

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

**Date:** Tuesday 15<sup>th</sup> September 2020, 14.00 – 16.00

**Venue:** WebEx Conference Call

**Chair:** Dr David Mabin

### Minutes

Item	Notes and Actions
1.	<b>Welcome, introductions and apologies</b> - Personnel update
	<p>DM welcomed the attendees to the network's virtual board meeting via WebEx and noted apologies. He shared the digital meeting etiquette, noting also that the WebEx chat question function is available.</p> <p>CMc updated the Network Board on recent personnel changes – welcoming Jessica Hughes who is starting as the new job share Band 8a lead nurse (0.3 WTE) from October, working closely with SV who has retired and returned on reduced hours (0.4WTE). CMc also welcomed Gemma Wright, Chief Physiologist in Truro, and Rowan Kerr-Liddell, PEC in Torbay to the board meeting.</p>
2.	<b>Approval of minutes and action tracker</b>
	<p>The minutes of the Network Board on 23<sup>rd</sup> June 2020 were agreed to be an accurate record.</p> <p>The action log was updated as appended. Notable comments:</p> <p><b><u>120 – discharge communication work</u></b>                      Recently conducted a PEC survey on discharge communication – the positive feedback is that improvements have been made, but more to do. Catherine Armstrong is currently working on a standard operating procedure for discharge. This will be shared with the clinical governance group when completed.</p> <p><b><u>121 – network stakeholder event</u></b>                      Postponed this year due to Covid-19, but hoping to do in 2021 with board support.</p> <p><b><u>124 – Transition pathway to adult services – Plymouth</u></b>                      There is a group in BRHC who are currently looking at the transition model for peripheral centres – to be updated later on the agenda under level 1.</p> <p><b><u>130 – ACHD clinic input</u></b>                      Network team flagged to level 1 centre who confirmed that they had already been in discussions with Exeter around capacity.</p> <p><b><u>131 – Link Nurse, Gloucester</u></b>                      SV is in discussions with the link nurse following her leave.</p> <p><b><u>132 – Concern regarding long waiting times in Wales</u></b> (linked to action 126)                      Closed - Letter sent to WHSCC about these concerns, who met with the health boards to discuss actions around this. On the agenda under regional updates for AR from WHSCC to provide an update.</p>

	<p><b><u>133 – Patient database</u></b> Completed – have shared KH database with those interested.</p> <p><b><u>134 – SOP for physiologist led clinics</u></b> Completed – SOP shared.</p> <p><b><u>135 – VLAD update</u></b> On the agenda - SM providing an update.</p> <p>No further actions to report on.</p>
<b>3.</b>	<b>Patient Representative Update</b>
	<p>SV shared that the patient representatives had a virtual catch up in early September to re-group. Looking at patient reps linking in with the charities to bring back feedback to the board, and promote their work on the network website in a clearer way. Planning to meet quarterly in advance of the network board and to have another workshop in Spring 2021. NM and FC introduced themselves and the expertise they bring.</p> <p>FC shared that she has had two open heart surgeries during her lifetime, and as a job does freelance work for the theatre and BBC. FC is keen to help raise the profile of patient reps and encourage a more diverse range of patients to get involved. Youth at Heart are currently seeking a youth representative who can convey their feedback back to the Board.</p> <p>NM shared that she is a parent of a 14 year old with CHD who has had 5 open heart surgery operations at BRHC. NM has been involved in numerous ways with the network and support groups. She explained that more recently she has become involved with the charity Heart Heroes (more paediatric focused), and is in the process of setting up a Bristol hub with the aim of running coffee mornings and social events to support cardiac families. Whilst face to face contact is limited due to Covid-19, Heart Heroes have started to run some online events. Once the hubs have established more of a network with families will look into virtual events too.</p> <p>One board member asked if charities are aware of what other charities are doing to avoid duplication. NM explained that Heart Heroes run more face to face events, whereas Heart Families South West and Heart Families Gloucester are primarily Facebook support groups. These groups are currently working together on a collaborative project to put together a book of positive heart children stories for under 5s and for 5years plus, to help support families during challenging times. The plan is that these books will be available to buy and also available in outpatient areas across the network.</p> <p>The network website has a charities page for clinicians to signpost patients to.</p> <p>AT raised about how the peer review encouraged PPV representation and NHS England to provide training to support this role. There is currently no existing training for PPV. Looking to work with other networks to provide training.</p> <ul style="list-style-type: none"> <li>○ <u>Action:</u> AT to escalate to the CRG re: PPV training</li> </ul> <p>The patient reps were asked what they do if patients raise concerns to them, e.g. related to waiting times, and they responded that they tend to sign-post to the cardiac liaison nurses etc and try to keep a neutral position. Guidance on this would be helpful.</p> <ul style="list-style-type: none"> <li>○ <u>Action:</u> SV to develop guidance for patient reps on responding to particular patient feedback or queries.</li> </ul>

4.	Update from Level 3 centre(s)
	<p>CMc led an update on the behalf of the level 3 centres. The key updates are outlined in the exception report in the papers. Key themes to note: Covid-19 effect on the waiting lists, recruitment of key link nurses and consultants, and concerns about the memorandum of understanding. In some centres, clinical activity particularly in peripheral clinics has been severely reduced due to social distancing measures and infection control, whereas other areas haven't been affected as much.</p> <p><u>Adults</u></p> <ul style="list-style-type: none"> <li>● <b>Taunton</b> – BL shared that recently held a paediatric transition clinic with the normal number of appointments. Joint clinics have been running via Attend Anywhere.</li> <li>● <b>Exeter, Barnstaple and Swindon clinics</b> - RB updated that in Barnstaple these have remained virtual via Attend Anywhere video with the plan for RB to visit in October. In Exeter, have run telephone clinics with debriefs and diagnostic tests afterwards. In Swindon, have run joint clinics with the option to dictate letters remotely. RB shared that her learning is that there is no one solution that fits everyone and have to tailor this to meet local needs.</li> <li>● <b>Virtual peripheral joint clinics</b> with level 1 using platforms such as attend anywhere – CMc recognised the challenges of this and questioned whether be worth exploring this more, particularly with winter ahead.</li> <li>● <b>Plymouth</b> asked whether there are any network triage tools to apply and focus GP referrals to ensure the quality of referral is appropriate. <ul style="list-style-type: none"> <li>○ <u>Action</u>: Ask PECs and other network clinicians if issue requires a network project. AT</li> </ul> </li> </ul> <p><u>Paediatrics</u></p> <ul style="list-style-type: none"> <li>● <b>South Wales</b> - HW shared that the level 3 centres have mainly be running virtual tertiary clinics, which have been successful and worked well with follow up patients. Have deferred a number of 12 month follow ups to next year, which may cause issues in 2021.</li> <li>● DW shared that the group in the <b>Aneurin Bevan Health Board</b> have continued with telephone clinics and started face to face appointments, clearing their backlog of patients. Activity is continuing, but limited by PPE and social distancing measures.</li> <li>● <b>Torbay</b> – GS shared that appointment numbers have reduced, but are working hard to increase this.</li> <li>● <b>Taunton</b> asked for continued support in establishing a robust system for image transfer – This has been raised with NHSE as this is common problem amongst all of the ODN networks and requires wider work. AT shared that this ongoing issue is partly resolved in that images can be shared via video conference however MDTs are limited by the frame rate. Improving image sharing remains on the network work plan.</li> <li>● JH commented on the difficulties of having genetic studies done on children with FH ICC, even when the genetic deletion is known. The lab requests that the family is seen by Genetics but there is a huge waiting list.</li> <li>● <b>Truro</b> <ul style="list-style-type: none"> <li>▪ Asked for support with SOP for discharge communications – This is in progress. Catherine Armstrong is currently drafting a SOP. More to follow at the next meeting.</li> <li>▪ More leverage for CHD patients to have prioritised dental access in Cornwall – AT will raise via CRG. KH has just completed an audit in Cornwall, which noted a patient with</li> </ul> </li> </ul>

	<p>endocarditis who did not have a dentist.</p> <ul style="list-style-type: none"> <li>○ <u>Action</u>: AT to raise Cornwall dental issues with CRG.</li> <li>○ <u>Action</u>: CMC to raise as a risk on the NHSE quarterly report.</li> <li>▪ Development of ICC pathways with follow up clarification – AT shared that this has been escalated with little response. <ul style="list-style-type: none"> <li>○ <u>Action</u>: DW offered to share ICC guidelines used in Wales as a starting point.</li> </ul> </li> <li>▪ Access to JCC – These are being run virtually. Clinicians were encouraged to contact the level 1 centre if they would like to join the invite list for the adult or paediatric JCC. <ul style="list-style-type: none"> <li>○ <u>Action</u>: RD to share the email address of who to contact to request to be added to the JCC invite list.</li> </ul> </li> </ul>
<b>5.</b>	<b>Update from Level 2 centre</b>
	<p>DW presented an update for the Level 2 centre - the key updates are outlined in the exception report in the papers. Notable comments included:</p> <p><u>Level 2 paediatric CHD service:</u></p> <ul style="list-style-type: none"> <li>• Staffing crisis looming on Pelican ward.</li> </ul> <p><u>Level 2 adult CHD service:</u></p> <ul style="list-style-type: none"> <li>• Greg Szanthy has a new appointment in Bristol starting in October, and the C&amp;V service are planning for an interim/new consultant. The phase 2 funding will cover a replacement and an additional consultant. The two consultant posts went out to advert yesterday closing on 11<sup>th</sup> October. Phase 2 funding also includes investment in CNS, physiologist and psychology staffing <ul style="list-style-type: none"> <li>○ <u>Action</u>: network to advertise on twitter.</li> </ul> </li> </ul>
<b>6.</b>	<b>Update from Level 1 centre</b>
	<p>The key updates are outlined in the exception report in the papers.</p> <p><u>Level 1 adult CHD service</u></p> <p>RB shared the key items to note:</p> <ul style="list-style-type: none"> <li>• Planning to run face-to-face clinics once a month for every consultant. Have started a new HOT clinic.</li> <li>• Virtual MDT is running smoothly with no waits for discussion – planning to continue these as they are working well with wider engagement. Keen to encourage further level 3 involvement with this. <ul style="list-style-type: none"> <li>○ <u>Action</u>: Radwa Badair to share details of how level 3 clinicians can join the MDT.</li> </ul> </li> <li>• Diagnostic backlog is a problem, however otherwise have done really well to get back on track.</li> </ul> <p><u>Level 1 paediatric CHD service</u></p> <p>RD shared the key updates to note:</p> <ul style="list-style-type: none"> <li>• Currently running at four days for cardiac surgery rather than five.</li> <li>• Risk of increased waiting lists in all areas due to Covid-19 – looking to manage this as best as</li> </ul>

	<p>possible.</p> <ul style="list-style-type: none"> <li>In the last year, SSQD dashboard shown a positive turnaround in fetal cardiology screening times. Well done to the fetal cardiology team.</li> </ul>
<p><b>7.</b></p>	<p><b>Network Board update</b></p>
	<p>CMc updated the Board on the key work being undertaken within the Network, with supporting papers: quarter 1 update (April to June 2020); work plan 2020/21; published annual report 2019/20 and Memorandum of Understanding. Please refer to the presentation slides for further detail.</p> <p><u>Network update</u></p> <p>CMc shared that Jess Hughes starts in post in October as a joint network lead nurse working with SV. A number of other education events are being held, which are mainly being run virtually. The network team have been delighted to work with Patricia Caldas on the fetal cardiology webinar series, and offered to help those who are interested in creating webinars. Looking ahead, the focus is to develop the priorities for 2021/22 and welcomed engagement with this. Re-launching the self-assessment visits which were put on hold due to Covid-19; these are likely to be run virtually.</p> <p><u>Network work plan 2020/21 update</u></p> <p>In reference to a presentation slide, CMc provided a summary noting the status of the network work packages.</p> <p><u>Annual report 2019/20</u></p> <p>Included in the papers for information. The network team welcomed suggestions for next year's report.</p> <p><u>Memorandum of Understanding</u></p> <p>This document that describes the roles and relationships within the network arrangement has been published, and is awaiting sign off by the CEOs and Medical Directors of the organisations involved. This is about the demonstration of commitment and mutual support to the ODN networks. The networks report on a quarterly basis to a NHSE network programme board (run by Peter Wilson for the South West); the ODN governance flow chart shows the process of escalation.</p> <p>AR shared that for Wales, despite the different governance arrangements she is keen that similar processes are followed. She noted that the Memorandum of Understanding needs to come through the CEO joint committee and that she is discussing this Friday with the WHSCC executive team how best this can be supported.</p> <ul style="list-style-type: none"> <li><u>Action:</u> AR to update Network board on outcome of meeting with WHSCC executive team to discuss CHD standards and the MOU</li> </ul>
<p><b>8.</b></p>	<p><b>National and regional updates</b></p>
	<p><u>National update</u></p> <p>AT provided a brief national snap shot – please refer to the presentation slide for further details:</p> <ul style="list-style-type: none"> <li>CHD standards and peer review of the level 1 and 2 centres – the national report has not yet been published. There has been progress to recruit to CNS posts in the BRHC which addresses one of the recommendations of the peer review.</li> <li>Covid-19 centre stage for 6 months now. National network of CHD networks conference calls continue to run on a regular basis and are an invaluable group for communication and support. This group together with the CRG and other professional bodies are working with NHSE in developing plans for protecting the service in the event of any further Covid-19 outbreaks.</li> </ul>

	<p><u>Commissioner updates</u></p> <ul style="list-style-type: none"> <li>• WHSCC, South Wales – AR presented the key updates outlined in the presentation slide. Of key note is that the:</li> <li>• ACHD Phase 2 Business Case has been approved in August 2020 releasing £790k to support recruitment of staff and service development. The funding release letter has been sent to providers. The challenge is around implementation.             <ul style="list-style-type: none"> <li>○ <u>Action</u>: AR to share letter with outline of phase 2 business case support</li> </ul> </li> <li>• Have asked the Health Board about mitigating the risk around Greg Szantho’s post with him leaving in October; the clinical board are meeting next week to discuss this.</li> <li>• For paediatrics, there is a business case that is due to be signed off next month of around £400k to support staffing             <ul style="list-style-type: none"> <li>○ <u>Action</u>: AR to update on the paediatric business case at the next Network Board.</li> </ul> </li> <li>• The CHD standards are not yet formally signed off in Wales, however Wales have commissioning policies and service specs – therefore in the meantime the proposal is to develop a service spec that is based entirely on the NHSE cardiac standards, so can implement this.</li> </ul> <p><b>NHS England, South West</b> – CI presented the key updates outlined in the presentation slide.</p> <ul style="list-style-type: none"> <li>• The phase 3 national correspondence issued on 31<sup>st</sup> July by Simon Stevens focusses mainly on restoration and addressing health inequalities, which is shaping the operational plan for the remainder of the year.             <ul style="list-style-type: none"> <li>○ <u>Action</u>: CI to circulate the letter on phase 3 from Simon Stevens.</li> </ul> </li> <li>• STPs are submitting recovery plans to NHSE/I in September. Currently have a block financial contract arrangement with each Trust in the South West until end of September 2020, but expecting this to be extended until the end of the financial year.</li> <li>• The new ODN Memorandum of Understanding (MOU) has been issued, and it is hoped will help raise the profile of ODN’s excellent work, bring partners closer together across the system and promote the work of the networks.</li> </ul>
<b>9.</b>	<b>Network performance</b>
	<p><b><u>Performance dashboard</u></b></p> <p>The performance dashboard was included for information. CMC flagged that a number of centres have not submitted data and if this requires action. CI shared how commissioners could help with the memorandum of understanding and encouraging engagement, appreciating it is a difficult time with Covid-19.</p> <p><b><u>Restoration of activity</u></b></p> <p>Following a survey, the slide shows the limited responses. The board was asked if they need more assurance around this</p> <p><b><u>NHSE Specialised Services Quality Dashboards (SSQD)</u></b></p> <p>The Adult Level 1 SSQD Quarter 4 2019/20 dashboard and Paediatrics Level 1 for Quarter 4 are included in the papers for information.</p>

	<p><b><u>Surgical performance update</u></b></p> <p>At the last board meeting, AP presented some details of the VLAD plots detailing surgical outcomes in 2019. SM provided an update presentation on this explaining that VLAD plots are a chronological plot of expected mortality minus observed mortality on a case by case basis, and how these are constructed. This indicator of trends shows how many fewer (or more) deaths there are over time compared to what would be expected, and are commonly used to display outcomes following cardiac surgery both in adults and congenital areas.</p> <p>The VLAD plots are regularly reviewed by centre as part of the governance process. The plot shows that over a 5 year period there has been good performance, however in the second half of 2019 the charts suggests a decline. This was taken very seriously and each case was looked into closely by the surgeons. At least 3 out of the 6 cases in that 6 month period were extremely high risk. Nevertheless, have identified means to improve the outcomes – this includes two consultant surgeons scrubbed for neonatal/high risk cases where possible; engagement of the complete team in JCC and improvement in JCC documentation. Since then this has improved. This links in with the child death review process.</p>
<b>10.</b>	<b>Network risks – for information</b>
	<p>CMc tabled the network risk report. The report includes current risks and their risk rating, what controls are in place and recent actions. There are currently 6 open risks on the network risk register. The Network Board is responsible for managing risks. No new risks to note.</p> <p>The Board are asked whether all the relevant network risks are recorded; to check the risk ratings; to check the controls in place are adequate; to decide whether further controls or actions are needed; and whether any other risks need to be escalated.</p>
<b>11.</b>	<b>Any Other Business</b>
	<ul style="list-style-type: none"> <li>• Evaluation forms - Board members were asked to complete the meeting evaluation form via the survey monkey</li> <li>• Next Board Meeting, Tuesday 8<sup>th</sup> December 2020 (virtual) - Board members were asked to inform the network team of any agenda items for the next network board meeting which is being held virtually.</li> </ul>



### Attendees

Name	Inits.	Job Title	Organisation	Present/ Apols
Andre Clinchant	AC	Lead Nurse	Taunton and Somerset	Present
Andrea Richards	AR	Senior Commissioner	Welsh Health Specialised Services Committee	Present
Andy Arend	AA	Consultant paediatrician	North Devon, Barnstaple	Apologies
Andy Tometzki	AT	CHD Network Clinical Director / Consultant Paediatric Cardiologist	CHD Network Team	Present
Becky Lambert	BL	Staff Nurse ACHD	Taunton and Somerset	Present
Becky Nash	BN	Patient Representative		Apologies
Bethan Shiers	BS	ACHD specialist nurse	University Hospital of Wales	Present
Bill McCrea	BMc	Consultant	Great Western Hospital, Swindon	Apologies
Caryl Evans	CE	Adult CNS	University Hospitals Bristol	Present
Cat McElvaney	CMc	CHD Network Manager	CHD Network Team	Present
Charlotte Ives	CI	System Transformation Lead – Specialised W&C Services	NHS England and NHS improvement – South West	Present
Daniel Meiring	DM	Lead Physiologist	University Hospitals Bristol	Apologies
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology and Network Board Chair	Royal Devon and Exeter	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	University Hospital of Wales	Present
Frankie Carlin	FC	Patient Representative		Present
Ganga Bharmappanavara	GB	Consultant	Taunton and Somerset	Apologies
Helen Liversedge	HL	Consultant Fetal	Royal Devon and Exeter	Apologies
Helen Wallis	HW	Consultant Cardiologist	ABMU Health Board	Present
Jennifer Holman	JH	Consultant Paediatrician	Gloucester Hospital	Present
Jessica Hughes	JHu	Network Lead Nurse (joint)	CHD Network Team	Present
Karen Sheehan	KS	Paediatric Cardiac Research Sister	University Hospitals Bristol	Apologies
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals	Present
Lisa Patten	LP	Paediatric CNS	University Hospitals Bristol	Present
Manish Gandhi	MG	Consultant cardiologist	Royal Devon and Exeter	Apologies
Marion Schmidt	MS	Consultant Paediatrician	Royal Gwent Hospital, Newport	Apologies
Mark Dayer	MD	Consultant Cardiologist	Taunton and Somerset	Present
Melissa Winn	MW	Service Manager	Royal Cornwall Hospitals	Present
Nicola Morris	NM	Patient Representative		Present
Nigel Osborne	NO	Paediatrician with Expertise in Cardiology	Royal Devon and Exeter	Apologies
Orhan Uzan	OU	Consultant Cardiologist	University Hospital of Wales	
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	University Hospitals Bristol	Apologies
Rachel Burrows	RAB	CHD Network Support Manager (note-taker)	CHD Network Team	Present
Rachel Tidcombe	RTi	Patient Representative		Apologies
Radwa Bedair	RB	Consultant cardiologist	University Hospitals Bristol	Present
Rowan Kerr-Liddell	RKL	Paediatrician with Expertise in Cardiology	Torbay Hospital	Present



Name	Inits.	Job Title	Organisation	Present/ Apols
Rosalie Davies	RD	General Manager of Paediatric Cardiac services, Neurosurgery and PICU	University Hospitals Bristol	Present
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals, Truro	Present
Sandeep Ashketar	SA	Consultant paediatrician	Royal Gwent Hospital, Newport	Apologies
Sarah Finch	SF	ACHD specialist nurse	University Hospital of Wales, Cardiff	Present
Shafi Mussa	SM	Consultant Surgeon	University Hospitals Bristol	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present
Soha Elbehery	SE	PEC / Consultant Paediatrician	Nevill Hall Hospital	Present
Stephanie Curtis	SC	Consultant cardiologist	University Hospitals Bristol	Apologies
Susie Gage	SG	Paediatric cardiology and surgical pharmacist	University Hospitals Bristol	Present
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team	Present
Zoe Trotman	ZT	Lead nurse, paediatric cardiology	University Hospitals Bristol	Present