

Congenital Heart Disease Network South Wales and South West Service Delivery Group Meeting

Date: Friday 18 January 2019, 9.30 – 3.30pm
Venue: Holiday Inn, Filton Road, Bristol, BS16 1QX
Chair: Dr David Mabin

Minutes

Item	Notes and Actions
1.	Welcome, introductions and apologies
	<p>DM welcomed the attendees and noted apologies.</p> <p>CMc updated the service delivery group on recent personnel changes in the network team. CM is on secondment as Deputy Divisional Director of the Women and Childrens division at University Hospitals Bristol and CMc is covering the network manager role during this time. CM also introduced MB who started her substantive role as network support manager in October.</p>
2.	Action tracker
	<p>CMc explained that following the change to the network structure actions from the action tracker have been assigned, as appropriate, to the three different network groups. The service delivery group was assigned two key actions.</p> <p>The action log was updated as appended. Notable comments:</p> <p><u>Action number 68: Grace's story video on website</u> CMc informed the group that the video is now on the website. Action is signed off and closed.</p> <p><u>Action number 28: Access to UHW systems through Cardiobase</u> AT explained that Cardiobase is the electronic patient administration system used in Wales that may be useful for consultants in Bristol to access for their patients in Wales. It was noted that the Cardiff Paediatric Team now have iPads and it was queried whether they would be available for adults teams also. Further discussion is required to clarify who would benefit from access to Cardiobase, how access will work in practice, and then set up of interested parties on Cardiobase. Action: MB to take lead on Cardiobase actions and update at next SDG meeting.</p>
3.	Terms of reference (Chairperson, key responsibilities & reporting)
	<p>CMc outlined the new network board structure with sub groups and new governance arrangements (see slides for detail). The new structure will be evaluated after a year. CMc presented the specific role and responsibilities of the service delivery group, informed the group that each sub group needs a chairperson, and explained that each sub groups is expected to report into the network board, which acts as an oversight and assurance group. Task and finish groups will be developed as and when they are needed for specific projects. CMc outlined the governance of the network, with the network being hosted by University Hospitals Bristol and reporting into the joint cardiac board and senior leadership team (SLT) at UH Bristol, and also reports to NHS England and WHSC. CMc described the remit of the service delivery group describing as the 'doing group' of the Network and went through the work plan for the group.</p> <p>The membership of the group was discussed and in particular whether there was good representation</p>

	<p>from the different centres in the network. It was questioned whether paediatricians with expertise in cardiology (PECs) in district general hospitals (DGHs) were present in all the network groups. It was noted that it is important to know about work happening in peripheral locations, therefore level 3 adult and paediatric managers, PECs and nominated nurses are needed from South Wales and the South West in each of the groups but particularly in the service delivery group. It was agreed that Task and Finish groups would be a useful component of the service delivery group meetings. The important relationship between the community nurses and inpatient services was acknowledged, and that currently there is only one community nurse on the membership list, which may need addressing. Pharmacists were highlighted as also having an important role to play It was explained that local teams tackle safe guarding issues.</p> <p>Action: Draft a formal letter of invitation and invite new members. AT/SV Action: Invite community nurses to be on service delivery group. SV Action: Invite Ann Miller, UHB children’s complex care coordinator, to be on service delivery group.SV</p> <p>CMc explained that the group will report to the network board with a progress report including a plan for 6 months, work done, risks and issues. The role of the chair was discussed and members were invited to express their interest to the network manager should they be interested in undertaking this role. In the meantime, David Mabin, the current Network Board Chair, has kindly offered to be the chair for the network group. It was noted that the terms of reference were signed off at the last network board meeting in November but there are some small amendments to be made.</p>
<p>4.</p>	<p>Service delivery group work plan</p>
	<p>CMc explained there are 16 pieces of work allocated to the service delivery group from the network work plan. 1 is closed, 15 are work in progress.</p> <p>The work plan was discussed in detail in an afternoon focus session.</p>
<p>5.</p>	<p>Implementation of Nursing Strategy</p>
	<p>SV updated the group on the implementation of the network nursing strategy (see slides for detail). SV informed the group that the strategy and link nurse job description were signed off at the last network board meeting in November. SV highlighted the joint nurse meetings which have been established involving level 1 and 2 clinical nurse specialists (CNS). Successes include the paediatric transfer from Bristol to Cardiff where a video of Pelican ward in Cardiff has been developed which can be shown to families in Dolphin ward in Bristol before they are transferred to Cardiff. SV noted good outcomes from the Link Nurse meeting in November such as joint working between adult and paediatric teams in Taunton. Monthly Link Nurse meetings are held in Bristol Royal Hospital for Children (BRHC) where discussions take place about how to improve the service and communicate with link nurses. Good points include theatre staff understanding ECHMO, transfers to PICU and knowing how to contact CNS teams. The nursing strategy and link nurse job description documents will be on the network website. SV presented a summary of the Link Nurse survey results explaining that the results are useful but incomplete. The purpose of the survey was to understand what is happening with the link nurse role across the network. (See presentation for detail)</p> <p>The group were updated on the CHD nurse meeting in Taunton. BL explained that communications between the adult and paediatric team are good, she is going to attend clinics with teenager, and that the service is definitely improving. She noted that there is new adult consultant in Taunton, Mark Dayer.</p> <p>SV highlighted the challenges of the link nurse role including time to support clinics or inpatients,</p>

	<p>education, and support for nurses and management. She explained the plan moving forward including six monthly meetings with Level 1 and 2 CNS with level 3 Link Nurses to be invited, visits to centres, and a planned visit to Exeter.</p> <p>The need for greater awareness of the link nurse role, the resources required, and the need for communications about the role were discussed. DM highlighted that having a conference call with SV, as the Network Lead Nurse, with their local PEC, manager, and a senior nurse was helpful to progress the discussions and understanding locally about the role of the link nurse. It was noted that whilst the time commitment is a challenge for nurses in their roles but it does not have to be on only one person's job plan, the 0.25 could be between two individuals. It was questioned where the 0.25 WTE came from and whether it is based on numbers or clinics, or whether it is irrespective of case load. A question was raised whether the link nurse role could be a community based or outpatients based link nurses.</p> <p>BS explained that in the Cardiff adult service the nurses currently travel to local clinics but numbers of these clinics are increasing. SV explained that a similar model is not possible in Bristol and suggested that the service in Wales will need reviewing in the future for ongoing feasibility. BS explained the team have learnt a lot going into peripheral clinics but questioned whether long term it is sustainable. The first Level 2 link nurse meeting was held in Cardiff and was hugely beneficial. Feedback from the day was that nurses would like more education and the plan is for a 6 monthly nurse study day in Cardiff.</p> <p>It was noted that there is enthusiasm from nurses to shadow the CNS teams however there have no requests and this could be due to time restraints and funding.</p> <p>Business cards with CNS and consultant contact details were discussed. Clinic letters in peripheral clinics should have the CNS details on them. The network team are going to send out posters with CNS details on them to go up in outpatient clinics and on the ward.</p> <p>Action: Look into business cards for CNS contact details. (Grand appeal funded) LP</p>
<p>6.</p>	<p>Improving discharge communications</p>
	<p>CA presented a summary and update on the improving discharge communications project (see slides for detail). She explained the background to the project, the discharge communications survey results, information management and technology (IM&T) context, and the outcomes of the first task and finish group session in October.</p> <p>The significant number of places and people the letters have to get to was highlighted as one of the challenges in discharge communication. CA noted that issues were raised by level 3 centres around quality, content and timeliness of discharge communications IT is a major enabler to improving discharge communications and there have been many discussions with the IT team to understand what might be feasible now and in the future. University Hospitals Bristol Trust is rolling out new IT including apps, for example Careflow, which could be helpful for discharge communications, but it was noted that this adds another system to use in the current unwieldy process. Using Ipads has helped improve systems for the Welsh team. Points were raised such as information needing to flow earlier in the discharge and the discharge starting at admission. DM gave positive feedback explaining that communication is good but aspects could be better, suggesting that most of the time good information is received. He explained that this is helped by good personal relationships with visiting consultants and many DGH colleagues have previously worked in Bristol. CA noted that the CNS team are good at contacting teams before discharge.</p>

	<p>The group was asked if they were interesting in being involved in the project to contact CMc/CA. The second workshop is provisionally booked for the 21st February. The project group will report back to the service delivery group as the work progresses.</p>
7.	Patient Representatives moving forward
	<p>SV presented the network patient engagement objectives and challenges, plan for recruitment, plan for involvement and support for patient reps (see slides for detail). The group were asked for suggestions to help recruit patient representatives. SV explained the network is aiming for 10-15 representatives. Suggestions included forums such as NICOR and the CRG as well as organisations outside of the network. Conflicts of interest were raised as a concern. Managing expectations and challenging representatives if they step outside of the guidelines of the role was discussed. It was noted that everyone needs to help recruit more patient representatives. The patient representative information will be on the network website.</p> <p>Action: Add conflict of interest question on patient rep application form. SV</p> <p>Action: Circulate patient rep documents. MB</p> <p>Action: Link to heart families south west to recruit patient reps via Nicola Morris. SV</p>
8.	Psychology in the network
	<p>VG presented an update on the psychology services explaining how the service is set up, resources available to clinicians and families, the surgical pathway, what the service offers, referral criteria and how to refer, and the plan for 2019 (see slides for detail).</p> <p>VG explained that more information is planned to go onto the network website and that the support booklet is already available there. VG highlighted the Taunton psychology service and the plan to organise the first network psychology day.</p> <p>Questions proposed by VG to the group were: How to raise awareness of the current service and resources? How to get out information for referral criteria? What do you need as clinicians?</p> <p>There is a section on how to refer to psychology for specific cardiac related issues is on the website this should be through the clinical nurse specialist or consultant cardiologist.</p> <p>Clarification was sought on what the network psychology team offer in comparison to what the local psychology services offer and whether both team liaises with other VG explained that the network team offers services specifically related to cardiac anxiety, they offer 4-6 sessions related to a cardiac condition providing information and support as needed. The importance of linking to the play service therapists was noted. It was agreed that it would be helpful for the Level 3 centres to have an outline of the psychology service and the referral criteria It was noted that GPs should refer to clinicians/consultant.</p> <p>Action: Send network psychology information leaflets to level 3 centres, including the referral criteria MB/VG</p>
9.	Charities and support groups
	<p>SV presented an overview of local charities, which provided an update on their work, and highlighted the next steps for the network (see slides for detail). SV explained that a charity day would get a number of charities together to present their work and programmes of activity and allow them to refer to each other. Questions were raised related to transplant groups, the charity for cardiac risk in the young, charities for bereavement and charities for genetic conditions.</p> <p>Action: Look into transplant patient charity. SV</p>

	<p>Action: Catch up with families and find out what support they have had. Possibly Kevin Mashford? SV</p> <p>Action: Contact Ups and downs charity. SV</p>
10.	DRAFT finance guidance
	<p>CMc introduced the draft finance guidance for the network. AA presented DGH coding and tariffs including a funding stream diagram. He highlighted that there are different financial models for the provision of current services in DGH clinics currently and that these models and funding need verifying with NHSE.</p> <p>A task and finish group was suggested as a possibility to capture these different models of funding across the network.</p> <p>The importance of understanding the funding arrangement was acknowledged by the group, as it acts as a lever to improving the core offer; funding for link nurses, psychology, ECHO technology etc. Differentiating funding by clinical commissioning groups and specialised commissioning was highlighted.</p> <p>CMc concluded that confirming the objectives of work would be useful, including deciding what the preferred outcomes would be, and what is in the sphere of influence of the network</p> <p>Action: set up task and finish group with AA and GS to look at potential piece of work on models of clinic funding within the network.</p>
11.	NHS peer review
	<p>CMc gave an overview of the forthcoming peer review explaining that the NHS England Quality Surveillance Team will be undertaking a review of the national CHD networks and progress against the CHD standards commencing nationally in May 2019. She explained that the peer review will be completed over three days reviewing the network, Level 1 and Level 2 centres. Level 3 centres will be invited to attend part of the network review visits. Peer review training will be held on 2nd April in Bristol to brief the teams for the peer review as well and train reviewers. There is an application form and FAQs for colleagues interested in becoming a reviewer. Details of the peer review will be on the network website and information including FAQs will be sent out via email.</p>
12.	AOB
	<p>The next service delivery group meeting will be held as an afternoon session as part of the network stakeholder day in July, date tbc.</p> <p>The next meeting is the clinical governance group meeting on 21st March, Coldra Court, Newport. Followed by the network board meeting on 1st May, Taunton.</p>

Comments and actions from afternoon focus sessions

Item	Notes and Actions
1.	Work plan 2019/20
	<p>CMc explained the background to the existing work plan and gave a review of achievements to date. She asked the group to review the service delivery group work plan, discuss and feedback the top 3 priorities for 2019/20 (see slides for detail).</p> <p>Top priorities suggested by the group were: discharge communication; nursing strategy; information and communication including education and marketing; access to CNS at level 1 centre including information on letters and posters; review of OPD capacity and provision; and refining the dashboard.</p>

	<p>Other feedback from the group included: Continue to look at finance for level 3 centres and also look at level 1 and 2 centres; look into doing self-assessment/engagement visits again and demonstrate improvements as well as a refresh of the core priorities; look at specific actions for nursing, funding for link nurses and succession planning; look at psychology in terms of awareness, education, level 3 links; look at transition including the equity of access across peripheral clinics and doctor, nurse led or joint clinics.</p> <p>Action: Amend the workplan to incorporate the discussions and decision at this focus session. Include ideas for workplan 2019/20 on Network Team Away day agenda re. agreeing workplan 2019/20 (SV/CMc/AT)</p>
<p>2.</p>	<p>Further development of the CHD network website and social media presence</p>
	<p>AT presented a summary of the CHD website use discussing monthly usage, new and returning users, user access, top pages, time spent on website, number of pages visited, bounce rate and devices used to access the website (see slides for detail). As part of the session the group were asked to navigate common scenarios a patient or clinician may access on the website and feedback.</p> <p>A link to the website on clinic letters was discussed. Putting the link at top of letter, in the header or in the management section of the letter was suggested.</p> <p>Action: Website and CNS contact details in Level 3 centres clinic letter headers. MB/Level 3 managers</p> <p>Feedback included: improving the search tool; navigation issues; naming and alphabetical order of hospitals; PDF links not working on all browsers; changing the wording of titles; and improving search engine optimisation.</p> <p>Action: Contact web box about search engine optimisation to raise profile in search and other edits to the website as per group suggestions during focus session MB</p>
<p>3.</p>	<p>Proposed ways of supporting GPs about clinical management and current services</p>
	<p>LoP presented what GPs need to know about CHD management and services, and how to facilitate GPs education (see slides for detail).</p> <p>GP STP3 training on CHD in the cardiac session and e- learning were mentioned. It was explained that GPs would always refer to paediatricians in the first instance.</p> <p>There are a number of ways that communication with GPs and training on CHD could be improved including the use of FourteenFish GP training website and learning pack for GPs on the network website.</p> <p>Action: Add work relating to GP training onto the network workplan. SV/AT</p> <ul style="list-style-type: none"> - Look into the GP matters, Royal United Hospital Bath (RUH) newsletter. - Look into FourteenFish GP training website. Discuss with Louise Paterson. - Put a learning pack for GPs on the network website including guidelines for referral for murmurs. <p>Action: Additions of useful resources for GPs on CHD Network website SV/MB/LoP</p> <ul style="list-style-type: none"> - Put GP guidelines for red flags on CHD Network website - Put contraception advice on CHD Network website - Website, CNS contact number and pharmacist contact number on GP intranet

Attendees

Name	Inits.	Job Title	Organisation
Cat McElvaney	CMc	CHD Network Manager	CHD Network Team
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team
Morwenna Bugg	MB	CHD Network Support Manager	CHD Network Team
Andy Tometzki	AT	CHD Network Clinical Director / Consultant Paediatric Cardiologist	CHD Network Team
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team
Sarah Finch	SF	ACHD specialist nurse	University Hospital of Wales
Rebecca Lambert	RL	Staff Nurse ACHD	Taunton and Somerset NHS Foundation Trust
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology and Network Board Chair	Royal Devon and Exeter NHS Foundation Trust
Victoria MacFarlane	VM	Deputy Divisional Director, Women's and Children's Division	University Hospitals Bristol NHS Foundation Trust
Gina Skipwith	GS	Women's and Children's Operational Manager	Torbay and South Devon NHS Foundation Trust
Lisa Patten	LP	Clinical Nurse Specialist, Paediatric Cardiology	University Hospital Bristol
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	University Hospital Bristol
Andy Arend	AA	Consultant Paediatrician	North Devon NHS Foundation Trust (Barnstaple)
Louise Paterson	LoP	GP	
Andre Clinchant	AC	Lead Nurse	Taunton and Somerset NHS Foundation Trust
Wendy Visser	WV	Senior Staff Nurse	University Hospital Bristol
Wendy McCay	WM	Paediatric registrar	University Hospital Bristol

Apologies

Name	Inits.	Job title	Organisation
Caryl Evans	CE	Clinical Nurse Specialist, ACHD	University Hospital Bristol
Marion Schmidt	MS	Consultant Paediatrician	Newport, Aneurin Bevan UHB
Bethan Shiers	BS	ACHD Nurse	University Hospital Wales
Helen Liversedge	HL	Associate Specialist Obstetric and Gynaecological Ultrasound	Royal Devon and Exeter NHS Foundation Trust
Peter Wathen	PW	Gloucestershire Hospitals NHS Foundation Trust	General Manager