

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

**Date:** Thursday 21<sup>st</sup> March 2019, 9.30 – 3.30pm  
**Venue:** Coldra Court by Celtic Manor, Newport, NP18 2LX  
**Chair:** Dr David Mabin

### Minutes

Item	Notes and Actions
<b>1.</b>	<b>Welcome, introductions and apologies</b>
	<p>DM welcomed the attendees and noted apologies.</p> <p>CMc updated the Clinical Governance Group on recent personnel changes in the network team explaining that CM has accepted the permanent role of Deputy Divisional Director for Women's and Children's division at University Hospitals Bristol NHS Foundation Trust. CM also introduced MB who started her substantive role as Network Support Manager in October.</p>
<b>2.</b>	<b>Action tracker</b>
	<p>The action log was updated as appended. Notable comments:</p> <p><u>Action number 1 – Clinical champions to take forward roll-out of</u>  <b>Action – closed</b></p> <p><u>Action number 2 – Palliative Care Toolkit</u>  <b>Action – closed</b></p> <p><u>Action number 3 – Feedback on paediatric protocols</u>  Paediatric protocols on agenda.</p> <p><u>Action number 4 – Audit opportunities</u>  Audit on agenda  <b>Action - closed</b></p> <p><u>Action number 5 – Website details on patient letters</u>  It was noted that work has been done and this should be happening across the network.  <b>Action – closed</b></p> <p><u>Action number 6 – Review PICU VLAD chart</u>  Add to agenda for M&amp;M meeting in September. <b>MB</b></p> <p><u>Action number 7- Joint working with CDOP and CHD Network M&amp;M meetings</u>  AT is meeting with Mary Gainsborough and James Fraser at the end of March.</p> <p><u>Action number 8 – Review imaging process at level 1 centre</u>  MY has left the trust – waiting for his replacement. On hold until replacement is in place.</p> <p><u>Action number 9 – Implement Careflow</u>  This is ongoing work. <b>Action – closed.</b>  It was highlighted that it is used in Bristol to share information with Wales</p>

**Action:** Send Careflow presentation slides to group members. **MB**

**Action:** Put Careflow on the agenda in a future meeting. **MB**

Action number 10 – Tour of Dolphin/PICU for expectant parents

A meeting is planned with the ward manager and matron for Dolphin and PICU to progress this task. It is an action which came out of the Independent Review. **Action – closed.**

Action number 11 – Film/video of the fetal journey

On NICU work plan. Confirm this with NICU **MB**

Action 12 – Link with South West Neonatal network review/Tim Overton to look at capacity and efficiency of clinic

Look at minutes of the M&M meeting for details on this action. AT explained that this action relates to a case in Torbay where the issue was short term sickness and not a capacity issue. **Action – closed.**

Action 13 – Repatriation policy

The policy is being drafted for peer review **SV**

Action 14 – Network Terms of Reference

Terms of reference for network board new structure have been completed and signed off by the network board. **Action – Closed.**

Action 16 – Transfer and repatriation policy

On agenda. **Action – closed.**

Action 17 – Lost to follow up

Work in progress for peer review. On agenda.

Action 18 – Identify dental contacts

Dental contacts have been established and updated. **Action – closed.**

Action 19 – Dental guidance and dentistry page on Network website.

Dentist page to be created on Network website **MB**

Action 20 – Education for families around dental care in hard to reach groups

MA explained that there are named links for dental services in different areas. He highlighted that there is useful information about dental care on the website and in the network newsletter including the brush DJ app which will help people to access information. Further work will be done on the network website dental page. **Action – closed.**

Action 21 – Audit dates

The Audit dates have been clarified and they do not link across the region. **Action – closed.**

Action 22 – Palliative Care Toolkit

Completed. **Action – closed.**

Action 23 – Training and education strategy feedback

Training and education strategy previously signed off. On agenda. **Action – closed.**

Action 24 – Invite pharmacy representative to discharge communications group

Completed. SG is member of the group. **Action – Closed.**

	<p><u>Action 25 – Paediatric starvation guidance</u> Clarify with TM about changes to the guidance. Upload onto Website from the DMS <b>MB</b></p> <p><u>Action 26 – Adult starvation guidelines</u> Ask Adrian Wagstaff to advise on this.</p> <p><u>Action 27 – Share work done on ACHD data and palliative care</u> Ask VN to send work.</p> <p><u>Action 28 – Paediatric protocols/guidelines group</u> Currently Level 1 and Level 2 protocols are being prepared for peer review. On agenda.</p>
<b>3.</b>	<p><b>Network Update</b></p> <ul style="list-style-type: none"> <li>- <b>Network Governance</b></li> <li>- <b>Peer review</b></li> </ul>
	<p>CMc outlined the new governance arrangements for the network with two new sub groups; Clinical Governance Group and Service Delivery Group reporting into the Network Board (see slides for detail). CMc described the remit of the Clinical Governance Group summarising the specific role and responsibilities of the group, which include education and training; incident management; annual M&amp;M; audit; clinical guidance; and patient information.</p> <p>The membership of the group was discussed and in particular whether there was good representation across level 1, 2 and 3 centres in the network. It was highlighted that if there was a repeat of the self-assessment visits to the centres it would provide a good opportunity to promote the CHD Network and recruit new members to the network groups. Recording meetings and the use of video conferencing was suggested.</p> <p><b>Action:</b> Active recruitment of members to network groups. <b>AT/SV</b></p> <p><b>Action:</b> Email copies of the actions to PECs. <b>MB</b></p> <p><b>Action:</b> Explore options and benefits of video conferencing. <b>CMc</b></p> <p>CMc informed the group that each sub group needs a chairperson and explained that the group will report bi-annually to the network board with a progress report including a plan for 6 months, work done, risks and issues. It was highlighted that the new structure will be evaluated after a year.</p> <p>CMc updated the group on key headlines and preparation for the CHD Network peer review taking place on 10<sup>th</sup> – 12<sup>th</sup> June 2019 (see slides for detail). Further details of the peer review were discussed in an afternoon focus session.</p>
<b>4.</b>	<p><b>Service delivery group work plan</b></p>
	<p>CMc explained there are 14 key work packages for the clinical governance group on the work plan which are all underway. The group were updated on 8 of these in more detail as part of the meeting. The work plan was discussed in detail in an afternoon focus session.</p>
<b>5.</b>	<p><b>Network research – update on British Heart Foundation CHD programme in South West</b></p>
	<p>GB presented an update on the British Heart Foundation CHD research programme in Bristol on behalf of Professor Massimo Caputo. GB gave an overview of ongoing work in Bristol, a summary of his own research and the team's research including both clinical and basic science research. He highlighted that the team have collaborations with other university departments, as well as nationally and internationally. GB explained the four main topics of CHD research: imaging; 3D printing; tissue engineering; and trials and database. GB explained that a 3D lab has been established at the Clinical</p>

	<p>Research and Image Centre (CRIC) Bristol with support from The Grand Appeal charity. GB highlighted the REDCap study which is building databases of surgical patients with CHD including TOF, BAV, and CoA which allows retrospective analyses including outcome data. GB highlighted that patient and public involvement informs elements of research. GB described The Heart of the Matter project which was developed with an artist and involved working with patients in workshops with scientists, artists, students and nurses to turn patient stories into artwork. The exhibition toured nationally including Bristol.</p> <p>A question was asked about how to involve wider network in research. It was noted that patients from across the network are involved in studies and that when patients are enrolled into a study that the cardiologist/PEC should be made aware, but at times it was challenging to access the correct information to do this. It was highlighted that the Universities in the network region are Bristol, UWE, Cardiff, Swansea, Plymouth and Exeter. Including the information on discharge summaries was suggested.</p> <p><b>Action:</b> Investigate whether the discharge summaries from level 1 centres can include information relating to clinical trials <b>CMc</b></p>
<b>7.</b>	<b>Audit</b>
	<p>HW updated the group on the CHD audit programme across South Wales and the South West (see slides for detail). She summarised the standards relating to audit, and explained her role as the network audit lead which is to promote the importance of audit across the network, record ongoing audit and facilitate the presentation of completed audits. She noted that audit is different to research and the focus of audit is whether we are meeting the standards and assessing against the standards.</p> <p>HW summarised current practice noting that several audits were completed in 2018 and have been presented. Having requested details of any audits currently underway in the Network, Helen updated the group on 3 audits that had been flagged up: Surgical waiting times and post op anticoagulant management; assessment of the current standards/detection rate for fetal cardiac anomaly scanning in the South West region for TGA, ToF, HHS and cAVSD; and screening for liver disease in Fontan patients across South Wales.</p> <p>HW highlighted some challenges to undertaking audit that had been highlighted including funding or resources to complete audit. It was noted that each individual centre should have an audit leads. CMc emphasised that undertaking audit and learning from audit is a key responsibility of the Clinical Governance Group and the network as a whole and that there is an expectation that audits are presented at future meetings. HW presented solutions for undertaking audit such as: help from medical students/junior doctors who need to undertake audits and supervising them; and combining resources and working across the network to undertake audits.</p> <p>HW requested that the group email HW or MB if they have any audits currently underway that aren't currently listed or if they commence a new audit so she can update the database. HW explained there at least two audits need to be presented at the next network clinical governance group meeting in September. The fetal audit, DNA/transition data, and fontan data were suggested as possible presentations. Members of the group were asked to go back to their teams/trusts and ask about audits taking place and to let HW know.</p> <p><b>Action:</b> Network members to email MB or HW with details of audits underway and also to confirm if they will be ready to present at the next Network Clinical Governance Group. <b>All</b></p> <p><b>Action:</b> Two clinical audits to be presented at next clinical governance group. <b>HW</b></p> <p><b>Action:</b> Update website audit list. <b>MB</b></p>

8.	<b>Protocols for agreement</b>
	<p><b><u>Paediatric drug protocols update and plan for 2019</u></b></p> <p>SG updated the group on the paediatric drug protocols (see slides for detail). SG noted the emergency management of Hypercyanotic spells guideline is already on the CHD Network website and on the clinical document management system in UH Bristol: <a href="https://www.swswchd.co.uk/en/page/clinical-information-children">https://www.swswchd.co.uk/en/page/clinical-information-children</a>. SG explained that there are a number of finalised guidelines which are awaiting upload to the website: Palivizumab &amp; Respiratory Syncytial Virus (RSV) Prophylaxis in Paediatric Congenital Heart Disease, Carvedilol, Flecainide, Captopril and ACE Inhibitor Therapy, Warfarin and Low molecular weight heparin.</p> <p>SG informed the group that to date there has been limited feedback on the protocols and that they are a work in progress. SG expressed the need for people to use the protocols and see if they are appropriate. She explained she has had questions from District General Hospitals (DGH's) and noted that some of these were not aware of the network website. Connecting with key people in different centres, SG sharing with the pharmacy network, and tweeting new protocols were suggested. SG highlighted the fact that the network website is an open website so to be aware patients can see them. DM explained that in Exeter the protocols are linked on the paediatric homepage which makes it easy to access them.</p> <p>SG highlighted that a conversation is needed around the use of two protocols in Wales and whether they will use the Bristol/Network protocol or a Welsh one. It was noted that DW follows Welsh protocols but it is hard to get a feel for the rest of region. South Wales links to Cardiff and the South West links to Bristol.</p> <p><b>Action:</b> Invite SG to present at the PEC day in July. <b>AT/MB</b></p> <p>Guidelines being finalised include: Dinoprostone guidelines – the network draft is to be amended and circulated; and the UHF/anticoagulation guideline which is being revised. Other guideline updates included: Amiodarone has been previously worked on but there was no consensus within Bristol, this will be reviewed. It was suggested it may be useful to have an immunisation guideline and annual influenza information but no other suggestions were received by SG.</p> <p>SG presented some questions to the group: What are the most important things relating to drug protocol for PECs? When there are problems nationally how do we get the message out to centres?</p> <p><b>Action:</b> DM work with SG on paediatric drug protocols. <b>DM/SG</b></p> <p>A reluctance of GPs to take on prescribing was highlighted and it was noted that there is work taking place on this in Bristol.</p> <p><b><u>Dental Pathway – arrangements for urgent assessments for CHD patients</u></b></p> <p>RP presented the proposed guidance document for paediatric patients (See slides for detail). She summarised section M of the CHD Standards and the 6 main standards in the dental section explaining that these are covered in the Dental Care Pathway for Children with Congenital Heart Disease. A draft document was sent to the group as a paper for the meeting.</p>

RP explained the main issue of dental caries highlighting that CHD patients are at higher risk than average. She noted that dental services can be difficult to navigate and there are three types: General, Community and Hospital dental services.

The dental care pathway for children with congenital heart disease covers: early years, continuous care, pre-surgery, transition to adult services, and audit. The early years section covers standards M1, M3, and M6. RP explained it is a key responsibility of the cardiac team to advise parents on preventing dental disease and attending dental check-ups, information should be given to parents by the time their child is age 1, information should be given on how to access a dentist which will be available on the website and as a leaflet in the appendix. RP noted that standard M6 describes referral to dental services. During continuous care the cardiac team should check patients are receiving regular dental care, there should be ongoing availability of advice. Pre-surgery is covered in standard 2. A dental assessment should be undertaken before surgery, with assessments carried out as soon as possible to prevent surgery delays. Patients can be seen by a community dentist where an appointment is time sensitive due to surgery. RP questioned whether the assessment request form and fit for surgery form should be sent to the cardiologist or waiting list administrator. Cardiologists should request whether a patient needs antibiotics post-surgery. Agreeing a consensus within the network on antibiotics was highlighted. A questions was raised as to whether a PEC should refer to dentists or cardiology consultants and it was explained that interventions should go via the cardiologist and it is the step before the surgical clinic where a patient needs to be referred to the dentist. It was highlighted that any child having surgery needs to see a dentist and should see a community dentist within 6 months prior to surgery. RP questioned urgent reviews after endocarditis and how to advise, it was explained that patients with endocarditis would be inpatients in level 1 and level 2 centres.

**Action:** UH Bristol prevention leaflet relabelled for network and made available **RP/MB**

**Action:** Dental access information for England/Wales to be put on Network website. **MB**

**Action:** AT link to JCC for dental work when listed to surgery. **AT**

**Action:** JH link for dental work and clinic for practical issues. **JH**

MA presented the Draft care pathway for Adults with Congenital Heart Disease (See slides for detail). He explained that most adults will go to the general dental services and described the commissioning of dental services. He summarised challenges to dental care which include limited NHS provision in certain areas, contractual restrictions, worries from general services around medical emergencies, and differing systems across Wales and England. MA described the adult dental care pathway which is based on existing work on the pre-surgery pathway with additions to meet the NHSE CHD standards. Evaluation of the pathway will include assessment of quality of referrals, PROMS/PREMS, feedback from the cardiology team, annual revision of the guidance for the CHD Network. MA highlighted the Scottish dental clinical effectiveness programme as being a useful resource. It was noted that referral systems are outlined in the pathway documents.

MA asked the group for any questions, ideas or help that is needed. MA explained that the cardiologists know their patients and the dentists know the risk of interventions so should be able to provide/prescribe antibiotics if they are needed. It was noted that the European Society of Cardiology (ESC) guidelines for adults are used in Bristol. It was suggested that the network agree and formalise the use of guidelines for antibiotic prophylaxis

**Action:** Agreement on guidelines for antibiotic prophylaxis. **SC /AT**

#### **Draft Transfer and Repatriation policy**

SV explained that the Children's Transfer and Repatriation policy is currently being developed and has gone to the Wales and West Acute Transport for Children service (WATCH) for comments. Transfers



	from Cardiff via helicopter were highlighted as an issue that has been raised at the Children's Cardiac Clinical Governance Group in UH Bristol
<b>9.</b>	<b>Image sharing</b>
	AT summarised the survey questions sent out to the network about image sharing. Outputs included concerns where centres aren't meeting the standards, and IT links to use to solve the issue of transfer images bilaterally.
<b>10.</b>	<b>Lost to follow up rates</b>
	<p>SV presented lost to follow up rates and discussed the problems that can occur during transition (see slides for detail). There are challenges with calculating a lost to follow up ratio due to challenges with capturing information relating to the patient journey. For example it is not clear how many young people's clinics there are peripherally, whether the transfer letters are copied to the adult CNS team, and if all young people are transferred to the Bristol Heart Institute (BHI) or whether some see their consultant in peripheral clinics.</p> <p>SV highlighted that there is an increase in A&amp;E attendance at transition. She summarised the reasons for young people being lost to follow-up which include: not receiving adult appointment, don't know where to attend adult appointment, scared to go to adult appointment, feel well. Actions to reduce lost to follow up rates include: planned audit of all Bristol Royal Hospital for Children (BRHC) discharges for transfer to BHI or peripheral clinics, patient and staff education on the importance of life long follow up for CHD patients, and copying letters to the outpatient coordinator.</p>
<b>11.</b>	<b>Training &amp; Education</b>
	SV summarised the upcoming training events at a network, national and European level (see slides for detail). The 2019 events are on the Network website. She explained that there is work in progress to identify education leads in Level 1 and Level 2 centres; link with education leads in level 3 centres; development of GP education and resources; online resources on the website; online nurse education module.
<b>12.</b>	<b>AOB</b>
	<p>The next clinical governance group meeting will be October, date tbc.</p> <p>The next meeting is the network board meeting on 1<sup>st</sup> May, Taunton.</p>

## Comments and actions from afternoon focus sessions

Item	Notes and Actions
<b>1.</b>	<b>Work plan 2019/20</b>
	<p>CMc explained how the network work plan is developed. She asked the group to review the Clinical Governance 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: Raising the profile of the network and network website; Risks when transferring patients from one organisation to another; Increasing Level 3 centres and the community of people involved; Imaging; Link nurses; and audit.</p>

	<p>Other feedback from the group included: Promoting and raising awareness of where to find paediatric guidelines and getting them used; awareness of linking incidents to the network; making the network M&amp;M and audits useful; setting a minimum standard for image sharing; identifying level 3 education champions; making what is on the work plan more 'useful' with deliverable tasks.</p> <p><b>Action:</b> SV to email HW Welsh link nurse contacts. <b>SV</b></p>
<b>2.</b>	<b>Deep delve into incidents</b>
	<p>AT outlined the Network Morbidity and Adverse incident reporting policy. AT explained the reporting and learning flow chart from the policy explaining the process for reporting an incident to the network. It was highlighted that the role of the Network is to share learning and best practice from these incidents whilst the local organisation would be responsible for managing the incident as per business as usual processes. AT presented a summary of the network incidents by date of incident, by centre, by incident category, and further detail of some specific incidents. Currently there are 18 incidents reported the network recorded on Datix.</p> <p><b>Action:</b> Include examples of incidents that should be reported to the network in email when sending out incident form. <b>MB</b></p> <p><b>Action:</b> Include an incident presentation at the PEC day in July. <b>AT</b></p>
<b>3.</b>	<b>NHS England Peer review preparation</b>
	<p>CMc highlighted the key details for the National CHD Networks Peer Review (see slides for detail). The NHS England Quality Surveillance Team will be carrying out the SWSW CHD Peer review on the 10<sup>th</sup>-12<sup>th</sup> June 2019 to review the Network, Level 1 and Level 2 centres against the CHD Quality Indicators. As part of the peer review there will be a review meeting, which the multi-disciplinary team for the centre under review attends, and then a feedback session with the Executive lead for the centre later in the day. The initial output of the review is a report that is provided on the day followed by a more formal report in the following weeks. This gives the centres an opportunity to comment and feedback on the initial report before its finalised. It is expected that a national report will be produced following completion of all the peer reviews across the country. In preparation for the review, evidence folders have to be submitted four weeks in advance and this includes contextual information, an operational policy, annual plan and work plan for the network, level 1 and level 2 centres. The network team have had peer review preparation meetings with each of the level 1 and level 2 centres and work is underway to gather the evidence required. Peer review training is being held on 2<sup>nd</sup> April 13 00-16 30 in Bristol. Invitations to the network peer review meeting will be sent out.</p> <p><b>Action:</b> Invitations to attend the Peer Review Meetings will be sent out as relevant <b>MB</b></p>



### Attendees

Name	Init.	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
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology and Network Board Chair	Royal Devon and Exeter NHS Foundation Trust
Helen Wallis	HW	Consultant cardiologist	ABM ULHB
Zoe Trotman	ZT	Sister, Paediatric Cardiology	University Hospitals Bristol
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	University Hospitals Bristol
Rosie Power	RP	Consultant in Paediatric Dentistry	University Hospitals Bristol
Mick Allen	MA	Consultant in Special Care Dentistry	Aneurin Bevan University Health Board
Giovanni Biglino	GB	Senior Lecturer in Biostatistics	Bristol Heart Institute, University of Bristol
Karina Simmonds	KS	Clinical Nurse Specialist	University Hospital Wales
Greg Szantho	GS	Consultant Cardiologist	University Hospital Wales
Caryl Evans	CE	Adult Clinical Nurse Specialist	University Hospital Bristol
Jennifer Holman	JH	Consultant Paediatrician	Gloucester Hospitals NHS FT
Steph Curtis	SC	Consultant Cardiologist	University Hospitals Bristol

### Apologies

Name	Init.	Job title	Organisation
Catherine Blakemore	CB	Consultant Cardiologist	Torbay
Radwa Bedair	RB	Consultant Cardiologist	University Hospitals Bristol
Emma Hubert-Powell	EHB	Paediatric Consultant	Plymouth
Rebecca Chawner	RC	Nurse	Exeter
Ola Elmasry	OE	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall NHS Trust
Francis Edwards	FE	Paediatric Palliative care clinical nurse specialist	BRHC
Nigel Osborne	NO	Consultant paediatrician with Expertise in Cardiology	Exeter
Andrew Parry	AP	Consultant Congenital Heart Surgeon	University Hospitals Bristol