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

Date: **Thursday 11th July 2019, 9.30 – 13.00**
Venue: **Junction 24 Ltd, TA6 6DF**
Chair: **Dr David Mabin**

Minutes

Item	Notes and Actions
1.	**Welcome, introductions and apologies**
	DM welcomed the attendees and noted apologies. DM congratulated and welcomed CMc who has been appointed substantively as the network manager. DM updated the group that AT will continue his role as Network Clinical Director for another three year tenure. CMc explained that the demand and capacity training scheduled for the afternoon session has been postponed due to a number of last minute cancellations.
2.	**Action tracker and minutes from last meeting**
	The minutes of the service delivery group meeting on 18th January 2019 were agreed as an accurate record of the meeting. The action log was updated as appended. Notable comments were; Action number 29 – Draft a formal letter of invitation and invite new members Action on hold. Will form part of the discussion at the engagement and self assessment review visits with level 3 centres. Formal letter to follow up and invite new members will be sent post visit. Action number 30 – Invite community nurses to be on service delivery group Agreed to invite community nurses as and when required. **Action – closed.** Action number 31 – Invite Anne Miller to be on service delivery group Agreed to invite AM as required. **Action – closed.** Action 32 – Look into business cards for CNS contact details Dolphin ward cards have CNS contact number. **Action – closed.** Action 36 – Send psychology information leaflets to level 3 centres, including the referral criteria Leaflet and letter agreed. Letters will be sent out week commencing 15th July. Action 37 – Look into transplant patients charity Link to transplant charity is on website. **Action – closed.** Action number 39 – Contact ups and downs charity **Action – closed.** Action number 41 – Website and CNS contact details in Level 3 clinic letter headers On work plan. Details are on Level 1 centre letters. Check they are on peripheral centre letters.

Action number 42 – Contact webbox about search engine optimisation to raise profile in search
Webbox has been contacted but using their services would be expensive. This action will be picked up as part of a project MB is working on. **Action – closed.**

Action number 43 – Add work relating to GP training onto network work plan
Change due date to July 2020. Work is on network work plan. **Action – closed.**

Action number 44 – Additions of useful resources for GPs on CHD Network website
Change due date to July 2020. Add to network work plan. **Action – closed.**

3. Service Delivery Group work plan

CMc highlighted that each sub group of the Network Board has a work plan and then outlined the key items in the workplan for the Service Delivery Group (See slides for detail). The group were asked to let the network team know if they are interested in getting involved in any of the specific pieces of work. CMc explained that there are sixteen key work packages for the Service Delivery Group. Thirteen work packages have been carried forward and have new actions to progress. There are three new work packages: Youth worker in BHI, training and education, and benchmark/mapping arrangements for CHD care at all referring hospitals. SV updated the group on the new youth worker role in the BHI. She explained that Alexander Cooke has been appointed and will be supporting 16-25 year olds at the BHI. The role, based on the teenage cancer youth worker role, is charity funded by youth @ heart and is initially for two years and it will then be evaluated. Alexanders work will include supporting inpatients and young people clinics, buddying up, supporting young people with looking for and applying for jobs, and providing academic support. An introduction to Alexander and further information about his role will be in the next network newsletter in September. SV outlined the training and education work related to nursing. One of the considerations for nurse education and training in the network currently is around the use of competencies. She highlighted the Royal College of Nursing competency documents and the potential aim to raise the profile of this resource across the network. She noted that these competencies have been used on some wards already. CMc explained that a query has been sent to NHS England to get clarity on the expectation to undertake a bench marking/mapping of arrangements for CHD and non-CHD centres in the network as set out in their circular to networks in September 2018 (SCC188 NHS England) outlining key deliverables for the network in 2018/19 and 2019/20.

Acting on the results of performance monitoring was discussed. It was noted that the Network Board acts as an oversight group with responsibility for monitoring how centres are performing. Questions included how are the measures being used, and how the data is used to improve practice. It was suggested that a sub group could work on the dashboard to improve it and develop how the data can be acted on. It was highlighted that not all centres are reporting in the same way, and that a dashboard which can be populated by all centres and that can be used for benchmarking is needed. Work will be done to improve the current dashboard including making it more user friendly. It was noted that the dashboard provides a way of the Network Board having oversight of performance and waiting list management across the network but that issues are dealt with and management of performance takes place in local centres. CMc highlighted that demand and capacity training can be provided if it would be helpful and the network team can work with specific areas as requested. It was agreed that the service delivery group would be the group to work on improving the dashboard and increasing its use and effectiveness.
Action: Improving the use and effectiveness of the performance dashboard to become part of SDG remit and to be added to the SDG work plan. **CMc**

CMc noted another key work package for the group was around understanding finance in level 3 centres and uniform tariffs. AA presented at the Service Delivery Group meeting in January 2019. There will be work done with Clinical Commissioning Groups (CCGs) to see if it is feasible to get uniform tariffs across the network. Under improvements in quality of care there is the discharge communications project which CA presented at the Service Delivery Group meeting in January 2019. Improvements in the discharge process are strongly linked with improvements in digital processes. In terms of implementing the nursing strategy, the aim is to increase the number of active level 3 link nurses and continue engagement work with level 1, 2, and 3 centres. There is work from the independent review involving establishing a fetal working group, the first meeting of which has been set up for September. The youth worker at the BHI is also under this section. Under equitable, timely access for patients there is work on transition including drafting a plan for transitional provision in level 3 centres moving forward. Support for final approval and implementation of the phase II investment in Wales is ongoing. Under patient and family experience there is work with charities and support groups including a six monthly joint event to encourage collaborative working. There is work with the patient reps including a programme of activity and involvement in the board including time on the agenda and a briefing session before the meetings. The number of adult cardiologists was highlighted relating to training and experience in ACHD. Determining a specific piece of work around medical staffing for the year, and some of the risks and issues relating to this, was discussed and noted that it would be useful to do this. Under information and communication there is work to improve the use of the website, and the networks communications including the newsletter and social media. It was explained that the peer review recommendations will go onto the network work programme when received.

Action: Peer review recommendations to be added to network work plan. **CMc**

The group were asked to contact the network team if they would like to lead on pieces of work. CMc highlighted the next steps which are: a monthly plan for each work package/key milestones; leads from network; report progress to Network Board; and the Network Annual Report to be published in August.

4. Peer review recommendations

AT gave feedback from the recent National CHD Network peer review to the group (see slides for detail). AT described the preparation of evidence in advance of the peer review and he outlined what happened during the peer review itself. AT noted that the network received positive initial feedback from the review team on the day, including being described as an ‘exemplary network’ and that the review team had to ‘dig deep to criticise’. AT highlighted the feedback from the network team regarding their experience of the peer review process which included: “good team working; great representation from network members; lots of preparation; and limited feedback on the day”. AT noted that there was wide support for network on the day and that this was appreciated. AT summarised the initial review feedback for the network. The achievements highlighted were: the network was cited as an ‘exemplary network… leading the way nationally’; excellent network structure and governance; highly commended on preparation, organisation, documents and evidence provided for the peer review. Areas for improvement included: image transfer; patient and public voice representative training; memorandums of understanding signed by network organisations; transition in peripheral clinic currently too level 1 focused; 5 year plan for the network; developing research strategy and improving recruitment numbers; and multi-disciplinary training and education.

RD gave feedback to the group from the level 1 paediatric peer review. RD explained that in May three large documents, an operational policy, work plan and annual report, were submitted to NHS England. She described the day as intense but overall a useful experience noting that the team learnt a lot about the service they provide as they prepared for peer review. RD summarised the initial feedback and highlighted that the service was commended on patient information and support, research and education. There were three serious concerns raised which included workforce concerns related to CNS staffing numbers and not having a dedicated fetal and transition nurse. Whilst the team were praised for the transition service within the level 1 centre, transition clinic provision in peripheral centres was noted as a serious concern. RD explained that work is in progress, with network support, to address the transition issues and this will include a gap analysis of current and future service provision, level 1 centre workforce analysis and developing a proposal for what's required. The third serious concern was the workload of the cardiac surgeons and recruitment of a 4th surgeon. RD explained that further discussions with NHSE are expected about this. RD described the areas for improvement. She noted that meeting the interventions standard was an expected area of improvement and reflected what was happening in other centres. She explained that mitigations against not meeting this standard had already been agreed with NHS England and these included regular quality and safety monitoring via NHS England quarterly reviews and producing an annual report for the service. Lack of CT/MRI specialist was an area for improvement and it was noted that the adult team are trained and support paediatrics. The process for buying equipment was highlighted as needing improvement. RD explained that replacement equipment is on the risk register and one piece is funded and one is being worked on. MDT working including the attendance at JCC was an area for improvement. The final area for improvement was the seven day services audit. It was noted that all trusts have to do the audit and it was highlighted that the audit needed to be more specific for paediatric services.

CMc presented the feedback from the level 1 adults peer review noting that there was good representation at the Peer Review MDT meeting on the day. Achievements included: cohesive team, ACHD journal club; 'what would you like to talk about today' survey; free @ 3 teaching; youth worker; young people's evening; 3D bio printing; and transition clinics. Serious concerns raised were around CNS capacity to deliver service and surgical workload. Areas for improvement were cath lab facilities and staffing; waiting times for surgery; review of ACHD patients with HDU needs; imaging representation at MDT meetings; and acting on patient feedback.

SV presented the feedback from the level 2 paediatrics peer review. Feedback from the level 2 paediatric team on the review included: it was challenging to collate the evidence and write reports in the required timescales; development of the work plan has already informed key actions for service development; and timing of the review probably helped in progressing the psychology business case. SV described the initial feedback. Achievements included: transition care; nurse presence at all fetal clinics; guidelines book; evidence of seeking user feedback and acting on that feedback. The serious concerns highlighted were problems with dicom storage and transfer of echo images in ABHB. Areas for improvement included staffing levels on pelican ward and the workload of the CNS team.

SV presented the feedback from the level 2 adults peer review. The achievements were: good quality service from the available resources; up to 'standards' 'phase 1' clinics and maternal cardiology service; significantly improved cardiac MRI service; exemplary transition service; and progress with phase 2 business case. Areas for improvement were: integration and equity of ACHD services in South Wales is needed; at least one more full time ACHD consultant; more CNS needed; more congenital dedicated physiology service needed; psychology service needed; complete database/audit tool with IT support needed; ACHD data coordinator/manager; more admin support needed.

CMc highlighted the next steps following the peer review visits: NHS England letters to Trusts with areas of serious concern; full reports to organisations six weeks after visits; action plans to address areas for improvement. CMc explained that there will be an annual self-declaration going forward and peer review as required. There will also be a national report post peer review with key findings and next steps.

5. Network psychology service progress report on level 3 referrals

VG presented an update on the network psychology service (see slides for detail). It was noted that whilst psychology is in the standards for CHD however there is no clear model for delivery of the service. VG explained that following the independent review the service expanded rapidly in Bristol and is developing across the network, albeit with finite resources. VG highlighted that there has previously been feedback from patients that they don't know how or where to get support. In 2017 a tiered approach to psychological support was established. Developing the model included creating resources, embedding psychology in existing clinics, and targeted 1:1 support. VG explained that the aim is to make resources and support as accessible as possible. An information leaflet has been created which describes all the support available and this will be sent to all centres. The toolkits, digibooks and pathways are all accessible on the network website. VG explained the rationale behind putting psychologists into existing clinics and the benefits of them being part of MDT decisions at the time the patient is seen rather than separately. Group support was highlighted such as the tree of life groups which are day long events for adults and young people and include discussions about the impact of their health condition on their life and opportunities.

VG outlined what the psychology service offers in 2019 including outpatient face to face clinics, outpatient telephone/virtual clinics, and inpatient appointments. The referral criteria for receiving 1:1 support are strict and the issue must be related to the patient's heart condition. Patients who meet the criteria can receive 4 sessions which is in line with the child and adolescent mental health services (CAHMS) model.

VG highlighted key data for the service. For 1:1 support from the ACHD/fetal post there were 821 slots in one year. It was highlighted that the number of patients seen is higher due to the MDT clinic. VG explained the opt in service and process for booking appointments which has increased referrals and decreased the DNA rate. The DNA rate for ACHD was 5% which was noted to be good. The paediatric data included number of referrals for the different pathways. It was noted that referrals from surgical, fetal, and catheter accounted for the majority of the referrals received. Data from ACHD showed health anxiety and pre-surgical/procedure anxiety as the most common reasons for patients receiving psychological support. VG summarised that the next steps for the service are to develop specialist services across network, such as in Taunton and Cardiff, to offer specialist care locally; develop links with local psychologists; and offer a link psychology training day annually.

VG also outlined a new #myquestion Facebook campaign which will start in September. It is based on FAQs from patients and families. There are two aims of the campaign which are to directly answer questions for patients and families, and to raise awareness of the resources available such as the toolkits and digibooks.

KP, Clinical Psychologist, explained her 0.2 WTE cardiac role in Taunton supporting children and their families. KP will offer two 1:1 appointments per week, three weeks per month and will attend an MDT meeting once per month with the consultants, link nurse, physio and dietitian. KP noted that there will be the opportunity for direct liaison between Bristol and Taunton. KP will link to UH Bristol for specialist knowledge of cardiac conditions and will have access to UH Bristol resources via an honorary contract.

The even distribution of inpatients was noted and a question was raised regarding the distribution of outpatients. It was suggested that referrals are dependent on the cardiologist and their awareness of the service. It was questioned whether there is signposting to the support on the website in clinic, and whether the website is on clinic letters.

6. **Engagement visits with Level 3 centres**

	CMc explained that engagement visits with centres will be taking place from October 2019 to May 2020. The teams will be sent self-assessments to update before the meeting. Attendees of the meetings should include: Clinical lead for CHD, matron, general manager, link nurse, lead for cardiology, local commissioners, and psychologist. Local teams can invite who is appropriate for their service. **Action:** Community nursing involved in self-assessment visits. **CMc** **Action:** Send out previous rag rated self-assessments to centres. **MB**
7.	**Communications update**
	MB presented an update on communications in the network (see slides for detail). MB explained the quality improvement project she is undertaking looking at the network website as part of her quality improvement training run by UH Bristol. The aim of the project is to increase the use of information on the CHD network website for clinicians and patients. MB explained the baseline data she has used: feedback from Service Delivery Group meeting on 18th January; analytics of website use; position in google search and a survey sent to network clinicians and patient representatives. MB presented the monthly usage of the website and highlighted the increase in use since January 2019. MB presented the results of the survey, explaining that fourteen clinicians and seven patient representatives responded. MB described the change ideas for the project: posters in patient areas; twitter posts; linking to charity and support groups; Trust websites; website on clinic letter; digital marketing; and changes to website pages and content. MB highlighted the next steps to the group: act on survey results; implement further changes; and determine whether the changes have resulted in an improvement. MB explained that the network twitter currently has 196 followers and there is a question around the audience and whether it reaches patients and families. Setting up a network Facebook page has been suggested and there is an idea to promote different teams around the network and link to Trust Facebook pages across the network. **Action:** Contact Nigel Osborne/DM to put the website on next PEC day agenda. **MB**
8.	**Evaluation of the network board structure**
	CMc explained that the network board structure will be evaluated in October. The group were asked to participate in this evaluation to support the network moving forward.
9.	**Update from national CHD network**
	AT explained that previous national CHD network meetings have been held in Bristol and Leeds. The most recent national CHD network meeting was held in London on the 21st May. The meeting included a showcase of what the services in London do. The next meeting will be hosted by Leicester in December. **Action:** Invite DM to next national CHD network meeting as deputy for AT. **MB**
10.	**Draft research strategy**
	The draft research strategy was submitted to the group for information.
11.	**AOB**
	The next service delivery group meeting is provisionally booked for 21st January 2020. The next network meeting is the clinical governance group and M&M meeting on the 8th October 2019 in Bristol. Followed by the network board meeting on the 28th November 2019 in Newport.

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
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology and Network Board Chair	Royal Devon and Exeter NHS Foundation Trust
Rosalie Davies	RD	General manager – Children's cardiac services, neurosciences and PICU	University Hospitals Bristol
Andre Clinchant	AC	Lead Nurse	Taunton and Somerset NHS Foundation Trust
Gina Skipwith	GS	Women's and Children's Operational Manager	Torbay and South Devon NHS Foundation Trust
Kat Peckitt	KP	Clinical Psychologist	Taunton and Somerset NHS Foundation Trust
Louise Challis	LC	Respiratory and Neonatal nurse	Torbay and South Devon NHS Foundation Trust
Helen Liversedge	HL	Associate Specialist Obstetric and Gynaecological Ultrasound	Royal Devon and Exeter NHS Foundation Trust

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
Sarah Finch	SF	ACHD specialist nurse	University Hospital of Wales
Louise Paterson	LoP	GP	
Lisa Patten	LP	Clinical Nurse Specialist, Paediatric Cardiology	University Hospital Bristol
Rebecca Lambert	RL	Staff Nurse ACHD	Taunton and Somerset NHS Foundation Trust
Andy Arend	AA	Consultant Paediatrician	North Devon NHS Foundation Trust (Barnstaple)