

Congenital Heart Disease Network South Wales and South West Clinical Governance Meeting

Date: Tuesday 11th September 2018

Venue: Taunton Racecourse, and Conference Centre, Orchard Portman, Taunton, TA3 7BL

Item	Title
1.	Welcome, introduction and apologies
	<p>AT welcomed attendees to the first clinical governance meeting within the new network board and sub-group governance structure. Attendance list below notes those present for the meeting.</p> <p>He asked attendees what they hoped to come from the Clinical Governance Group. Responses included opportunities for:</p> <p>Collaboration - Understanding pressures around the region - Improving quality - Learning from mistakes - Leading audits - Improving practice and communication - Learning about link nurse role – Learning whilst setting up a new psychology service - Improving local services - Equality of care in the region - Learning about the network - Multi-disciplinary team working - Pathway development - Informing future work - Teams being on the same page - Governance priorities - Realistic network goals - Meeting network stakeholders face to face.</p>
2.	Action Tracker
	<p>CM advised that several actions from the previous network board action tracker had been allocated to the Clinical Governance Group moving forward. Updates on these actions are noted in the Clinical Governance Group Action Tracker document. Key points included:</p> <ul style="list-style-type: none"> - Action 1: Legacy funding still available to all centres to support the purchase and set-up of telemedicine facilities, which can be used to support video-conferencing (e.g. in order to virtually attend Bristol Joint Cardiac Conference meetings), skype communication with patients or clinical teams across the network, etc. He noted clinicians could 'drop in' for part of JCC meetings if time was pressured in order to contribute to discussions on specific patients. - Action 4: All centres reminded that standards require them to complete one audit of clinical significance every year.
3.	New board structure and the role of the Network Clinical Governance Group
	<p>CM described the new board governance structure, consisting of two annual meetings of the network board, network clinical governance group and network service delivery group each per annum (six meetings in total per year), replacing the old structure of four board meetings per year. This was to reflect the growing ambition and maturity of the networks structure, with each group designated with element of the annual network work plan to deliver. Individuals were asked to commit to one group and two meetings per year if they wanted to remain part of the board/sub-group governance structure.</p> <p>The draft terms of reference were discussed and generally the group felt the contents were generally appropriate and correct. It was noted that they could be streamlined a little by being less specific on some items e.g. short term projects do not need to be referenced. Adoption and final sign-off of clinical protocols to be explicit within this group's remit. Need to meet with Level 1 Centre teams to ensure that processes are streamlined and avoid duplication. Action: CM to revise terms of reference document based on feedback and to meet with Level 1 Centre Leads to ensure streamlined</p>

	<p>processes/avoid duplication.</p> <p>It was noted as this was a new structure for the Network Board, functioning of the groups would be reviewed after their first year of operation Action: CM.</p>
4.	<p>Items in the network work plan for the Clinical Governance Group</p> <p>CM presented the items allocated to the Network CGG to attendees. The following comments were made in relation to the document:</p> <ul style="list-style-type: none"> - It was noted an adult <u>transfer and repatriation policy</u> already existed, ITU to ITU. Contact Graham Brant, Lead Nurse for Critical Care. Action CM. - <u>Lost to follow up</u>: TL queried whether NHS Digital could help with this work using HES data. Network team working with national networks collaborative about defining lost to follow up. SV and SC had begun some work locally in Bristol looking into this. It was noted patients can be lost to follow up but return when pregnant, very ill, re-referred by a GP. Patients used to get discharged because they were felt to be 'cured' but now known this is not the case. If patients DNA appointments clinicians write to GPs. SC noted this can happen at any point in patient journey. Transition very vulnerable time for this. NO stated that threshold for children much higher for discharge due to safeguarding. Lost to follow up affects income, quality, outcomes, so is very relevant. Around 20,000 patients are known to network. There is a 2.5million population in South Wales and 5.5million in South West. Therefore there seems to be a big gap in numbers of patients known to the service versus numbers that disease prevalence would predict. SV noted that there was a campaign in Denmark to find lost patients – posters were used on buses etc. to publicise the issue. Action: TL agreed to investigate number of diagnoses in last three years versus number of patients actively being seen. Noted engagement with Clinical Commissioning Groups (CCGs) would be required as well as NHS England.
5.	<p>Key progress updates:</p> <p><u>Dental working group progress:</u></p> <p>AT explained that dental care was especially important for CHD patients and surgery was not infrequently cancelled due to dental issues. The network has engaged with dental champions over recent months and work was being led by Mick Allen, specialist dentist in Wales & Rosie Power, paediatric dental consultant in Bristol. The network aim was for patients to be 'dentally fit all of the time'. He explained that patients are no longer continuously registered with a dentist but now have an episode of care and are discharged. There is no ongoing requirement for a dentist to follow them up. From personal practice, AT noted that he felt only around 50% of his patients had seen a dentist in the last 6 months. Good progress was being made by the dental champions and the aim is to have network-wide guidance. It was noted the group was struggling to identify dental contacts in Cornwall and Gloucester so local teams there asked to identify individuals. Action: SP</p> <p>At the stakeholder day the issue was raised that in some areas it was extremely difficult to access a dentist, particularly in Cornwall. The network team have raised this issue with commissioners about access because it is incompatible with standards. The network team will ask MA/RP to present at next meeting. Scottish dental guidance has been issues and the network team will circulate/create a page for dentistry on the website. Action CM.</p> <p>It was noted that general dentists can be reluctant to treat CHD patients. NICE Guidelines put them off.</p>

Endocarditis – higher risk if had before, higher risk of mortality. CH noted it was important to educate families and patients around dental issues in the community setting. The dental group will be refreshing patient leaflets to be available on website – CH noted this is unlikely to reach hard to reach groups. **Action: AT to clarify any action required with CH.**

Audit Programme

CM highlighted there is a network audit programme and all Centres are required to deliver one audit per year as per the standards. The network team will ask for current audits to be presented to this group when completed. Fetal audit cross-network begun but progress slow due to information sharing barriers. HW agreed to be network lead on audit.

Could the network link in with pre-existing audit days in England and Wales (noted unlikely to be same day). **Action: AT to clarify dates.**

Palliative care toolkit executive summary:

SV noted a new executive summary had been added to the palliative care toolkit, for those who preferred a shorter introduction to the issues. She explained the background on the toolkit, which relates not only to the standards but from one of the recommendations of the Independent Review of Children's Cardiac Services in Bristol by Eleanor Gray QC. She noted it is for use by all professionals and is a lifespan document. It contains lots of resources for professions and over-arching principles of good palliative and end of life care. It was noted it had been successfully used by the Cardiff team in Wales. Any feedback welcomed.

AT noted it would be useful to state congenital rather than cardiac patients in title. It was also noted that the 'Respect' (Recommended Emergency Summary Care Plan Tool) document regarding advanced care planning would need to be taken into account when published (expected 2019). **Action: SV to amend**

Network training and education strategy:

SV presented the new network training and education strategy for comment and feedback from the group. She explained it aims to target various professional groups e.g. link nurses, consultants and others. It aims to: provide learning resources so professionals can self-direct to appropriate training, to ensure the needs of all professionals are being met and to ensure the network is meeting the standards. Some training can be provided locally, some will be delivered by the network and some available nationally/internationally. The document will be reviewed regularly to ensure it continues to meet the needs of the network. **Action: SV asked members of the CGG to read the document and provide any feedback to her.**

Forthcoming training and education events:

SV also highlighted the following forthcoming events:

- ACHD training day Bristol, 2nd October – apply via SV.
- Inherited Cardiac Conditions Conference in Bristol, 5th Oct.
- ACHD save the date - 18th March.
- PEC day in spring - date tbc.
- BCCA meeting, Liverpool - Nov 14th -15th

Details of all relevant training and events can be found on the network website under the professionals section: <https://www.swswchd.co.uk/en/page/training-and-education>

Research communications group:

CM noted that she and SV have had meetings with research nurses in the BHI and BRHC in order to improve links with research teams in Bristol and work towards a formal programme of research for the

	<p>network, which is required by the standards.</p> <p><u>Discharge communications task and finish group:</u> CM noted a group had been set-up with representation from L1 and L3 centres in order to improve the timeliness and quality of discharge communications from the L1 centre. This was initially limited to paediatric services only but if successful, findings would be applicable to adult care as well in the later stages. SG asked to be involved in the group from a pharmacy perspective. Action: CM to send invite.</p>
6.	<p>AOB</p> <p><u>Paediatric starvation guidance:</u> AT asked is this a useful protocol for the network? It was noted it would help families across network know what to expect. Action CM to send to paediatric clinicians/nurses so they are aware and can manage expectations and add to network website under paediatric care.</p> <p>Discussion as to whether something similar existed for adult care. Thought this did not exist and TL agreed to look into this. Action TL.</p> <p><u>Final Thoughts on today's CGG meeting and M&M</u></p> <p>In a similar vein to the start of the meeting, attendees were asked to reflect on the usefulness of the event. Feedback included:</p> <p>Thank you to today's speakers – there was a lot of excellent learning shared. Engagement is key to the success of this group. Invitation to use network team for support – in future meetings, the team want the centres to be leading on agenda items more and them less. Action: VN noted she can share work with this group done on ACHD data and palliative care. Need to avoid duplication of work e.g. around M&M. Don't want to be box ticking – need programme aims around standards. Need to consider where are the gaps? Last minute cancellations are an issue. Could be added to future agendas for this group or board. Good idea to check – are we following our own guidelines. Good to identify different leads for different aspects of work. Noted ACHD representation at this (and other) network meetings was not as strong as paediatrics. Need a group to look at paediatric guidelines. Action: CM to create action plan. It would be helpful to have PEC input to drive forward as well as L1 consultant input. NO to consider possible involvement. Lots of learning about incidents relates to communication. Need to continue to promote website and communications network. Good shared learning. Not all sections are relevant to all parties consider breakout e.g. nurse to nurse. Lots to take back to level 3 centre. Benefits to patients. PEC day is an opportunity to discuss/talk freely. Good to include a business update. What guidelines would they like?</p>

Attendee List:

Name			Job Title	Organisation
Calcutt	Vikci	VC	Children's Community Nurse	Virgin Care LTD
Challis	Louise	LC	Respiratory & Neonatal Nurse	Torbay and South Devon NHS Foundation Trust
Curtis	Steph	SC	ACHD Consultant	Bristol Heart Institute
Driscoll	Sharon	SD	Sister	Aneurin Bevan UHB
Gage	Susie	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol Royal Hospital for Children
Garratt	Vanessa	VG	Specialist Clinical Psychologist	CHD Network South Wales and South West
Harrington	Cathy	CH	Paediatric Cardiac Nurse Specialist	Bristol Royal Hospital for Children
Hayden	Sam	SH	Staff Nurse	Aneurin Bevan UHB
Hetherington	Jane	JH	Matron for Paediatric & Neurosciences	Bristol Royal Hospital for Children
Hubert-Powell	Emma	EHP	Paediatric Consultant	Plymouth
Lambert	Rebecca	RL	Staff Nurse, Cath Lab	Taunton and Somerset NHS Foundation Trust
Lovell	Tim	TL	Consultant Cardiac Anaesthetist (Adult)	Bristol Heart Institute
Moss	Caitlin	CM	CHD Network Manager	CHD Network South Wales and South West
North	Victoria	VN	Registrar	Bristol Heart Institute
Osborne	Nigel	NO	Consultant Paediatrician with Expertise in Cardiology	Royal Devon and Exeter NHS Foundation Trust
Padmanabhan	Sam	SP	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals NHS Trust
Peckitt	Katherine	KP	Clinical Psychologist	Compass Service, Paediatric Palliative Care, Somerset
Tometzki	Andy	AT	Consultant Paediatric Cardiologist and Network Clinical Director	CHD Network South Wales and South West
Trotman	Zoe	ZT	Lead Nurse, Paediatric Cardiology	Bristol Royal Hospital for Children
Vernon	Sheena		CHD Lead Nurse	CHD Network South Wales and South West

Wallis	Helen	HW	ACHD Consultant	University Hospital of Wales
Wilson	Dirk	DW	Paediatric and Adult CHD Consultant	University Hospital of Wales