

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

**Date:** Tuesday 23<sup>rd</sup> January 2024, 14.00 – 16.30  
**Venue:** Microsoft Teams Conference Call  
**Chair:** Dr Dirk Wilson

### Minutes

Item	Notes and Actions
<b>1.</b>	<b>Welcome, introductions and apologies</b>
	<p>DGW welcomed the attendees to the Network’s virtual Board, providing a reminder on the digital meeting etiquette. The Board welcomed those joining for their first time:</p> <ul style="list-style-type: none"> <li>- Martin Gargan, BRHC Clinical Chair and Consultant Orthopaedic Surgeon (observing);</li> <li>- Dr Jennifer Shortland, Consultant Paediatric Cardiologist;</li> <li>- Alison Conchie, Yorkshire and Humber CHD Network Manager (presenting).</li> </ul> <p>A welcome was also given to Michelle Jarvis, who officially joined as South Wales and South West CHD Network Manager in late November.</p> <p><u>Board Chair</u></p> <p>DGW reminded the Board that this is his last time Chairing as he is taking partial retirement from February 2024. Thanks were given to DGW for the support and commitment he has given to the CHD Network, and for the expertise and experience he has brought.</p> <p>Following interviews for a successor, congratulations were given to Dr Radwa Bedair, ACHD Consultant at the Bristol Heart Institute, for her successful appointment to the position.</p>
<b>2.</b>	<b>Approval of minutes and action tracker</b>
	<p>The minutes of the Network Board on 12<sup>th</sup> October 2023 were agreed to be an accurate record.</p> <p>The action log was updated as appended.</p> <p><b><u>191, 192, 193, &amp; 194</u></b> – closed.</p> <p>No further actions to report on.</p>
<b>3.</b>	<b>Patient Story</b>
	<p>The Board listened to Rebecca’s pre-recorded presentation, as a 38-year-old born in Wales. At a young age, Rebecca was diagnosed with an aortic aneurysm and aortic stenosis. She had her aortic valve replaced in 1992 (aged 6).</p> <p>Rebecca conveyed that CHD had little impact on her childhood, however she did note that being admitted as a young person to an adult ward was a very daunting and unsettling experience, and that she sometimes felt different as she was unable to take part in the same activities as other children.</p> <p>Rebecca went onto describe her adult experience and the challenges of pregnancy with a CHD</p>

	<p>condition. The importance of having a specialist team and the joy of a successful pregnancy in 2013.</p> <p>Surgery to replace the valve was cancelled in 2014 which had a significant impact on Rebecca’s mental health. ACHD psychology support was later provided, however she expressed how feelings of uncertainty remain as the surgery is yet to happen.</p> <p>Rebecca shared that the invitation to be involved with the ‘Down to Earth’ group project in 2022 was life changing, providing a sense of belonging and safety with the support of others with CHD and a cardiac nurse present. This led to a peer support group and joining the ‘healing hearts and minds’ book club.</p> <p>For feedback to the Board, Rebecca praised the care she has received on her journey so far, and how grateful she is to the entire team at University Hospital Wales. How valuable it has been to have the opportunity to meet people in similar situations who understand on a deeper level. Rebecca acknowledged how living with CHD can have a huge impact on an individual’s mental health and how important it is to be mindful that living with CHD is difficult and complex. She highlighted how something seemingly insignificant such as rearranging an appointment or intervention can have huge implications for the patient.</p> <p><u>Key points discussed following the presentation:</u> The Board were grateful to Rebecca for sharing her powerful story. The Board picked up on Rebecca’s reflections on being a teenager (education is valuable to help patients understand what they can and are advised not to do), the mental impact of diagnosis and having (or not having) appointments, and the effects of aging on heart health. DGW also highlighted that following the CHD standards in 2016, the addition of psychologists in the team in recent years has had a huge positive benefit for patients.</p>
<p><b>4.</b></p>	<p><b>National and regional updates</b></p>
	<p><u>National update</u></p> <p>MJ provided a brief national snapshot:</p> <ul style="list-style-type: none"> <li>• <b>British Congenital Cardiac Association (BCCA)</b> – a huge well done to Dr Tim Murphy and all involved with this successful event hosted in Bristol in November 2023.</li> <li>• <b>National CHD network of Networks</b> – This annual face-to-face meeting was also hosted in Bristol in November 2023, with CHD Network representatives from around the country. Alison Conchie, Network Manager for Yorkshire and Humber and representative on the NHSE CHD Clinical Reference Group, provided a summary of the key areas of focus going forward:             <ol style="list-style-type: none"> <li>1. <u>Workforce</u> (identifying gaps and potential gaps in level 1, 2 and 3 centres).                 <p>All the networks have contributed to a benchmarking exercise against the CHD service standards. The identified gaps are ACHD cardiologists, specialist nurses, and surgeons. A PEC survey closed in December and the results are being collated. The results of a British Heart Foundation survey on the cardiology workforce is expected in March 2024. The next steps are to understand the gaps, developing training and education, and new roles.</p> </li> <li>2. <u>Data</u> – It has been identified that there is a lack of accessible data to support service</li> </ol> </li> </ul>

development. The North West CHD Network have developed a primary care data base which identifies all patients with CHD and will help with lost to follow up – the next steps are to roll out this tool across England. The group are also looking at expanding a SPaedIT tool for CHD to help with demand and capacity. Moreover, currently the waiting list data is manually collected monthly and there are plans to automate this. The next steps are to explore the data sources that would populate a CHD data platform.

3. Patient pathways and flow – there is variation in patient pathways and examples of good practice. The next steps are organising a clinical forum for the CHD Networks and Clinical Reference Group.

SM supported the acknowledgment that national training programmes need developing especially for surgeons. Mentorship is also important in the first years in post.

Commissioner updates

**Welsh Health Specialised Services Committee (WHSSC), South Wales** – presented by RP.

**Key updates including:**

**Adult CHD**

- Implementation of Phase 3 investment continuing to progress – consultant post due to be advertised imminently. Recruited to the Radiography posts – due to start in Feb/March 2024.
- Cardiff have advised of service pressures at level 1 centre (Bristol) and have corresponded with the CHD Network.

**Paediatric CHD**

- Cardiac surgery concerns have deescalated given improvements in reporting and length of time patients waiting.
- WHSSC, CHD Network and Cardiff meeting on 31<sup>st</sup> January to discuss delayed flow in care.

**NHS England, Southwest**

Presented by CK

**Key updates including:**

- Network 24/25 Workplans – Networks have submitted workplans for review – these are to focus on measurable outcomes, so the benefits are clear. Final workplans will be reviewed at the Women’s and Children’s Programme Board on 20<sup>th</sup> February.
- Peripheral clinic SLA – with Bristol to progress. Being reviewed as part of workplan priorities.
- Integrated Care Board (ICB) and Network Event, 8<sup>th</sup> February – to share work of networks with ICB senior leaders.

**5. Network Performance Dashboard**

Key headlines from Quarter 3 Network Performance Dashboard

The Network Board has a role in monitoring performance of centres within the Network and

	<p>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.</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, and South Wales ACHD, and a similar rate to usual for level 3 otherwise. 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 we work with centres to explore any barriers.</p> <p><u>Did Not Attend (DNA)</u></p> <p>Gloucester have reduced their rates across visiting and local consultants for paediatrics and maintained their 0% DNA rate for adults. The increase noted in Cardiff last quarter has reduced although still relatively high at 10%.</p> <p><u>Data consistency</u></p> <p>Moving forward, the report will not be using 0-2 month in the follow up backlog figures.</p> <p><u>Waiting time for new patients and overdue follow up backlog.</u></p> <p>Please refer to the performance report. HW questioned the Witybush ACHD waiting times; HW to clarify this with the Witybush team.</p> <p><u>Inpatient report – year to date waiting list trends for Level 1 (Bristol)</u></p> <p>For surgical (patients listed and awaiting procedure), an increase in the waiting lists for both paediatrics and adults for quarter 3 was noted. Significant improvement has been made in longest waiting patient for paediatrics from 93 weeks in quarter 2 down to 57 weeks this quarter with surgical RTT performance at 75%. Longest wait has remained static for adults through this reporting year and is lower than this time last year (53 weeks). Adult RTT performance for surgery sits at 21% this quarter.</p> <p>For interventional, the paediatric waiting list number remains static between Q2 and Q3 at 147 patients however is higher than this time last year (117). There has however been a jump in longest wait from 67 weeks in Q2 to 79 weeks this quarter. Paediatric RTT performance for interventional is at 25% of the 92% standard.</p> <p>The longest wait for adults continues its downward trend and is much lower than this time last year (79 weeks) however there has been growth in the numbers on the waiting list between Q2 and Q3 and we may see the impact of that on the length of waits in the next reporting period. Adult interventional RTT rate for this quarter sits at 67% of the 92% standard target.</p>
6.	<p><b>Update from Level 3 centre(s)</b></p> <p>The key updates are outlined in the exception report in the papers.</p> <p><b>Adult CHD:</b></p> <p>Key themes to note for adults included:</p> <p><b>Key updates:</b> Included in the papers. Of particular note:</p> <ul style="list-style-type: none"> <li>○ Exeter need resource to include an ACHD consultant.</li> <li>○ Taunton are running two young people clinics each year and started running nurse-led clinics.</li> <li>○ Prince Charles Hospital outlier is being looked into by DGW.</li> <li>○ Singleton clinics – will be supported by local cardiologist from April 2024 onwards,</li> </ul>

	<p>doubling the patients being seen.</p> <p><b>Key risks/concerns:</b></p> <ul style="list-style-type: none"> <li>○ Exeter – retirement of 1 of the 2 ACHD consultants – awaiting resource to recruit.</li> <li>○ Gloucester – Local Consultant seeing more ‘simple ACHD’ patients directly.</li> <li>○ Taunton – Mark Dayer (local ACHD consultant) left the Trust in January.</li> </ul> <p><b>Actions/support required from the network:</b></p> <ul style="list-style-type: none"> <li>○ Taunton – support for specialist nurse business plan</li> </ul> <p><b>Paediatric CHD</b> NO led an update for southwest – the key themes to note for paediatric level 3 centres included:</p> <p><b>Key updates:</b> Included in the papers.</p> <ul style="list-style-type: none"> <li>○ For the southwest, Barnstaple have issues with echo workstations. Capacity continues to be an issue in PEC and visiting consultant clinics, with some progress. One of the Gloucester PECs is retiring.</li> </ul> <p><b>Risks/concerns to be escalated:</b> None noted this quarter.</p> <p><b>Actions/support required from the Network:</b> None noted this quarter.</p>
7.	<p><b>Update from Level 2 centre</b></p>
	<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>Level 2 adult CHD service:</b></p> <p><b>Key updates:</b></p> <ul style="list-style-type: none"> <li>○ New physiologist led simple lesion clinics implemented. New aortopathy clinic implemented to try and reduce caseload on ACHD clinic. Successful recruitment of ACHD Fellow and additional ACHD secretary. Additional 3<sup>rd</sup> consultant post planning ongoing. Ongoing discussions with BHI team regarding improvements to JCC process and communications, which has improved dramatically over the last 6 months. South Wales patient information/engagement day (Bridgend) being held 27<sup>th</sup> January 2024.</li> <li>○ JCC tracker developed and shared with the Network.</li> </ul> <p>The Board commended the achievements of the Cardiff team.</p> <p><b>Risks/concerns:</b></p> <ul style="list-style-type: none"> <li>○ Long waiting times for JCC and treatment in Bristol (communications regarding this has improved significantly over the last 6 months).</li> <li>○ Increasing pressures on the University Hospital Wales ACHD clinic because of long waiting times elsewhere have resulted in reduced clinic flexibility and marked difficulties in offering patients timely appointments.</li> </ul> <p><b>Actions/support required from network:</b> Ongoing work regarding communication with the Bristol team (already showing great improvement) and tracking of JCC pathway from start to finish.</p> <p><b>Level 2 paediatric CHD service:</b> DGW presented an update for the Level 2 centre:</p>

	<ul style="list-style-type: none"> <li>• <b>Key updates:</b> DGW partial retirement in February 2024 (will retain one session) – appointments process in place for replacement. Third sonographer still not provided despite funding.</li> <li>• <b>Risks/concerns:</b> Long waiting lists – outpatient department and surgical remain a concern. WHSCC escalation processes in place regarding the surgical waits.</li> <li>• <b>Actions/support required from the Network:</b> None noted.</li> </ul>
<b>8.</b>	<b>Update from Level 1 centre</b>
	<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>SC presented the key updates for the level 1 ACHD centre:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> Permanent fifth ACHD consultant in post and new BHI Deputy Divisional Director (Cat McElvaney) starting in February 2024.</li> <li>• <b>Risks/concerns to be escalated:</b> The intervention waiting list is still long and meetings are being held to address this. CNS support is limited as understaffed.</li> <li>• <b>Actions/support required from the Network:</b> Support with the concerns raised.</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> Weekend waiting list activity for cardiac surgery has commenced. Zero patients are now waiting over 52 weeks for first outpatient appointment following significant waiting list initiative activity. Increased capacity in Cath lab intervention following the return of Wednesday afternoon list.</li> <li>• <b>Risks/concern:</b> Ongoing impact of industrial action by both the British Medical Association and the Society of Radiographers. Theatre anaesthetic ODP staffing issues creating increased waiting list in electro-physiology.</li> <li>• <b>Actions/supports required from Network:</b> None noted.</li> </ul> <p><b><u>Congenital cardiac surgery update</u></b></p> <p>SM reported that the positive news is ACHD surgery is in a reasonable position. Access remains good and there is improvement in overall CICU beds at the Bristol Heart Institute (BHI). The issues at the BHI are more to do with emergency surgery and how this affects the operating schedule the next day – this is being looked into. There are some ongoing issues with JCC due to the lack of administrative support due to long term sickness – this was discussed at CHD Network M&amp;M (23/01/2024) and SC is raising this with senior management. SC urged that BHI ideally need a co-ordinator to monitor the waiting list to prevent patients coming to harm, like the BRHC and Cardiff have – this was supported by the Board.</p> <p>The paediatric waiting list remains a concern and is high on the BRHC risk register. To help mitigate this weekend waiting lists have commenced but this does depend on other factors such as staffing and bed availability. Theatre staffing (ODP) continues to be a challenge, but the PICU capacity has been less of an issue.</p>

	<p>Communication has improved between Wales and Bristol regarding the surgical waiting list – there is now a weekly waiting list update during the performance meeting (JCC) and the Welsh waiting list is being sent to Alan Pateman (Paediatric Clinical Lead in Cardiff) on a weekly basis to flag specific patients of concern. The Cardiff team thanked the surgeons for this new correspondence.</p> <p>The Board thanked SM and team for their hard work on this ongoing challenge.</p>
<b>9.</b>	<b>Patient representatives update</b>
	<p>On the behalf of the patient representative team, GS reported that there are several face-to-face engagement events coming up. The Somerville Heart Foundation ‘Living well with CHD’ annual national conference is being held in Bristol on 11<sup>th</sup> May 2024; the Gloucester patient family listening event is being held on 25<sup>th</sup> January 2024 (showing joined up working between level 1 and level 3 centres); and a patient engagement day on 27<sup>th</sup> January in Bridgend being run by the Cardiff ACHD Clinical Nurse Specialists. It was expressed that these events are valuable for networking and building connections, as well as being a communications opportunity.</p> <p>The Book Club is going exceptionally well in Cardiff and is being rolled out in Bristol. Both are based on the ‘healing hearts and minds’ book, which acts as a helpful springboard for discussions.</p> <p>NM had a positive experience presenting at the national British Congenital Cardiac Association conference in November 2023. Sadly, the patient reps had a negative experience being involved with the national champions project, reiterating the importance of being aware of subject matter that can cause triggers.</p> <p>NM is on the National CHD Clinical Reference Group (CRG) and described this as an ‘engaged and well represented group.’ The next meeting is in March 2024.</p> <p>The Board thanked GS for the clear delivery of the updates. 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 2023/24</b>
	<p><u>Network updated report (Quarter 3)</u> Please refer to the papers for further detail: quarter 3 update (Oct-Dec 2023); and the work plan 2023/24.</p> <p>In addition to some of the key highlight achievements covered in the project updates, the ACHD ECHO 2024 series prepared for in quarter 3, has now commenced with the first webinar held last week with excellent attendance and feedback.</p> <p><u>Update on current key measurable 2023/24 workplan projects.</u></p> <p><b>1. Transfer of care (TOC) between paediatric and adult CHD services (led by SC)</b></p> <p>CA updated that a new JCC form has been created by UHBW IM&amp;T, which will allow both presentation and a report that can be sent to peripheral hospitals if requested – this went live on Monday 22<sup>nd</sup> January 2024. It is hoped that this will improve JCC flow and letters. CA was invited to join the task and finish group.</p>

<b>Project Title: Transfer of Care between paediatric and adult services</b>		<b>Insert Date:</b> 18/01/2024				
<b>Project Manager:</b> Steph Curtis		Project Reports to: T&F group and CHD Network Board				
<b>Project Aim</b>	To identify patients lost to follow up between <u>paed</u> 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>Project RAG</td></tr> <tr><td>Progress against plan</td></tr> <tr><td>Risks and issues</td></tr> <tr><td>Benefit Realisation</td></tr> </table>	Project RAG	Progress against plan	Risks and issues	Benefit Realisation
Project RAG						
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<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 <u>paed</u> cardiologists. Issues with new digital noting system. Plan to incorporate.</li> <li>Audit of lost to FU patient 2017-18. 114 <u>px</u>, 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), full analysis at CG meeting Oct. 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</li> </ul>						
<b>Aims for Next Quarter</b>						
<ul style="list-style-type: none"> <li>Finalise leaflet for each centre (full list of L3 <u>adults</u> teams now available) – discussion re NW/trust docs</li> <li>how to do <u>TOC</u> form in L3 centres <u>tbd</u></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 <u>paed</u> cardiologist involved until January (locum who is leaving)</li> <li>Ideal pathway and docs <u>tbd</u></li> </ul>						

## 2. Flow of inpatients between paediatric centres (previously known as delay of transfers between paediatric centres) – Cardiff and Bristol.

Jennifer Shortland shared that it would be appropriate for loop recorder patients to recover on a general day case ward (rather than Dolphin ward) if this would help flow. ZT is meeting with cardiac co-ordinator to move this forward. MFG showed his support for this too.

<b>Project Title: Flow of inpatients between paediatric centres</b>		<b>Insert Date:</b> 18.1.2024
<b>Project Manager:</b> 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>Audit (March to date) has revealed <u>the majority of</u> delays are from Bristol to Cardiff, due to lack of beds in Cardiff (specialty beds being used for general medical patients). Results shared with WHSSC, who can also access audit form returns in real time.</li> <li>Meeting between L2 <u>paed</u> cardiology lead, WHSSC and medical directorate but no solution</li> <li>New process of escalation to on-call clinician on day 2 of delay, unclear if this has had an effect</li> </ul>		
<b>Aims for Next Quarter</b>		
<ul style="list-style-type: none"> <li>Meeting due between L2 <u>paeds</u>, WHSSC and Network to explore solutions – ring-fenced beds?</li> <li>Explore other causes - ?training of parents to facilitate d/c etc ?training of L2 nurses to care for complex patients</li> <li>Use of L1 <u>daycase</u> to free up beds on Dolphin ward to reduce pressure on CICU</li> </ul>		
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>		
<ul style="list-style-type: none"> <li>No submissions since September – why?</li> <li>Lack of control over medical beds</li> </ul>		



**3. 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>Project Title: Communication of Patient Information across Network</b>		<b>Insert Date:</b> 18/01/2024
<b>Project Manager:</b> Steph Curtis	<b>Project Reports to:</b> CHD Network Board	
<b>Project Aim</b>	To identify gaps in safe flow of patient information from L1 to L2 and L3 centres. To improve communication of patient events between L1 and L2 and L3 centres.	
<b>Key outcome:</b>	Safe and satisfactory communication of patient information, as measured by questionnaire.	
<b>Recent Progress</b>		
<ul style="list-style-type: none"> <li>All JCC outcomes go to common email address and then onto WCP for L2, L3 consultant secretaries for L3</li> <li>Secretary training and master email list – all ACHD letters to have L2/L3 centres cc'd and Welsh to Welsh email for WCP</li> <li>CNSs now inform local teams about IP medical and surgical discharges and send d/c summaries, working well</li> <li>Informal feedback that changes have been noticed and appreciated –ACHD issues effectively closed</li> <li>Last meeting attended by L1 <u>paed</u> consultant and co-ordinator</li> <li>Sec training in L1 <u>paed</u> centre and letters and JCC summaries will now be copied to L2 and L3 centres</li> </ul>		
<b>Aims for Next Quarter</b>		
<ul style="list-style-type: none"> <li>Further meetings to be <u>paeds</u> only; aim to tackle in similar way – still need solution for <u>paed</u> d/c summaries</li> <li>Reaudit once changes made (likely Q 1 or 2 2024)</li> <li>Comms around patients awaiting surgery Intervention to be tackled in forthcoming JCC Pathway T&amp;F group</li> </ul>		
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>		
<ul style="list-style-type: none"> <li>Unable to introduce fully automated systems as planned due to new IT system in L1 (will have to rely on staff training and culture)</li> <li>Lack of L1 <u>paed</u> cardiology engagement pre-2024</li> <li>JCC coordinator in L1 ACHD on long term sick leave – no replacement – pathway coordinator desired (managers acting down)</li> <li>Staff using combination of new system and <u>Heartsuite</u> – new system not as functional for <u>paed</u></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).**

<b>Project Title: Transition pilot project</b>		<b>Insert Date:</b> 23/01/2024				
<b>Project Manager:</b> Jess Hughes	<b>Project Reports to:</b> CHD Network Board					
<b>Project Aim</b>	To deliver transition consultations to young people ages 12-16 across the <u>South West</u>					
<b>Key outcome</b>	All young people aged 12-16 to attend dedicated transition clinics at each outpatient attendance with CNS presence					
<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
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<ul style="list-style-type: none"> <li>Successful Torbay clinic held on 19<sup>th</sup> October</li> <li>Second Taunton clinic held</li> <li>Transition Network SOP approved</li> <li>fourth transition study day achieved</li> </ul>						
<b>Aims for Next Quarter</b>						
<ul style="list-style-type: none"> <li>Potential change of approach to continue to progress aim- discuss with team</li> <li>Continue to check in with Gloucester re: link nurse and offer support, self-assessment process to aid this</li> <li>Focus group with Young people to gain feedback post clinic experience</li> <li>Explore Welsh care plan and potential to adopt with permission</li> </ul>						
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>						
<ul style="list-style-type: none"> <li>Lead nurse time limitations</li> <li>Education for link nurses</li> <li>CNS resource to support clinic</li> <li>Recruitment of link nurses</li> </ul>						

**5. Image transfer across the Network, particularly Echo transfer between Wales and England** (led by SC) – the key outcome is for all centres to be able to transfer/view images to/in the Level 1 centre from Level 2/3 centres.

<b>Project Title: Image Transfer Across Network, particularly Echo Transfer between Wales and England</b>		<b>Insert Date:</b> 18/01/2024
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>		
Mapping all centres for <a href="#">paed</a> and adult done Breakthrough with new portal to Swansea (firewall crossed), up and running, all users have accounts (Dec to July) Progressing in Aneurin Bevan (James Stevens) and Stephen Morris supporting Hywel Dda ( <a href="#">Catrin Williams</a> and Nerys James) and Cwm Taf (Matthew Jones) – links established, accounts almost finished (delay with SM sickness) Progress on Exeter <a href="#">paed</a> storage issue		
<b>Aims for Next Quarter</b>		
Ensure all Welsh echoes have links to Bristol Bath have now decided to go with Philips - ?compatibility Usure what Cardiff plan is		
<b>Key Messages (Challenges, Risks, Awareness, Discussion)</b>		
Different HBs/trusts using different systems <a href="#">Paed</a> /adult issues separate systems/requirements Financial restraints if capital investment required		

Those interested in joining any of these task and finish group are invited to contact the core Network team.

**Refreshed Plan on a page for 2024/25**

There are no significant changes to the last version, but a more streamlined plan was included in the papers for Network comment/agreement. This aligns with the Network functions as set out by NHSE. MJ highlighted that there is an additional proposed project around the scoping of JCC.

The proposal is to run the Self-Assessment process in the South West in May/June 2024.

**11. Update on Psychology Services 2024**

Dr Anna McCulloch, Consultant Clinical Psychologist in the Welsh ACHD service and Co-Lead Psychologist within the Network, presented an update on the adult psychology services in Wales.

In summary, this commenced with a reminder that psychology in a health setting is thinking about peoples’ psychological needs and embedding these in every aspect of their care, and being aware that each person carries a unique history of experiences. AC then unpacked how early experiences affect how we develop and our life as adults, e.g., how people behave/respond to medical situations, triggers, and expectations of what they can achieve.

Having a ACHD condition can get in the way of the factors needed to help people thrive (e.g. the importance of feeling valued and feeling psychologically and physically safe). This in turn can make it harder for people to look after their health. Poor mental health increases the likelihood of having more severe disease.

	<p>The key message from the CHD National Standards, NICE guidelines for long term conditions and NHS Wales Integrated medium term plan 2023-2026, is that people living with CHD should be supported to thrive and have access to psychological support.</p> <p>The South Wales ACHD psychology service is based at University Hospital Wales, Cardiff, and covers five Health Boards across a wide geographical area. The current psychology provision is not enough with two days of consultant clinical psychology and an unfilled 2.5 day band 7 clinical psychologist. This service includes direct patient contact (1:1 appointments, outdoor wellbeing groups etc.), indirect working (supporting MDT staff to deliver psychologically informed care, reflective supervision, attend regular MDT and Network meetings etc.) and teaching, training and presentations.</p> <p>The South West ACHD psychology service is based at the Bristol Heart Institute, Bristol, and covers the South West of England, working in collaboration with South Wales. The current psychology provision is a full-time psychology post. Bristol run a similar service with 1:1s, supervisions, developing resources, Network events and patient support groups.</p> <p>Another key message is that the psychology service helps people process very difficult information. A patient fed back ‘without psychology, I would have taken months to process my health changes, instead, I worked through it in one session.’</p> <p>AM shared that the future plans and ideas for the psychology service involve physio-nursing-psychology collaboration (have put in a bid to the British Heart Foundation to develop this service), completing the ‘book club’ and social prescribing collaborations such as working with the Network with the aim of facilitating how can spread and scale the model for outdoor wellbeing groups, enabling people to have access to projects that may help them thrive.</p> <p>The key challenges for the psychology service are the current unfilled post, limited resource, wide geographical area, the waiting list, and funding for social prescribing models.</p> <p>GS highlighted the value of the Down to Earth project and the subsequent peer support groups in bringing people together. DW fed back that integration of psychology with the MDT is really valuable.</p>
<p><b>12.</b></p>	<p><b>Issues Log</b></p>
	<p>Operational Delivery Networks no longer own risks but have a role in oversight and supporting risk reduction via mitigating action. This new process aligns with the NHSE southwest risk framework for ODNs.</p>
<p><b>13.</b></p>	<p><b>Any Other Business</b></p>
	<ul style="list-style-type: none"> <li>• <u>Board Chair</u> – A huge thank you to Dirk for support with the Board and with the National CHD Network meeting.</li> <li>• <u>Research</u> – GB updated that Heart Festival (this has been postponed to enable school engagement) and the Research Forum is commencing soon.</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</li> </ul>

	<p>Board meetings to continue to be held virtually.</p> <ul style="list-style-type: none"> <li><u>Next Board Meeting</u>, Thursday 18<sup>th</sup> April 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>
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### Attendees

Name		Job Title	Organisation	22/01/24
Amanda Davies	AD	Patient Representative		Present
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Alison Conchie	AC	CHD Network Manager	Yorkshire and Humber CHD Network	Present
Becky Lambert	BL	ACHD Nurse	Taunton, Musgrove Park Hospital	Present
Becky Nash	BN	Patient Representative		Present
Beth Greenway	BG	Patient Representative		Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Present
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Debasis Biswas	DB	Consultant	Hywel Dda	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Present
Ed Roberts	ER	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Emma Whitton	EW	Commissioner	NHS England South West	Present
Frankie Carlin	FC	Patient Representative		Present
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present
Jennifer Shortland	JS	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Present
Martin Gargan	MG	Clinical Chair (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Rebecca	RW	Patient Representative		Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Nagendra Venkata	NV	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
Radwa Bedair	RB	ACHD Consultant Cardiologist	Bristol, University Hospital Bristol and Weston	Present
Richard Palmer	RP	Senior Planner Commissioner	Welsh Health Specialised Services Committee	Present
Rowan Kerr-Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torquay, Torbay District General Hospital	Present
Sandeep Ashketar	SA	Consultant paediatrician	Aneurin Bevan, Royal Gwent Hospital	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present

Name		Job Title	Organisation	22/01/24
Stephanie Curtis	SC	Network Clinical Director / Consultant cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	Bristol, University Hospitals Bristol & Weston	Present
Gareth Strange	GS	Patient Representative		Present
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Present
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Shafi Mussa	SM	Consultant Surgeon	Bristol, University Hospitals Bristol & Weston	Present
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Apologies
Andrew Parry	AP	Consultant Cardiac Surgeon	Bristol, University Hospitals Bristol & Weston	Apologies
Andy Tometzki	AT	BRHC Clinical Director / Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	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
Andre Clinchant	AC	Lead Nurse	Taunton, Musgrove Park Hospital	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
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	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
Daniel Meiring	DM	Fetal & Paediatric Cardiac Physiology Service Manager	Bristol, University Hospitals Bristol & Weston	Apologies
Danielle McPeake	DMP	Clinical Nurse Specialist ACHD	Bristol, University Hospitals Bristol & Weston	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
David Withers	DW	ACHD Link Nurse	Gloucester	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
Faamy Hassan	FH	Consultant Paediatrician with	Hywel Dda	Apologies

Name		Job Title	Organisation	22/01/24
		Expertise in Cardiology		
Frances Cantin	FC	ACHD Specialist Nurse	Plymouth, Derriford Hospital	Apologies
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
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
Holly Jones	HJ	Patient Representative		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
Justin Thuraisingham	JT	Consultant Paediatrician with Expertise in Cardiology (newly appointed)	Exeter	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
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Apologies
Kimberley Meringolo	KM	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Apologies
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	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
Martin Heatley	MH	Consultant		Apologies

Name		Job Title	Organisation	22/01/24
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
Nicola Johnson	NJ	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Nicola Morris	NM	Patient Representative		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
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
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospitals	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
Cat McElvaney	CM	Deputy Divisional Director (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Sree Nittur	SN	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol University Hospitals Bristol & Weston	Apologies
Tatiana Rjabova	TR	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	Apologies
Tim Murphy	TM	Consultant Anaesthetist (Paediatrics)	Bristol, University Hospitals Bristol & Weston	Apologies
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team	Apologies
Vishwa Narayan	VN	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Apologies
Yusf Museji	YM	Consultant – ACHD	Glangwilli	Apologies