

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

**Date:** Thursday 18<sup>th</sup> April 2024, 14.00 – 16.30  
**Venue:** Microsoft Teams Conference Call  
**Chair:** Dr Radwa Bedair, ACHD Consultant Cardiologist

### Minutes

Item	Notes and Actions
<b>1.</b>	<b>Welcome, introductions and apologies</b>
	<p>RB introduced herself as the new Board Chairperson and welcomed the attendees to the Network’s virtual Board, providing a reminder on the digital meeting etiquette.</p> <p>The Board welcomed those joining for their first time: Aisal Khan, ACHD Fellow at Cardiff, and Grace Warren, Fetal Medicine Network Manager (attending to observe).</p> <p>Acknowledgement and thanks were given to Jess Hughes, CHD Network Lead Nurse, who is leaving her role at the end of April 2024 to train as an advanced care practitioner.</p>
<b>2.</b>	<b>Approval of minutes and action tracker</b>
	<p>The minutes of the Network Board on 23<sup>rd</sup> January 2024 were agreed to be an accurate record.</p> <p>The action log was updated as appended.</p> <p><b>195 – Clinical Reference Group (CRG) Allied Health Professional (AHP) workforce</b>            SG noted that she is the main AHP representative on the CRG and is doing ongoing work to look at involving AHPs in the workstreams and the CHD standards. Closed.</p> <p>No further actions to report on.</p>
<b>3.</b>	<b>Patient Story</b>
	<p>The Board listened to Dan’s pre-recorded presentation (23-year-old). Dan was first diagnosed with a dilated cardiomyopathy caused by anomalous left coronary from the pulmonary artery (ALCAPA), with successful corrective open-heart surgery in 2001.</p> <p>Dan had an active and positive experience throughout childhood, however, as a teenager ongoing health issue culminated in a negative impact on mental health which he tried to resolve through counselling. He described how he felt apprehensive about the transition to adult care and had a negative experience of this, together with chasing appointments and results (including MRI scan), exacerbated by Covid-19.</p> <p>A further diagnosis of a dilated aortic root, led to corrective surgery via personalised external aortic support (PEARS) procedure – the initial operation was cancelled due to an external specialist surgeon being unavailable, causing significant strain on Dan’s well-being, however this was undertaken successfully in Bristol in 2023. Dan described his inpatient experience and delivery of care during this admission to be extremely impressive and praised the surgeons for saving his life.</p>

	<p>Dan also praised the in-patient care at the BHI, the clinical nurse specialist teams, the psychology team, and Xander, ACHD youth worker.</p> <p>For feedback to the Board, Dan raised that effective communication between patient and staff is fundamental, as the lack of communication leads to a lack of trust in the service. The actions or outcomes from meetings (including internal) must be clearly communicated to the patient, and that early engagement with the patient to showcase support groups, charities and sources of information that could be utilised is extremely important.</p> <p><u>Key points discussed following the presentation:</u></p> <p>The Board thanked Dan for sharing his moving and articulate presentation of his journey, and that it was so helpful to hear his experience. The Board picked up on Dan’s reflections, noting the importance of communication, referring to psychology, nurse resource, transition, and youth worker support earlier in the process.</p>
<p><b>4.</b></p>	<p><b>National and regional updates</b></p>
	<p><u>National update</u></p> <p><b>NHS England CHD Clinical Reference Group</b></p> <p>Susie Gage (SG) presented an update as a clinical member (allied health professional link) of the CRG and paediatric cardiac pharmacist at the Bristol Royal Hospital for Children. The CRG is a national NHS England lead and inform group that was re-established in 2023.</p> <p>There are several workstream project groups leading on for example, patient flow and capacity, CHD national alliance, CHD workforce, fetal service levelling up, health inequalities in CHD and integrations. Other topics recently discussed at the CRG are coding CHD anomalies and defects, national approaches to research (Nigel Drury) and integration of ICC. Unfortunately, the CHD transformational proposal bid to the NHS England national team was not approved.</p> <p><u>Commissioner updates</u></p> <p><b>Joint Commissioning Committee (formerly known as Welsh Health Specialised Services Committee, WHSSC), South Wales</b> – presented by KM.</p> <p>WHSSC has recently joined with the Emergency Ambulance Services Committee (EASC) and the National Collaborative Commissioning Unit (NCCU) to form the new Joint Commissioning Committee (JCC).</p> <p><b>Key updates including:</b></p> <p><b>Adult CHD</b></p> <ul style="list-style-type: none"> <li>○ Implementation of investment phase 3 continues to progress. The third consultant post is now out to advert.</li> <li>○ Recently discussed the impact of phase 1-3 investment with Phil Meredith (Aneurin Bevan Health Board) and will be undertaking investigatory work intended to ascertain how the outcomes relates to health board delivery.</li> </ul> <p><b>Paediatric CHD</b></p> <ul style="list-style-type: none"> <li>○ Worked with the CHD Network to analyse the delayed transfers of care between Bristol and Cardiff. Several actions have been agreed and are being worked through.</li> <li>○ Continuing to work with BRHC on current waiting times for paediatric cardiac surgery.</li> </ul>

	<p><b>NHS England, Southwest</b> Presented by EW</p> <p><b>Key updates</b> including:</p> <ul style="list-style-type: none"> <li>○ ODN 24/25 workplans have been finalised.</li> <li>○ Women’s and Children’s Programme Board next meet in May.</li> <li>○ 8<sup>th</sup> February ICB/Network event – all South West Networks in attendance.</li> <li>○ NHSE 2024/25 priorities and operational planning guidance has been published. <a href="https://www.england.nhs.uk/operational-planning-and-contracting/">https://www.england.nhs.uk/operational-planning-and-contracting/</a></li> </ul>
<b>5.</b>	<b>Network Performance Dashboard</b>
	<p><u>Key headlines from Quarter 4 Network Performance Dashboard</u></p> <p>The Network Board has a role in monitoring performance of centres within the Network and addressing areas of concern. The Board is asked to review the performance reports included in the papers and agree any actions required to address issues. MJ presented an update.</p> <p><u>Response rate</u></p> <p>The response rate from centres is positive with 100% for all paediatric and ACHD centres returns for level 1 and level 2. For ACHD level 3, the return rate was 63% for the South West (same as Q3) and 86% for South Wales (dip from 100% in Q3). For paediatric level 3, the return rate was 78% for the South West (same as Q3) and 43% for South Wales (slight dip compared to Q3 at 57%). Thank you to centres who submitted these. There remain a couple of ACHD level 3 centres who have routinely not provided the information required, and the self-assessment reviews may help to further explore any barriers.</p> <p><u>Did Not Attend (DNA)</u></p> <p>Limited DNA rate returns across the Network continue for quarter 4 (Q4). Cardiff adults have jumped to a rate of 14% in Q4, and Gloucester’s progress through the year has been impacted with a rate of 6% following 6 months at 0%.</p> <p>Hywel Dda Glangwili DNA rate has reduced for the visiting consultant for the first time this year now at 12%, rather than more than 20% seen consistently previously. The high rates seen in Aneurin Bevan paediatric local consultant clinics in Q2 (12%) have reduced to 1%.</p> <p><u>Data consistency</u></p> <p>The ‘blip’ in the Network data dashboard noted in Q3 has now been resolved and the inclusion of 0-2 month activity in follow up backlog figures removed.</p> <p><u>Waiting time for new patients and overdue follow up backlog.</u></p> <p>Please refer to the performance report for further details.</p> <p>For adults, the new outpatient waits have stayed consistent in most centres that submitted data, although less returns this quarter for this measure. The Exeter ACHD local consultant waits continue to increase, which is of concern. The Exeter team have advised that the very longest waits are directly linked to patient availability.</p> <p>In paediatrics, Bristol continue to reduce their new waits and Cardiff new waits have nearly halved Q1 to Q4. Hywel Dda Glangwilli very high visiting consultant waits continue.</p> <p><u>Inpatient report – year to date waiting list trends for Level 1 (Bristol)</u></p> <p>For surgical, ACHD shows a significant reduction since Q3, and this follows the trend from 2022/23.</p>

	<p>Adults at highest length patient wait for the year despite significant improvement in numbers on list (related to a specific complex patient / issue with patient availability / booking).</p> <p>For paediatrics, the surgical waiting list shows an increase towards volumes seen at the beginning of 2023/24, following the trend of an increase seen between Q3 and Q4 in 2022/23.</p> <p>For interventional, in adults, the waiting list reduced in Q4 (following a climb in Q1 to Q3) and continues a downward trend. For paediatrics, the interventional waiting list increased, appearing as an outlier nationally, however the team are investigating this, and it is likely linked to EP patients, and so are checking with the other level 1 centres how this is being calculated/recorded elsewhere.</p>
<b>6.</b>	<b>Update from Level 3 centre(s)</b>
	<p>The key updates are outlined in the exception report in the papers.</p> <p>SV and HW updated that:</p> <p><b>Adult CHD:</b></p> <p><b>Key updates:</b> Included in the papers.</p> <p><b>Key risks/concerns:</b></p> <ul style="list-style-type: none"> <li>○ In South Wales, Cym Tag Morgannwg raised difficulties in obtaining outpatients space to run additional clinics. HW and MJ plan to meet with the Health Board. HW noted that Swansea data submission was inaccurate and is being reviewed again locally.</li> <li>○ In South West, Gloucestershire increasing waiting times reflect the need to expand the provision of joint clinics, however this is dependent on several factors including funding, staff resource and clinic room availability.</li> <li>○ Taunton – no consultant identified to work alongside the visiting consultant, and local consultant is running a list concurrently. The Board recognised that having level 3 ACHD Consultant roles (like in Truro) would be advantageous with the increasing peripheral service demand.</li> <li>○ Torbay – DNA rate was low due to phoning patients prior to appointments, however with recent operational management support issues, this has not been possible.</li> </ul> <p><b>Paediatric CHD</b></p> <p>AP and SP presented the key themes to note for paediatric level 3 centres:</p> <p><b>Key updates:</b> Included in the papers.</p> <ul style="list-style-type: none"> <li>○ For the southwest, Barnstaple noted that previously reported governance risks regarding coding of paediatric clinics have now been addressed locally. In Exeter, digital storage is slowly moving forward with clinician testing of workflows due to take place soon.</li> <li>○ For South Wales, AP updated that there are long waits for the visiting specialists that are affecting through flow. Mitigating actions regarding clinic templates are being looked into. An uplift in clinics was offered in the phase 2 business case when the sixth consultant was appointed, but this does not seem to have reduced the waiting list, and clinics are being offered in Carmarthen, to compromise the travel journey between visiting clinicians and West Wales patients.</li> </ul> <p><b>Risks/concerns to be escalated:</b></p> <ul style="list-style-type: none"> <li>○ Main risk in capacity of Level 1 visiting consultant led clinics – peripheral need to increase</li> </ul>

	<p>tertiary input with more patients per clinic. Discussions are ongoing, however level 1 capacity is limited.</p> <p><b>Actions/support required from the Network:</b></p> <ul style="list-style-type: none"> <li>○ Raised whether nirsevimab has been authorised by NHS England and whether other units are using single vaccine for cardiac patients.</li> </ul>
<b>7.</b>	<b>Update from Level 2 centre</b>
	<p>HW 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><b><u>Level 2 adult CHD service:</u></b></p> <p><b>Key updates:</b></p> <ul style="list-style-type: none"> <li>○ ACHD Fellow commenced in March 2024. Third ACHD consultant recruitment ongoing.</li> <li>○ CNS secondment advertised to cover maternity leave.</li> <li>○ Additional Singleton clinic ran face-to-face in February 2024 – from May, HW will be supported by alternating local cardiologists so the capacity will double.</li> <li>○ Ongoing discussions with Bristol team re: JCC process and waiting times.</li> </ul> <p><b>Risks/concerns:</b></p> <ul style="list-style-type: none"> <li>○ JCC waiting time from listing to discussion is currently around 5 months (target 6 weeks).</li> <li>○ Short term issues with CNS staffing due to training commitments and maternity leave.</li> <li>○ Issues recruiting into open psychology post (no applicants on two rounds of advertisements), putting increasing pressure on the clinical psychologist to cover the service alone.</li> </ul> <p><b>Actions/support required from Network:</b></p> <ul style="list-style-type: none"> <li>○ Continued support in conversation with Bristol for improving JCC process and waiting times.</li> </ul> <p><b><u>Level 2 paediatric CHD service:</u></b></p> <p>AP presented an update for the Level 2 centre:</p> <ul style="list-style-type: none"> <li>● <b>Key updates:</b> <ul style="list-style-type: none"> <li>○ DW has partially retired from 11PA to 1PA. Appointed two substantive consultants (one started in April and the other hopefully in July). Another locum will be required to cover planned leave.</li> <li>○ CNS retirement and plan for secondment to cover hours. Transition CNS has recently left.</li> <li>○ Some recent junior (and consultant) level industrial action – some clinic cancellations but as normal as possible service delivery.</li> <li>○ Validation exercise undertaken on follow up not booked (FUNB) lists, which is impacting capacity.</li> <li>○ Paediatric physiologist post to be advertised soon.</li> </ul> </li> <li>● <b>Risks/concerns:</b> <ul style="list-style-type: none"> <li>○ Increasing incidence of communication issues with Bristol re: patient information. SC</li> </ul> </li> </ul>

	<p>noted that the Network are keen for level 1 paediatric consultant engagement with the T&amp;F group on this. The identified ACHD communication issues have been resolved.</p> <ul style="list-style-type: none"> <li>• <b>Actions/support required from the Network:</b> None noted.</li> </ul>
8.	Update from Level 1 centre
	<p>The key updates are outlined in the exception report in the papers.</p> <p><b><u>Level 1 adult CHD service</u></b></p> <p>CM presented the key updates for the level 1 ACHD centre:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> ACHD cath lab time has increased and so it should reflect in reducing waiting times this year.</li> <li>• <b>Risks/concerns to be escalated:</b> <ul style="list-style-type: none"> <li>○ Still short 1.4WTE ACHD CNS, against the standards and peer review.</li> <li>○ Do not have a dedicated ‘MDT and interventional/surgical pathway co-ordinator’ which was also recommended in the standards, and benchmarks negatively against other centres currently. Currently lobbying for funding.</li> </ul> </li> <li>• <b>Actions/support required from the Network:</b> <ul style="list-style-type: none"> <li>○ Help in pressurising funding bodies to achieve above risks.</li> </ul> </li> </ul> <p><b><u>Level 1 paediatric CHD service</u></b></p> <p>ER shared the key updates to note:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> <ul style="list-style-type: none"> <li>○ Reduction in waits for cardiac MRI due to increased capacity and mutual aid from Bristol Heart Institute for 16+ year olds.</li> <li>○ Growing numbers on surgical waiting list. Reduction in those awaiting discussion at Joint Cardiac Conference.</li> </ul> </li> <li>• <b>Risks/concern:</b> <ul style="list-style-type: none"> <li>○ Ongoing impact from industrial action taken by the British Medical Association</li> <li>○ Paediatric CNS team are facing challenges with vacancies which will affect the service.</li> </ul> </li> <li>• <b>Actions/supports required from Network:</b> Support and update already provided on the delays in transfers project - following the successful data gathered and centre engagement.</li> </ul> <p><b><u>Congenital cardiac surgery update</u></b></p> <p>On the behalf of the cardiac surgeons, SC presented a quick update on the paediatric surgery weekly dashboard outlining the number of P1 to P4 cases awaiting surgery. The monthly surgical waiting list over the last year shows how winter pressures increase the waiting list, and this usually reduces over the summer.</p> <p>For the ACHD service, 18 patients are awaiting surgery with 9 dated. Key issue at present is funding a designated ACHD surgical pathway co-ordinator to support this process together with the CNS team.</p>

<b>9.</b>	<b>Patient representatives update</b>																								
	<p>NM reported that on the behalf of patient/families, how cancellations/waiting lists are impacting families and raised the importance of communicating realistic (not optimistic) expectations of timelines. SC noted that the Network have received a couple of escalated incidents recently regarding surgical cancellations and resources for staff.</p> <p>HJ fed back about the lack of clarity of antibiotic prescribing/dental care issues. SC noted that this was discussed at the morning Network clinical governance meeting and teams are looking into an alert.</p> <p>The Somerville Heart Foundation conference is being held in Bristol on 11<sup>th</sup> May 2024; the Cardiff and Bristol book clubs have been successful with the 'healing hearts and minds' book being a springboard for discussions.</p> <p>RAB updated on the national patient engagement event in Leicester in March with representatives from around the country. A key focus was on collaborative working, supporting patient reps with training and resources. This was discussed at our local patient rep group meeting and next steps from the event are awaited.</p> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved.</i></p>																								
<b>10.</b>	<b>Network Update 2024/25</b>																								
	<p><u>Network updated report (Quarter 4 2023/24)</u> Please refer to the papers for further detail on the quarter 4 update (Jan-March 2024). In addition to some of the key highlight achievements, of particular note is that the plan for the South West self-assessment reviews have progressed for delivery in May-July 2024.</p> <p><u>Update on current key measurable 2023/24 workplan projects.</u></p> <p><b>1. Communication of patient information across Network project (led by SC) – This has progressed for adults but need paediatric representatives to help progress for paediatrics.</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td colspan="2" style="background-color: #0070C0; color: white;"><b>Project Title: Communication of Patient Information across Network</b></td> <td style="background-color: #0070C0; color: white; text-align: right;"><b>Insert Date:</b> 17/04/2024</td> </tr> <tr> <td colspan="2" style="background-color: #D9E1F2;">Project Manager: Steph Curtis</td> <td style="background-color: #D9E1F2;">Project Reports to: CHD Network Board</td> </tr> <tr> <td style="background-color: #0070C0; color: white;"><b>Project Aim</b></td> <td colspan="2" style="background-color: #D9E1F2;">To identify gaps in safe flow of patient information from L1 to L2 and L3 centres. 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## 2. Flow of inpatients between paediatric centres (previously known as delay of transfers between paediatric centres) – Cardiff and Bristol.

<b>Project Title: Flow of inpatients between paediatric centres</b>		<b>Insert Date:</b> 10.04.2024
Project Manager: Michelle Jarvis		Project Reports to: T&F Group and CHD Network Board
<b>Project Aim</b>	To audit delayed transfers. To support centres to investigate the barriers to the seamless delivery of care. To identify mitigating actions to reduce delayed transfers.	
<b>Key outcome</b>	To reduce delayed transfers of care between paediatric centres across the Network (main issue is between L1 and L2)	
<b>Recent Progress</b>		
<ul style="list-style-type: none"> <li>Ongoing audit (March 23 to date) revealed the majority of delays are from Bristol to Cardiff, due to lack of beds in Cardiff (with specialty beds being used for general medical patients)</li> <li>Next stage Task &amp; Finish group meeting held in March 24 with leads from level 2 centre, WHSSC and core network team</li> <li>SOP developed by level 2 centre to describe new process of escalation between flow leads at both centres to facilitate transfers from Dolphin (Bristol) to Pelican (Cardiff) including pre-emptive ring fencing of beds when a transfer is due</li> <li>Validation of retrospective audit confirmed 40% medical patient occupation of specialist beds in Pelican ward (Cardiff)</li> <li>Anecdotal feedback from level 1 centre that the new escalation process and focus on reducing transfer delays by the team at Cardiff is having a positive impact</li> <li>Meadow ward (daycase unit at Bristol) leads confirmed simple cardiac patients can be accommodated on the ward to support capacity on Dolphin ward (Bristol) / pressure on PICU and work is being done to increase loop recorder patients and consider ajmaline trial patients on the unit</li> </ul>		
<b>Aims for Next Quarter</b>		
<ul style="list-style-type: none"> <li>WHSSC to confirm commissioning position on the actual specialist bed capacity on Pelican ward</li> <li>Task and finish group will meet again in May to review the findings of the ongoing audit and understand impacts of the newly developed escalation process</li> </ul>		
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>		
<ul style="list-style-type: none"> <li>Lack of control over access to specialist beds remains a challenge</li> <li>Delay in transfer audit continues; both to understand delays and whether escalation process is having an effect</li> </ul>		


ZT updated that due to the Dolphin (cardiac) Ward limited footprint, the team are looking at other ways to enable flow. Being able to accommodate simple cardiac patients on Meadow Ward will help with this.

## 3. Transfer of care (TOC) between paediatric and adult CHD services (led by SC)

<b>Project Title: Transfer of Care between paediatric and adult services</b>		<b>Insert Date:</b> 17/04/2024				
Project Manager: Steph Curtis		Project Reports to: T&F group and CHD Network Board				
<b>Project Aim</b>	To identify patients lost to follow up between paed and adult care. To investigate the causes of this, explore implementation of new TOC system, and ensure adequate TOC. Ultimately improving safety and reducing unnecessary medical follow-up.					
<b>Key outcome:</b>	To reduce the risk/and hopefully end the loss of patients between services. To improve info transferred and patient/staff experience.					
<b>Recent Progress</b>		<table border="1"> <tr> <td><b>Project RAG</b></td> </tr> <tr> <td>Progress against plan</td> </tr> <tr> <td>Risks and issues</td> </tr> <tr> <td>Benefit Realisation</td> </tr> </table>	<b>Project RAG</b>	Progress against plan	Risks and issues	Benefit Realisation
<b>Project RAG</b>						
Progress against plan						
Risks and issues						
Benefit Realisation						
<ul style="list-style-type: none"> <li>Task and Finish Group met June, July, September and January</li> <li>TOC designed and presented to L1 paed cardiologists. Issues with new digital noting system. Plan to incorporate.</li> <li>Audit of lost to FU patient 2017-18. 114 px, 54% delayed (median 7m [3.2m to 48m!]), spread across sites, 6% lost (50% Glos) shorter delay for complex (18% v 51% for mod and 49% for simple), <b>presented at NW Board 17.4.24</b>. Larger Welsh audit ongoing.</li> <li>Guideline "Simple Lesions to Discharge" complete, approved at NW CG group, disseminated and published on NW website</li> <li>Transition leaflet (who to transfer to) done, with patient input</li> <li>Pathway scoped in each centre; <b>ideal model being explored with paed cardiologists and nurses</b></li> </ul>						
<b>Aims for Next Quarter</b>						
<ul style="list-style-type: none"> <li>Finalise leaflet for each centre (full list of L3 adults teams now available) – discussion re NW/trust docs</li> <li>how to do ToC form in L3 centres tbd</li> <li>Finish and report Welsh audit</li> <li>To start using TOC document in L1 (meeting with IT to improve) and explore roll-out to L3 centres – progressing in Taunton</li> </ul>						
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>						
<ul style="list-style-type: none"> <li>Diversity of IT systems unable to emulate TOC document in L3 centres, will need input from L3 teams to explore options in L3 centres</li> <li>No L1 paed cardiologist involved until January (locum who is leaving)</li> <li>Local pathway and doc <b>to be discussed after audit and discussion</b></li> </ul>						



**4. Transition pilot project (led by JH) – aim to deliver transition consultations to young people aged 12-16 in three participating centres (Taunton, Torbay, and Gloucester).**

Project Title: Transition pilot project Update Date: 18-04-2024							
Project Manager: Jess Hughes		Project Reports to: CHD Network Board					
<b>Project Aim</b>	To support delivery of patient transition from the age of 12 across the Network in line with NICE guidelines & NHSE service spec guidelines.						
<b>Key outcome</b>	All young people aged 12-16 to receive dedicated transition support at each outpatient attendance with CNS presence						
<b>Recent Progress</b>			<b>Aims for Next Quarter</b>				
<ul style="list-style-type: none"> <li>Ad-hoc transition in place in Truro</li> <li>Transition nurse in Exeter now embedded</li> <li>Barnstaple link nurse starting 'low level' transition clinics</li> <li>Successful Torbay clinic held on 19<sup>th</sup> October</li> <li>Third Taunton clinic held</li> </ul>			<ul style="list-style-type: none"> <li>Potential change of approach to continue to progress aim- discuss with team</li> <li>Support link nurses and local CNS' delivering transition</li> <li>Continue to check in with Gloucester re: link nurse and offer support, self-assessment process to aid this</li> <li>Explore Welsh care plan and potential to adopt with permission</li> <li><b>Use self-assessment visits to drive change</b></li> </ul>				
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>							
<ul style="list-style-type: none"> <li>Lead nurse time limitations</li> <li>CNS resource to support clinic</li> <li>Recruitment of link nurses</li> </ul>							
<b>Delivery RAG</b>	<b>Performance Metric</b>	<b>Baseline (Q4 22/23)</b>	<b>Q4 23/24</b>	<b>Q1 24/25</b>	<b>Q2 24/25</b>	<b>Q3 24/25</b>	<b>Q4 24/25</b>
	1. Number of South West centres with dedicated transition clinics	1/9	3/9				
	2. Number of South West centres working towards and offering some element of transition delivery	1/6	5/9				
	3. Number of South West centres with capability of delivering some transition clinics	1/9	5/9				
	4. Number of paediatric link nurses in SW centres to support delivery of transition clinics	1/9	5/9				
	5. Number (0/5) of paediatric link nurses attending transition study day out of total network link nurses	0/5	5/5				
(Guest)	6. Number of centres (0/9) joining network developed governance SOP to guide, support and manage transition of CHD patients	0/9	3/9				

LP noted that while the Bristol paediatric CNS team are depleted, they are available to provide remote support and resources as needed. This is very much valued by nurses across South West.



**5. Image transfer across the Network, particularly Echo transfer between Wales and England (led by SC)**

It was reported today that the Aneurin Bevan has now been resolved and the Bath Royal United Hospital's new system goes live on 8<sup>th</sup> May 2024.

<b>Project Title: Image Transfer Across Network, particularly Echo Transfer between Wales and England</b>		<b>Insert Date: 18/04/2024</b>					
Project Manager: Steph Curtis/Helen Wallis		Project Reports to: CHD Network Board					
<b>Project Aim</b>	To allow smooth transfer of all patient images throughout the Network						
<b>Key outcome</b>	All centres able to transfer/view images to/in the L1 centre from L2/3 centres						
<b>Recent Progress</b>							
<ul style="list-style-type: none"> <li>Mapping all centres for paed and adult done</li> <li>Breakthrough with new portal to Swansea (firewall crossed), up and running, all users have accounts (Dec to July)</li> <li>Progressing in Aneurin Bevan (James Stevens) and Stephen Morris supporting Hywel Dda (Catrin Williams and Nerys James) and Cwm Taf (Matthew Jones) – links established, accounts almost finished (delay with SM sickness)</li> <li>Progress on Exeter paed storage issue – <b>images will be permanently stored on PACS and worklists created</b> – Justin Thuraisingham leading</li> <li><b>Bath new system to go live 8 May so all images can be transferred</b></li> <li>Cardiff IEP working</li> </ul>							
<b>Aims for Next Quarter</b>							
Resume direct access project once cyber issues sorted							
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>							
<ul style="list-style-type: none"> <li>Different HBs/trusts using different systems</li> <li>Paed/adult issues separate systems/requirements</li> <li><b>Cyber hack stalled Welsh progress!</b></li> </ul>							

## 6. Ante-natal detection rate improvement (new project).

Together with key stakeholders, and collaboration with Grace Warren, Fetal ODN Manager, a new project has been scoped with work tasks including developing a SOP to guide best practice in level 3 centres, and a SOP to guide reporting of missed antenatal diagnosis. The Network clinical governance group discussed on 18<sup>th</sup> April the medico-legal issues related to this.

Project Title: Ante-natal detection rate improvement Update Date: 18-04-2024						
Project Manager: Jess Hughes and Grace Warren		Project Reports to: CHD Network Board and Fetal medicine network board				
<b>Project Aim</b>	<b>To improve overall cardiac antenatal detection rate</b>					
<b>Key outcome</b>	Improved education, pathways in place to report missed diagnoses and to support fetal cardiac sonography in L3 centres					
<b>Recent Progress</b>			<b>Aims for Next Quarter</b>			
<ul style="list-style-type: none"> <li>Project scoping with the fetal medicine network</li> <li>Engaging stakeholders- physiology leads, fetal sonographers, clinical leads</li> <li>Key areas of work agreed- see aims for next quarter</li> </ul>			<ul style="list-style-type: none"> <li>SOP to guide best practice</li> <li>Support high quality sonographer education</li> <li>SOP to guide reporting of missed antenatal diagnosis</li> <li>Develop guidance for <b>cardiac champions</b> in fetal medicine units</li> </ul>			
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>						
<ul style="list-style-type: none"> <li>Reduced team resource and time limitations -to consider, use of moving echo with colour, for implementation alongside SOPs</li> <li>Data lags behind by 3 years-</li> <li>Welsh involvement- to scope</li> </ul>						
<b>Delivery RAG</b>	<b>Performance Metric</b>	<b>Baseline (Q4 23/24)</b>	<b>Q1 24/25</b>	<b>Q2 24/25</b>	<b>Q3 24/25</b>	<b>Q4 24/25</b>
	1. Number of South West centres with fetal cardiac champions	0/11				
	2. Number of South West centres attending virtual teaching sessions	0/11				
	3. Number of South West centres following best practice guidance for scanning the fetal heart	0/11				
	4. Number of South West centres reporting 'missed diagnoses' from antenatal scans	0/11				

Those interested in joining any of these task and finish group are invited to contact the core Network team. The Board thanked the team and stakeholders for the progress on these projects.

Another project that is progressing is reviewing and recommending ways to improve the efficiency of the JCC. A survey on the ACHD JCC is currently open for feedback.

### **Network 2024/25 plan**

The [Network 24/25 plan on a page](#) which describes the priority areas of focus and workstreams for the current year was shared. The plan was designed in collaboration and signed off by Network stakeholders at the Board meeting in January 2024. All Network members are encouraged to get in touch with the core Network team if they would like to discuss the plan further or be involved in any workstreams.

## 11. Update on obstetric cardiology service

SC presented an update on the obstetric cardiology service in Bristol. 97% of patients with CHD are surviving to adulthood. New referrals to the service since it was established in 1998, have grown significantly. Over recent years, the referrals are levelling off as patients are now being triaged via virtual appointments, reducing the referrals to the all-day twice a month clinic in Bristol.

However, the patients in clinic are becoming more complex, partly due to more acquired heart conditions, as well as congenital. In this clinic most patients have CHD, however, the number of ICC patients has almost doubled in the last decade showing a changing pattern. In 2022, the South West Maternal Medicine Network (hosted by North Bristol NHS Trust) was officially formed, enabling some pregnant patients with more simple heart conditions to be referred elsewhere if appropriate.

	<p>Pregnancy does put pressure on the heart, particularly around birth, causing some patients to be particularly high risk (the ESC guidelines list the high risks). Pre-pregnancy counselling is a key part of the pathway, however around 43% of patients receive this. Involving senior clinicians from the multidisciplinary team as part of the pathway and delivery is also important.</p> <p>The Board thanked SC for the update on this excellent service.</p>
<b>12.</b>	<b>Issues Log</b>
	<p>SV reminded the Board that the Network no longer owns risks, however, does have a responsibility to keep an issues log with high priority issues reported from centres. The Network Lead Nurse and Manager have completed a review of the current Network issues log with a view to ensure consistency in the process for adding items to the log and the link to the Network workplan.</p> <p>The criteria for these are:</p> <ul style="list-style-type: none"> <li>- Issues the Network have been made aware of.</li> <li>- Issues leading to a further risk for patients and/or workforce.</li> <li>- Issues leading to non-compliance of national CHD standards which may result in poorer outcomes for patients.</li> </ul> <p>Key issues listed (many of which were mentioned during the Board meeting as items being worked on) include lack of investment, some centres not having the recommended staffing establishment, funding for link nurses, medical workforce succession planning, delayed transfers of care, patients and families not being communicated with effectively regarding the process and outcome of the paediatric joint cardiac committee (JCC) meetings, patients and families raising concerns with patient/parent representatives and families regarding surgical cancellations and the impact of re-attending pre-admission clinics.</p>
<b>13.</b>	<b>Any Other Business</b>
	<ul style="list-style-type: none"> <li>• DM highlighted a good news story regarding the pilot project on upskilling physiologists/sonographers in the region's level 3 centres – one of these sonographers has recently completed their accreditation in CHD, so there are now around 50% of centres across the south west with an accredited sonographer/physiologist provision for CHD.</li> <li>• <u>Board membership</u> – Need to ensure members send a nominated deputy if unable to attend.</li> <li>• <u>Feedback form</u> - Board members were invited to complete the meeting feedback form via the Microsoft Forms link circulated. Feedback has shown that the majority preference is for the Board meetings to continue to be held virtually.</li> <li>• <u>Next Board Meeting</u>, Wednesday 7<sup>th</sup> August 2024, 14:00 – 16:30 (virtual) - Board members were asked to inform the Network team of any agenda items for the next Network Board meeting.</li> </ul>

### Attendees

Name		Job Title	Organisation	18/04/24
Aisal Khan	AK	ACHD Fellow	Cardiff, University Hospital of Wales	Present
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Present
Andy Tometzki	AT	BRHC Clinical Director / Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present

Name		Job Title	Organisation	18/04/24
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Becky Lambert	BL	ACHD Nurse	Taunton, Musgrove Park Hospital	Present
Becky Nash	BN	Patient Representative		Present
Cat McElvaney	CM	Deputy Divisional Director (Adults)	Bristol, University Hospitals Bristol & Weston	Present
Dan	DS	Patient Representative		Present
Daniel Meiring	DM	Fetal & Paediatric Cardiac Physiology Service Manager	Bristol, University Hospitals Bristol & Weston	Present
Ed Roberts	ER	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Emma Whitton	EW	Commissioner	NHS England South West	Present
Frances Cantin	FC	ACHD Specialist Nurse	Plymouth, Derriford Hospital	Present
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Present
Grace Warren	GW	South West Fetal Network Manager		Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Holly Jones	HJ	Patient Representative		Present
Jennifer Shortland	JS	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present
Justin Thuraisingham	JT	Consultant Paediatrician with Expertise in Cardiology (newly appointed)	Exeter, Royal Devon University Hospital	Present
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Present
Kimberley Meringolo	KM	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Present
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Nicola Morris	NM	Patient Representative		Present
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Present
Rachel Burrows	RAB	CHD Network Support Manager (note-taker)	CHD Network Team	Present
Rachel Wyatt	RW	ACHD Clinical Nurse Specialist	Bristol, University Hospitals Bristol & Weston	Present
Radwa Bedair	RB	ACHD Consultant Cardiologist	Bristol, University Hospital Bristol and Weston	Present
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospitals	Present
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present
Stephanie Curtis	SC	Network Clinical Director /	CHD Network Team / Bristol,	Present

Name		Job Title	Organisation	18/04/24
		Consultant cardiologist	University Hospitals Bristol & Weston	
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol University Hospitals Bristol & Weston	Present
Tim Murphy	TM	Consultant Anaesthetist (Paediatrics)	Bristol, University Hospitals Bristol & Weston	Present
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	Bristol, University Hospitals Bristol & Weston	Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Apologies
Adam Duffen	AD	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Adrian Wagstaff	AW	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Amanda Davies	AD	Patient Representative		Apologies
Andre Clinchant	AC	Lead Nurse	Taunton, Musgrove Park Hospital	Apologies
Andrew Parry	AP	Consultant Cardiac Surgeon	Bristol, University Hospitals Bristol & Weston	Apologies
Andy Arend	AA	Consultant paediatrician	Barnstaple, North Devon District Hospital	Apologies
Ankita Jain	AJ	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Anthony Goodwin	AG	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Anthony Pearce	AP	Commissioner	NHS England	Apologies
Beth Greenway	BG	Patient Representative		Apologies
Bill McCrea	BMc	Consultant – ACHD	Swindon, Great Western Hospital	Apologies
Carys Williams	CW	Cardiac Physiologist	Swansea Bay	Apologies
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Apologies
Catherine Blakemore	CB	Consultant Cardiologist with interest in CHD	Torquay, Torbay District General Hospital	Apologies
Claire Logan	CL	Paediatric clinical nurse specialist	Cardiff, University Hospital of Wales	Apologies
David Lindsey	DL	Consultant Cardiologist with interest in ACHD	Gloucestershire Hospitals	Apologies
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Apologies
Debasis Biswas	DB	Consultant	Hywel Dda	Apologies
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Apologies
Dushen Tharmaratnam	DT	Consultant ACHD	Barnstaple, North Devon District Hospital	Apologies
Emma Hulbert Powell	EHP	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
Faumy Hassan	FH	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Apologies
Frankie Carlin	FC	Patient Representative		Apologies
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Gareth Strange	GS	Patient Representative		Apologies

Name		Job Title	Organisation	18/04/24
Georgina Ooues	GO	Consultant Cardiologist ACHD	Truro, Royal Cornwall Hospital	Apologies
Geraint Morris	GM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Gergely Szantho	GS	Consultant cardiologist	Bristol, University Hospitals Bristol & Weston	Apologies
Gui Rego	GR	Senior Echocardiographer (ACHD)	Bristol, University Hospitals Bristol & Weston	Apologies
Helen Fardy	HF	Medical Director	Welsh Health Specialised Services Committee	Apologies
Helen Liversedge	HL	Consultant Fetal	Exeter, Royal Devon University Hospital	Apologies
Idoia Grange	IG	Consultant Paediatrician Cardiologist	Bristol	Apologies
Jennifer Holman	JH	Consultant Paediatrician	Gloucestershire, Gloucester Hospital	Apologies
Joanne Jones	JJ	Paediatric and Fetal Cardiac Sonographer	Bristol, University Hospitals Bristol & Weston	Apologies
John Madar	JM	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
Karen Sheehan	KSh	Paediatric Cardiac Research Sister	Bristol, University Hospitals Bristol & Weston	Apologies
Karikalan Kandasamy	KK	Consultant ACHD	Truro, Royal Cornwall Hospital	Apologies
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Apologies
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Apologies
Louise Challis	LC	Link Nurse	Torquay, Torbay District General Hospital	Apologies
Luisa Wilms	LW	Consultant Paediatrician with interest in cardiology	Taunton, Musgrove Park Hospital	Apologies
Maha Mansour	MM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Manish Gandhi	MG	Consultant cardiologist - ACHD	Exeter, Royal Devon University Hospital	Apologies
Marcia Scheller	MSC	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Marion Schmidt	MS	Consultant Paediatrician	Newport, Royal Gwent Hospital	Apologies
Matthew Beake	MB	Consultant Paediatrician with Expertise in Cardiology	Gloucestershire Hospitals	Apologies
Max Nathan	MN	Consultant Paediatrician with Expertise in Cardiology	Bridgend, Princess of Wales	Apologies
Muhammad Addin	MA	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	Apologies
Nagendra Venkata	NV	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Apologies
Nicola Johnson	NJ	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Orhan Uzan	OU	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	Bristol, University Hospitals Bristol & Weston	Apologies
Poonamallee Govindaraj	PG	Consultant Paediatrician	Cwm Taf Morgannwg, Royal Glamorgan	Apologies

Name		Job Title	Organisation	18/04/24
Pradesh Mappa	PM	Consultant Paediatrician	Swindon, Great Western Hospital	Apologies
PremKumar Pitchaikani	PP	Consultant	Hywel Dda	Apologies
Rainer Fortner	RF	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Richard Palmer	RP	Senior Planner Commissioner	Welsh Health Specialised Services Committee	Apologies
Rowan Kerr-Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torquay, Torbay District General Hospital	Apologies
Sandeep Ashketar	SA	Consultant paediatrician	Aneurin Bevan, Royal Gwent Hospital	Apologies
Shafi Mussa	SM	Consultant Surgeon	Bristol, University Hospitals Bristol & Weston	Apologies
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda, Glangwilli Hospital	Apologies
Simon Dunn	SD	Operational Service Manager	Torquay, Torbay District General Hospital	Apologies
Simon Macdonald	SM	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Soha Elbehery	SE	Consultant Paediatrician with Expertise in Cardiology	Aneurin Bevan, Nevill Hall Hospital	Apologies
Sree Nittur	SN	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Tatiana Rjabova	TR	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	Apologies
Vanessa Garratt	VG	Consultant Clinical Psychologist	Bristol, University Hospitals Bristol & Weston	Apologies
Vishwa Narayan	VN	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Apologies
Yusf Museji	YM	Consultant – ACHD	Glangwilli	Apologies