust
Mabin, David	DM	Chair of CHD Network and Consultant Cardiologist, Royal Devon & Exeter NHS Foundation Trust
Maddicks, Hilary	HM	PEC, Royal United Hospitals Bath NHS Foundation Trust
Marnell (now Moss), Caitlin	CM	Manager – CHD Network Team (currently on maternity leave)
Nash, Becky	RN	Patient Representative
O’Keeffe, Michelle	MO	Clinical Psychologist, University Hospitals of Bristol NHS Foundation Trust
Shiers, Bethan	BS	ACHD CNS, University Hospital of Wales, Cardiff
Tometzki, Andrew	AT	Clinical Director – CHD Network Team and Consultant Paediatrician, University Hospitals of Bristol NHS Foundation Trust
Tulloh, Rob	RMT	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Vernon, Sheena	SV	Lead Nurse - CHD Network Team
Walsh, Rod	RW	Senior Service Specialist, NHS England
Wilson, Dirk	DW	Consultant Paediatric Consultant, University Hospital of Wales, Cardiff

Apologies

Name	Inits.	Job Title
Amiri, Hussein	HA	Patient Representative
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
Clinchant, Andre	AC	Lead Nurse and Paediatric Oncology Outreach Nurse, Children's Community Nursing Service, Taunton and Somerset NHS Foundation Trust
Dunn, James	JD	Manager – CHD Network
Edwards, Francis	FE	Paediatric Palliative Care Clinical Nurse Specialist, University Hospitals of Bristol NHS Foundation Trust
Gilbert, Melanie	MG	Matron, Child Health and NNU, Royal Cornwall Hospital NHS Trust, Truro
Hawker, Corrina		Patient Representative
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Gloucester
Kerr-Liddell, Rowan	RKL	PEC, Torbay and South Devon NHS Foundation Trust
Lambert, Rebecca	RL	Staff Nurse (ACHD) Clinic, Taunton & Somerset NHS Foundation Trust
Lewis, Vaughan	VL	Clinical Director Specialised Commissioning NHS South
Liversedge, Helen	HL	Associate Specialist Obstetric and Gynaecological Ultrasound, Royal Devon & Exeter NHS Foundation Trust
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	Patient Representative
Padmanabhan, Sam	SP	PECSIG, Royal Cornwall Hospital NHS Trust, Truro
Parker, Sally	SP	Heart Families South West
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
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB
Waters, Noelle	NW	Assistant Service Manager, Aneurin Bevan UHB