

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

**Date:** Wednesday 15 March 2017, 10:00 – 12:30  
**Venue:** Woodlands Castle, Ruishton, Taunton, TA3 5LU  
**Chair:** David Mabin

### Minutes

Item	Notes and Actions
1.	<p><b><u>Welcome, Introductions &amp; Apologies</u></b> (see appendix).  DM welcomed and introduced the attendees and noted apologies.</p>
2.	<p><b>Approval of Minutes</b></p> <p>The minutes of the December 2016 Board Meeting were agreed as an accurate reflection of the meeting.</p>
3.	<p><b>Actions</b></p> <p>The actions log was updated as appended. Notable comments:</p> <p><b><u>Action number 1 – Yeovil and Network Pathways</u></b>  AT outlined that the current arrangements with Yeovil require some tuning to protect patients that fall between the adjacent clinical networks, and that a better understanding of the local services is required. As a consequence there are some challenges. It is important pathways are clear and communication is good for those Yeovil patients who come to Bristol for their level 1 care. AT has spoken to the Yeovil Medical Director, Meredith Kane, about building a more collaborative pathway. He made it clear that there is no intention for Bristol to try to increase activity from Yeovil, but to ensure those existing patients are getting service in line with the wider network and the national standards. A meeting is being set up with Meredith Kane to take this forward. It was agreed that the Network Board needs to be assured that the clinical pathways and access for Yeovil-Bristol patients is functioning well.</p> <p>VL provided an update on this issue in relation to the NHS England consultation which is underway and due to close in June 2017. Until that consultation is completed there will be no changes to existing patient flows. Under the consultation NHS England are minded to cease commissioning level 1 services from Leicester and Royal Brompton. VL commented that NHS England is confident that neither the Southampton nor SWSW networks will struggle to meet the 2016 standards. The issue will come with the 2021 standards and the requirement to increase surgical numbers. The catchment areas, including flows from Yeovil/Plymouth will need to be reviewed at that point. The mapping to date is on the basis of redistribution of patients from Leicester/The Brompton to the next nearest units, meaning that any of the proposed closures will have minimal impact on the SWSW network.</p> <p>RMT noted that he has been in discussion with paediatric cardiologists from Oxford. They cannot continue to support clinics in Swindon, so over time these clinics will be taken over by Bristol consultants, with the patients moving into the SWSW network.</p> <p>VL noted that a meeting between the Southampton and SWSW networks cannot happen until the outcome of the consultations in early June. This outcome may be subject to judicial review.</p> <p><b><u>Action number 12 – MRI capacity in Wales</u></b>  CC noted that the project to review MRI capacity is ongoing. HW confirmed that there is a 12-month waiting list, which has reduced from 18-months. The Board will continue to monitor this quarterly</p>

**Action number 19 – Psychology support**

JD confirmed that the paediatric psychologist in Bristol will present at the June Network Board. The proposal is a tiered system of psychological provision between that provided locally through primary and secondary care and that provided by specialist cardiac psychologists. SV confirmed that an adult psychologist has just been appointed in Bristol and will work closely with the paediatric psychologists.

**Action number 21 – Website**

JD confirmed that the budget for the Network website is £15,000 and that a tender process is under way with a launch date of July 2017.

**Action number 22 – Clinical Protocols**

DM stated that any guidelines from the Welsh Paediatric Cardiac Network should ideally be acceptable from across the whole network. DW confirmed his agreement to this approach.

**Action number 23 – Pulmonary Hypertension Patients from Brompton**

RMT updated on the Brompton PH service. In the future Bristol PH patients who have had their care at the Brompton may go to St Bartholomew's Hospital or to Imperial's new Hammersmith site. If the service moves from London, these patients can come under the Bristol service.

**Action number 24 – NICU capacity / Out of Area Transfers**

JD stated that the Network would want to know if a baby was moved out of the area. NICU should record when a baby is refused and which centre it went to instead. CC said that the transport services should have this information, although RKL said that NEST does not cover the peninsula services.

**Action: Network team to arrange meetings with the transport services to develop joint working**

NM does not think that the transfer of babies out of the area, as far as she is aware, is something that often happens.

**Action number 30 – WHSSC adoption of standards**

This action was closed as this combines several actions which are either completed or postponed:

- UHB-UHW contract for oversight of adult interventional procedures performed at UHW is with UHW for signing. WHSSC may seek to ratify it once the provided Trusts have reached agreement
- WHSSC has now formally accepted the CHD TORs and governance arrangements.
- The Welsh adaptation of NHS England standards has been drafted but will not go out for consultation until after the NHS England consultation closes.

**ACTION: CC to report back on likely timeframe for Welsh standards after NHS England consultation has closed in July 2017**

**Action number 34 – Clinical Protocols**

SC is expecting the protocols to be signed off the week commencing Monday 20 March. VL stated that Network guidelines should be in line with NHS England standards. JD agreed that he would formalise this.

**ACTION: JD to formalise sign off process for guide-lines, including review against NHS England standards.**

**Action number 35 – Paediatric protocols**

AT stated that his intention to mirror the work that SC has done on the adult protocols. The PECs felt

	guidance on how to triage referrals would be helpful
<b>4.</b>	<b>Items for Approval</b>
	<p><b><u>Charity partner proposal</u></b></p> <p>JD outlined a proposal paper for Above and Beyond to be the charity partner and sought the views of the Board. There was broad support for the approach, subject to clarifying a few areas, specifically:</p> <ul style="list-style-type: none"> <li>- That funds should be easy to access by the network team and not require approval for every transaction. This was felt to not always have been the case with Above and Beyond</li> <li>- That there is transparency about where the funds go – a clear list of projects and annual budget reports in June</li> <li>- That there was a clear process for approving and allocating funds within the network and that this is equitable across locations and stages of the pathway</li> </ul> <p><b>ACTION: JD will update Charity partner proposal based on those comments and circulate to Board</b></p>
<b>5.</b>	<b>Network Update</b>
	<p>JD, AT and SV presented an update on the Network team’s activities, including:</p> <p><b><u>NHS England Consultation</u></b> - NHSE are proceeding with the consultation around the proposed re-designation of some level 1 centres. The UHB consultation event will take place at the Education Centre, Bristol on Monday 15<sup>th</sup> May. UHW consultation event took place 15<sup>th</sup> March</p> <p><b><u>Self-assessments</u></b> – the Team will check if they have received the self-assessments from Hywel Dda adults from HW, as she is sure that she has submitted it, and from Exeter adults.</p> <p><b><u>Patient engagement</u></b> – SV updated the Board on the engagement work underway, which includes: newsletters; a fetal patient survey; listening events; visits to outpatient clinics; a virtual reference group. And upcoming: Web site, July; Facebook, Jun 17; Pt engagement Cardiff, Autumn</p> <p><b><u>Working Group updates</u></b> – SV confirmed that the Palliative Care Working Group is meeting on 16 March. AT made a short presentation regarding the GE image exchange system which he is interested in trialling between Bristol and Cardiff.</p> <p><b><u>Upcoming education/training</u></b> – SV outlined the nurse education strategy which is phased over 3 years. Fundamental to this is centres identifying link nurses who can begin to be upskilled.</p> <p><b><u>Network Board dates</u></b> – JD proposed that the dates for the forthcoming Network Board meetings would be 28 September 2017, 19 December 2017 and 22 March 2018.</p> <p><b><u>Annual report - ACTION</u></b> – JD will circulate the heading titles for the Annual report and ask the Board members for feed-back.</p>
<b>6.</b>	<b>Dashboard/Exception Reports from Units</b>
	<p>JD presented the Network dashboard and summary of exception reports for March 2017.</p> <p><b><u>Adult Services – Highlight areas</u></b></p>

- Truro overdue FU: - risk to patients has been clinically reviewed, mitigation in place, with local plans needed for long-term additional capacity. **To be reviewed at next Board**
- RD&E wait for FU: - Insufficient number of joint and local F/U clinics. Local service to identify details of additional capacity needed and plans to address this. **To be reviewed at next Board**
- UHW overdue FU: - Figure likely to be over-stated as the data is not perfect. Additional capacity being arranged. **To be reviewed at next Board**
- Hywel Dda overdue FU / wait time: - high number of clinics cancelled due to day of week. Additional consultant input may be needed. **JD to discuss with HW and GS and WHSSC as part of phase 2 plans. To be reviewed at next Board**
- Cwm Taf – data provision: - Unable to provide any data and has requested additional data resource from WHSSC. At present this is not part of the funding plan as part of phase one of ACHD plan. **Network / WHSSC to contact local management about ability to monitor service management. To be reviewed at next Board**

#### **Children’s Services – Highlight areas**

- UHB outpatient wait and overdue FU: - Backlog is being validated to minimise. Additional sessions being put in place. **To be reviewed at next Board**
- Taunton overdue FU: Backlog has been triaged / is actively monitored. Reducing with SLA provided by RDE. **To be reviewed at next Board**
- Gloucester overdue FU: - Backlog is reducing with increase of 9 local sessions, and UHB input increasing to 30. **To be reviewed at next Board**
- Hywel Dda wait for new appointment and overdue FU - Whole paed service is under considerable strain due to a number of consultant vacancies. New referrals are triaged to minimise risk. Health Board has fewer sessions than other HBs. Raised with WHSSC, but this needs to be resolved by Health Board. **Network to write to Medical Director to understand local plans for resolution. To be reviewed at next Board**

There was general agreement that the dashboard is useful to highlight current status and risks. There were some suggestions to clarify the reporting, for example the follow up wait should reflect the difference between planned and actual follow up date. It was also felt that capturing number of PAs allocated would be useful. To enable useful data all centres should start to split CHD patients from other patients in both clinics coding and waiting lists

**Action: JD to incorporate these changes into next quarterly dashboard, and follow up on actions defined for each centre**

VL said that the Network could work with NHS digital. He said that NHS digital will have access to GP records.

**Action: JD to contact NHS Digital to see if they can help with data**

#### **Surgical Waits in Bristol**

RMT outlined an issue with the length of the surgical waiting list in Bristol. The waiting list had grown to 98 patients compared to a sustainable position of 30-40 patients. This is as a result of winter pressures impacting on PICU capacity; higher than expected pressures on PICU capacity in the summer months (when more cases would normally be done); and some sickness in the surgical team.

The whole waiting list has been assessed for clinical risk. Actions have been taken for a short term increase in activity, including ceasing catheter procedures for 2 weeks and running additional theatre

	<p>sessions. The 20 most urgent cases have been cleared, but a sustainable capacity plan is required in order to return the waiting list to a sustainable level. This plan will require changes across the service, including ward flows, PICU capacity and surgical efficiency. This plan will be presented to the UHB cardiac business meeting in April 2017.</p> <p><b>Action: The network team will review the UHB surgical capacity plan. Should there be any concerns about the ability of UHB to deliver this plan the network team will escalate this as appropriate.</b></p> <p>It was recognised that ultimately additional PICU capacity will be required to meet the ongoing increase in demand from both cardiac services and other users of PIC beds. VL reported that the NHS England review of PIC capacity is being held up by the CHD consultation. UHB may need to escalate concerns to NHS England if it is felt that the delay to the PICU consultation will jeopardise the delivery of the cardiac service.</p> <p>Opportunities for better coordination of PIC beds between Cardiff and Bristol were discussed, where a more proactive transfer of patients would improve flow in both units. It was also felt that lack of confidence in managing inpatients locally in level 3 centres often increased the demand on UHB ward beds, either because patients are transferred to Bristol when they could be managed locally or because there are delays repatriating patients from Bristol to local centres post-surgery.</p> <p><b>Action: Network team to identify if there are any opportunities for improved PIC transfers between UHB and UHW. To identify opportunities for reducing ward bed demand in UHB by increasing confidence in level 3 management of inpatients</b></p> <p>It was agreed that there needed to be clear communication with patients about the surgical waits. NM reported concern from Heart Families South West parents pre-Christmas about the number of cancellations. It was agreed that a letter should be sent to all patients on the waiting list explaining the delay, providing reassurance that the clinical priority of patients is being reviewed weekly, and providing a telephone number for concerns. The parent representatives were happy to review this letter before it is sent.</p> <p>All the patient representatives stated their view that it was very important that Bristol communicated with the parents about the delays in surgery, as their lives are on hold whilst they wait and uncertainty was the worst thing.</p> <p><b>ACTION: RMT/JD to communicate with parents about delays in surgery and ensure letter is review by parent reps before it is sent</b></p>
7.	<b>Patient/support group update</b>
	<p>NM reported that Heart Families South West is growing daily with 556 members and 2-3 requests a day. The group provides support through its Facebook page, social events and parties, giving a forum for families to discuss feeding, anxiety, surgery. The group are considering partnering with the Grand Appeal, the main charity of Bristol Royal Hospital for Children.</p> <p>They are working through the challenge of growing the support group whilst maintaining the personal contact that has been fundamental to its early success. SV has arranged to meet with them to help them develop a plan for the group, including the potential for sub-groups in Wales.</p> <p>NM said that UHB should communicate better with families when consultants move on, for example, AT in Torquay and Bev Tsai-Goodman in Barnstaple.</p> <p>NM will send some leaflets about Heart Families South West to DM. She said that it would be good if</p>

	<p>there were links for the group on the Network letters and newsletter.</p> <p>NM said that the group may combine with Heart Children Gloucester (Lucy Etheridge and Ruth Hansell) and have a group in South Wales. They are thinking of having an umbrella organisation with subsites.</p> <p>NM said that if her group can talk to and support parents, then they are less likely to contact the hospitals for support.</p> <p>HA provided an update of his patient representative activities via VC.</p>
<p><b>8.</b></p>	<p><b>Any Other Business</b></p>
	<p>DW confirmed that the Wales Heart Disease Delivery Group will complement the work of the Network Board. The first meeting will take place soon. He will look in to the possibility of members of the Network Team attending future meetings.</p> <p><b>KEY ACTIONS from afternoon workshops:-</b></p> <p><u>Pregnancy and Obstetric Care:</u></p> <ul style="list-style-type: none"> <li>- SV to summarise key points from the session and circulate to all clinicians along with pathway doc</li> <li>- SV to send Pathway to obstetricians and HW to review and amend these guidelines for Wales</li> <li>- SV to establish pregnancy training session as part of network training plan</li> </ul> <p><u>Patient communications:</u></p> <ul style="list-style-type: none"> <li>- Develop a patient folder with key information, access to leaflets, contacts etc.</li> <li>- Link with patient held records and future developments of apps</li> <li>- Use website as central resource for patient information</li> </ul> <p><u>Risks and incidents:</u></p> <ul style="list-style-type: none"> <li>- Contact local governance leads to simplify reporting for them and identify how local triggers can be used to identify network incidents</li> <li>- Send out new process to clinicians and governance contacts with a view to implementing immediately and reviewing after 6-months</li> </ul>
<p><b><u>Date, time and location of next meeting</u></b>  <b>The next meeting is Tuesday 13 June 2017, 10:00 – 16:00 in Wales. Venue details to follow. DW will look in to possible venues, possibly in Newport. DM will host September Board in Exeter.</b></p>	

### Attendees

Name	Inits.	Job Title
Amiri, Hussein	AM	Patient Representative (via VC)
Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB (via VC)
Benefield, Rachel	RMB	Administrator – CHD Network
Clinchant, Andre	AC	Lead Nurse and Paediatric Oncology Outreach Nurse, Children's Community Nursing Service, Taunton and Somerset NHS Foundation Trust
Coslett, Christopher	CC	Specialised Services Planning Manager Cwm Taf LHB - Welsh Health Specialised Services Committee
Curtis, Stephanie	SC	ACHD lead, UHB
Dunn, James	JD	Manager – CHD Network
Finch, Sarah	SF	ACHD CNS, University Hospital of Wales (via VC)
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Gloucester
Kelly, Nicola	NK	Service Manager - Paediatrics, Royal Gwent Hospital (via VC)
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
Mabin, David	DM	Consultant Cardiologist, Royal Devon & Exeter NHS Foundation Trust
Morris, Nicola	NM	Heart Families South West
Nash, Becky	BN	Patient Representative
Osborne, Nigel	NO	PEC, Royal Devon and Exeter Foundation Trust
Padmanabhan, Sam	SP	PECSIG, Royal Cornwall Hospital NHS Trust, Truro
Skipwith, Gina	GS	Women's and Children's Operational Manager, Torbay and South Devon NHS Foundation Trust
Tidcombe, Rachel	RT	Patient Representative
Tometzki, Andrew	AT	Clinical Director – CHD Network
Tulloch, Rob	RMT	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Vernon, Sheena	SV	Lead Nurse - CHD Network
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB
Wilson, Dirk	DW	Consultant Paediatric Consultant, University Hospital of Wales (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, UHB
Bowen, Samantha	SB	Technical Head of Echocardiography, Cardiff



Name	Inits.	Job Title
Edwards, Francis	FE	Paediatric Palliative Care, UHB
Hawker, Corrina		Patient Representative
Maddicks, Hilary	HM	PEC, Royal United Hospitals Bath NHS Foundation Trust
Mashford, Kevin	KM	Patient Representative
Packer, Liza	LP	Adult Representative
Parker, Sally	SP	Heart Families South West
Shiers, Bethan	BS	ACHD CNS, University Hospital of Wales
Stuart, Graham	AGS	Consultant Cardiologist, UHB
Walsh, Rod	RW	Senior Service Specialist, NHS England