

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

Date: Thursday 22 March 2018, 09:45 – 13:20
Venue: Coldra Court by Celtic Manor, Newport, NP18 2LX
Chair: Dr Dirk Wilson

Minutes

Item	Notes and Actions
1.	Welcome, Introductions & Apologies (see appendix).
	DW welcomed the attendees and noted apologies.
2.	Approval of Minutes
	The minutes of the Network Board meeting on 19 December 2017 were agreed as an accurate reflection of the meeting.
3.	Patient Story
	<p>The Board was shown a video entitled “Grace’s Story” – a patient story as recounted by Grace’s parents, Ben and Joanna Haywood. Grace was born with Hypoplastic Left Heart Syndrome and underwent Norwood procedures and Fontan operation at Bristol Royal Hospital for Children.</p> <p>The video was very well received by the Board. Members commented that the video raised issues such as the importance of well-informed patients and families, pre-assessment clinics and how crucial rapport and trust is with the hospital. The Board members also noted the impact that cancellations and unexpected complications have on patients and their families.</p> <p>Following the video OE asked what involvement play specialists had in the preparation of older children for surgery. LP explained the pre-assessment procedure at BRHC. These take place 7-10 days before the child’s admission, and the CNS and a play specialist attend. They talk for a long time with the families and discuss complications. The patient and families are offered a tour of PICU in the afternoon before their surgery day.</p> <p>Action – CM to upload Grace’s Story to website under patient stories if technically possible and if the Haywood family consent.</p>
4.	Actions update
	<p>The actions log was updated as appended. Notable comments:</p> <p><u>Action number 28 – Access to UHW Systems through Cardiobase</u></p> <p>Work is underway on this, but not yet completed. Team will prioritise this action after the launch of the Network website at the end of March. Alan Pateman from Cardiff is driving this initiative.</p> <p><u>Action number 46 – Pregnancy and Obstetric Care Protocols</u></p> <p>SV confirmed that 1 protocol (EP) will be uploaded on to the website and that the other 2 (referrals and anti-coagulation) will be uploaded at a later date. ACTION – CLOSED.</p>

Action number 60 – BHI to e-mail ACHD CNS in Cardiff if surgery cancelled

BHI team confirmed that this process is now in place. SF confirmed that she had only been informed of 1 cancelled operation and the situation had improved. **ACTION - CLOSED.**

Action number 61 – Video of Patient Experience to be shown at Senior Nurses Meeting

SV confirmed that the video had been circulated and noted that she had received no further feedback. **ACTION – CLOSED.**

Action number 62 - Telemedicine

No communication to AT on this. Funding still available and Centres encouraged to identify both clinical and IT champions to take up opportunity.

Action number 63 – Palliative Care Toolkit

DW commented that he felt the toolkit was quite big and therefore not easily useable. He suggested a summary on 2 A4 sides of paper. SF and LP indicated that they liked the toolkit. SV to consider whether a summary of the document to go alongside the main toolkit is feasible.

Action number 64 – Succession issue in Taunton adult Team

CM confirmed that there had been discussions since the last Board meeting and this issue had been resolved and recruitment being taken forward. **ACTION – CLOSED.**

Action number 65 – Clinical risk assessment of backlogs

CM explained that she had asked centres how they were handling the clinical assessment of their outpatient backlogs as had been reported for this quarter's dashboard/exception report.

AT indicated that the centres should have a mitigation plan and the Network Team should escalate the issue if not.

DW stated that if the centres do not provide a response to how they are addressing their backlogs the Network Team should highlight their concerns to the clinical lead and consider escalating the issue to the relevant Medical Director.

CM stated that the response rate from the centres this quarter was low. Therefore, she felt that it was difficult to escalate if many centres were not even reporting data.

Action number 66 – Paediatric Protocols

SV indicated that she and SG need to speak with the paediatric team about the protocols. Four of the drug protocols are complete and one is still to be completed.

Action number 67 – Centres to consider audit opportunities

The Paediatric team at Truro (OE) presented an audit to the Board. The Bristol Heart Institute has added an audit to the programme. Other Centres are still to identify and communicate any audits they have planned, in line with the standards.

5.	Items arising
	<p><u>1. Network Board Meetings Structure</u></p> <p>The Network team sought the views of the Board members about the structure of the Board meetings. CM shared a SWOT analysis of the current structure and described how the current structure was starting to feel inadequate given how the Network has matured over the last two years and how much there is to cover. CM presented a proposal to change the single board meeting to 3 groups – an overarching Board meeting, plus a Clinical Governance and Service Delivery Group. There would then also be short-term Task and Finish Groups as needed on specific projects. She invited the Board members to discuss in groups the proposal, its pros and cons, and any other ideas about how the structure might work differently.</p> <p>The main suggestions made by the 3 groups were as follows:</p> <ul style="list-style-type: none"> • Neonates have this sort of structure • Makes it more active rather than passive time • Extra layers may slow down progress • Don't want to increase the number of meetings for individuals • Could have less frequent main board – 2/3 times p.a. • Focus more on Level 3 centres • If smaller groups, could schedule around individuals – easier to get together • Have Task/Finish groups with defined timescales with Network oversight • Consider linking 2/3 of the Level 3 centres who would then have a lead who would feed in to the Network • Hold regional PEC meetings <p><u>2. 2018 - 2019 Work Plan</u></p> <p>CM sought the views of the Board members about the structure of the Board as to the Network Work Plan for 2018/2019 and asked the members to discuss this in small groups.</p> <p>The main suggestions made by the 3 groups were as follows:</p> <ul style="list-style-type: none"> • Disease related guidelines (bear in mind pre-existing documents) • Paediatric clinical pathways • Thresholds for Level 3 centres • Expectations of PECs • Transfer and repatriation document • Level 3 Centre standards – why are they falling short and how the Network can help • Two way comms – imaging processes • Increase awareness in Level 3 – Training/Engagement. • No money at Level 2 and Level 3 - income generation • IT based activities/systems to promote efficiencies • Developing psychology component. Equity vs distance/geography (skype?) • Service registry via website • Communication/training in primary care – with CPD accreditation • Is there scope to flip so that Level 3 centres lead on aspects? • Echo skills

6.	Level 3 Centres Update
	<p>OE presented the update to the Board for the Royal Cornwall Hospitals NHS Trust (Truro) paediatric service (see slides for detail).</p> <p>She outlined the paediatric cardiac services, the sources of patient referrals and the numbers of patients and projected numbers.</p> <p>OE then presented an audit which she and a colleague had carried out of new referrals to the cardiac clinic from May 2016 to November 2016 and posed the question, ‘Do we need Echo screening clinics for heart murmurs?’ The Board members then discussed the various approaches to dealing with heart murmurs for adults and paediatric patients in England, Wales and other countries.</p> <p>CC presented the update to the Board for the Torbay and South Devon NHS Foundation Trust, Torquay adult service (see slides for detail).</p> <p>She outlined the personnel changes, local ACHD centre requirements, IT, O&S and summarised the service at Torbay from 2014 – 2018.</p>
7.	Level 2 Centres Update
	<p>GS presented the ACHD update to the Board for the Level 2 centre (University Hospital of Wales, Cardiff) (see slides for detail).</p> <p>CM brought to the Board’s attention that SLA was signed between University Hospital of Wales, Cardiff and University Hospitals of Bristol NHS Foundation Trust for the ACHD service at the Level 2 centre as part of derogation against the NHS England standards for the SW and SW Network.</p> <p>DW and GS confirmed that the SLA was being complied with. It was noted that the required numbers of procedures were not being met in Cardiff but that this was not an issue unique to them as a centre.</p> <p>Due to time constraints, DW did not note an update to the board but confirmed relevant points were contained in the centres exception report.</p>
8.	Level 1 Centres Update
	<p>RA presented the ACHD update to the Board for the Level 1 centre (University Hospitals of Bristol NHS Foundation Trust - BHI) (see slides for detail).</p> <p>RMT presented the update to the Board for the Level 1 centre (University Hospitals of Bristol NHS Foundation Trust - BRHC) (see slides for detail).</p>
9.	Performance dashboard
	<p>CM presented the Network Performance Dashboards for March 2018 (see report for full details).</p> <p>CM drew the Board’s attention to a low response rate this quarter, particularly amongst paediatric centres (only 3 responses¹). She noted she had not had capacity to chase responses and this may have contributed to the low number of responses, but requested that centres do respond promptly were</p>

¹ Post meeting note - three further responses were received after the Board meeting, so a total of 6 for this quarter.

	<p>possible.</p> <p>There was a discussion of the areas of concern ‘hotspots’ as per noted on the dashboard itself. Follow-up backlogs remain an area of concern across several centres in the Network.</p>
10.	<p>Network Team Update</p>
	<p>The Team presented the Network Update (see slides for full details).</p> <p>Website – CM confirmed that the website is now live - www.swswchd.co.uk</p> <p>The website will be launched across the Network.</p> <p>Action - CM asked clinicians to consider adding it to letters to patients.</p> <p>She noted that it will be sent to all the major charities and support groups, to all the Network’s email database contacts, to all centre’s own communications teams and promoted on social media.</p> <p>L1 & L2 Centre Visits – CM confirmed that the Network Team has now met with the Level 1 and Level 2 centres for both paediatric and adults to review where they were against the standards and other issues.</p> <p>On behalf of Steph Curtis, ACHD Clinical Lead, CM asked if there is appetite in Level 2 and Level 3 centres for further telemedicine usage in ACHD. Centres encouraged to contact AT or SC to take this forward (already on action log).</p> <p>CHD patient survey – CM brought the Board’s attention to the survey – Chdpatientsurvey.co.uk – which is a patient reported experience measures survey, initiated by NHS England. Annual benchmarking of Level 1 centres and may be rolled out to Level 2 and 3 centres later on.</p> <p>Network Risks – CM summarised the risks. There have been no applications for the vacant PEC post in Torbay. A PEC has been appointed in Taunton. The Network Team is still concerned about succession plans in medical workforce (this could be put on the agenda for discussion for the Networks Day on 1 May), BRHC has long-term plans to expand PICU from 18 to 24 beds and the Network has concerns about the risk of inequitable care being provided to patients in some parts of South Wales due to delays to Phase II funding into CHD.</p> <p>Network Incidents – AT summarised the incidents reported to the Network.</p> <p>Network Events – SV updated the Board about recent and forthcoming Network Events.</p> <p>Funding in Level 3 Centres (England) – CM explained that this is a discussion which was requested by Andy Arend on behalf of the PECSIG group and suggested that this may be a topic for further discussion.</p> <p>(Please note the Network team slides are available on the website routinely following board updates).</p>
11.	<p>Commissioner Update</p>
	<p>AR provided the following update from WHSCC by way of email dated 22nd March. Please see appendix 1.</p>

	<p>RW provided the following update from NHS England:-</p> <ul style="list-style-type: none"> • There is no further news on Operational Delivery Networks funding, although RW has noted in their assurance returns that University Hospitals of Bristol NHS Foundation Trust were funding the Network function presently; • Responsibility for implementation, oversight and assurance of CHD standards may transfer from national to regional level to be more focused in specific regional areas (as an aside this Network is better developed than Networks in the South and as such a little ahead of the curve nationally).
12.	Any Other Business
	<p>Given the structure of the Board and Network Governance are under review at the moment, future meeting dates are to be confirmed.</p>

Attendees

Name	Inits.	Job Title
Ashrafi, Reza	RA	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Benefield, Rachel	RMB	Administrator – CHD Network Team
Cathy Carey	CC	Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust
Elmasry, Ola	OE	PEC, Royal Cornwall Hospital NHS Trust, Truro
Evans, Caryl	CE	ACHD CNS, University Hospitals of Bristol NHS Foundation Trust
Finch, Sarah	SF	ACHD CNS, University Hospital of Wales, Cardiff
Garratt, Vanessa	VG	Psychiatrist, University Hospitals of Bristol NHS Foundation Trust
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Gloucester
Hulbert-Powell, Emma	EHP	Consultant Paediatrician, Plymouth Hospitals NHS Trust
Lambert, Rebecca	RL	Staff Nurse (ACHD) Clinic, Taunton & Somerset NHS Foundation Trust
Moss (nee Marnell), Caitlin	CM	Manager – CHD Network Team
Nash, Becky	RN	Patient Representative
O’Keeffe, Michelle	MO	Psychiatrist, University Hospitals of Bristol NHS Foundation Trust
Paterson, Louise	LP	GP, Bradford on Avon and Melksham Health Partnership
Patten, Lisa	LP	Paediatric CNS, University Hospitals of Bristol NHS Foundation Trust
Szantho, Greg	GS	Consultant Cardiologist, 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
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB
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 (via VC)
Armstrong, Catherine	CA	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB (via VC)
Bedair, Radwa	RB	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Blakemore, Catherine	CB	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

Name	Inits.	Job Title
		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
Elbehery, Soha	SE	Consultant Paediatrician, Aneurin Bevan UHB (Nevil Hall)
Gage, Susie	SG	Paediatric Cardiology and Surgical Pharmacist, University Hospitals of Bristol NHS Foundation Trust
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
Kedward, Susan	SK	Assistant Planning Manager, WHSCC
Lewis, Vaughan	VL	Clinical Director, Specialised Commissioning NHS South, NHS England
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 Divisional 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
Mashford, Kevin	KM	Patient Representative
Morris, Nicola	NM	Parent/Support Group, 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
Parry, Andrew	AP	Consultant Paediatric Surgeon, 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)
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

Appendix 1

Update from WHSSC in regards to CHD

A paper is in the process of being written to update the Joint Committee of the current situation in regards to CHD services in Wales. This paper also asks JC for support to formally adopt the NHS England Standards in Wales. However agreeing standards such as this is slightly outside of WHSSC remit so I am seeking further advice on this before the paper is submitted.

WHSSC have also been working closely with NHS England in regards to the changes following the consultation, particularly in regards to the changes which affect the North Wales patients. Plans are being taken forward to manage the transition period and in developing the Network arrangements.

Update on Phase 2 ACHD South Wales

WHSSC agreed at the last SLA meeting with Cardiff and Vale Health University Board that a business case should be developed for submission to WHSSC in time for next years Integrated Commissioning Plan (this would need to be with us by the end of the summer, early autumn). The original proposal that was submitted back in 2014, consisted of a list of additional staff rather than a business case. Due to multifactorial reasons there has been a delay.

Since the submission there has been a change in the way any new funding is agreed. All cases have to be submitted through an agreed prioritisation process and the panel will be expected to prioritise cases against a set criteria; the current case will no longer stand up to scrutiny by the Health Boards who would need to agree the funding. We would expect the case to outline the need against any gaps in the Standards. WHSSC will work closely with HB staff to support the development of the case wherever needed.

We will undertake a risk assessment from a Commissioners point of view and add to our risk register.