

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

Date: Wednesday 6th August 2025, 14.00 – 16.30
Venue: Microsoft Teams Conference Call
Chair: Dr Radwa Bedair, ACHD Consultant Cardiologist

Minutes

Item	Notes and Actions
0.	Welcome, introductions and apologies
	<p>Dr Radwa Bedair (RB) welcomed the attendees to the Network's virtual Board, providing a reminder on the digital meeting etiquette.</p> <p>The Board welcomed attendees joining for the first time: Nick Davies, Service Manager for Hywel Dda Glangwilli.</p>
1.	Approval of minutes and action tracker
	<p>The minutes of the Network Board on 22nd May 2025 were agreed to be an accurate record.</p> <p><u>197 - Hywel Dda Glangwilli paediatric CHD high wait challenges</u> Meetings held 7th January and 1st May 2025. Local service team planning a meeting to share demand and capacity data with Amy Lewis from NWJCC to review against funding.</p> <p><u>204 – BHI DNA rates health equality project</u> On the agenda for November 2025 Board.</p> <p><u>209 – Allocation of paediatric consultant admin work in between peripheral clinics - SLA document</u> This is in progress. Meeting held with the legal teams to discuss the different models and the SLA as a whole. Complexities involved which the legal team are reviewing.</p> <p><u>211 – Commissioner view on Aneurin Bevan and Swansea Bay Health Boards ACHD provision limiting patient support due to financial provision, when in other areas Health Boards are providing the service</u> EK taken over from RP. Network will follow up an update.</p> <p>Closed actions:</p>
2.	Patient Story
	<p>The Board listened to Debbie's story, pre-recorded. Debbie is a 59-year-old diagnosed with transposition of the great arteries. She underwent an atrial septectomy at the age of 6 weeks in London, and various other heart procedures since. Debbie has been on the active heart transplant waiting list in Newcastle since January 2024 and received an ICD implant in October 2024. Debbie talked through her childhood and teenage experiences, as well as her pregnancy, and outpatient experiences. In more recent years, Debbie's local care has been in Swansea and Cardiff.</p> <p>Debbie praised the support of the South Wales psychology service and the support of Dr Dirk Wilson and Dr Helen Wallis. She outlined the challenges of applying for Personal Independence</p>

	<p>Payment (PIP).</p> <p>For feedback to the Board, Debbie shared how grateful she is for the good medical care and experience she has had. How having congenital heart disease can be isolating as it's a hidden condition, and how she enjoyed meeting other patients with CHD at the Somerville Heart Foundation conference in Bristol.</p> <p><u>Key points discussed following the presentation:</u></p> <p>The Board thanked Debbie for sharing her experience, which praised the excellent co-ordination of care between three centres, two of which are outside of our Network (Royal Brompton and Newcastle). Her story also highlighted the importance of the psychology service in South Wales.</p> <p>The Board discussed the challenges of claiming appropriate benefits (PIP in this case) for some patients and the difficulties of travelling to London for care.</p> <ul style="list-style-type: none"> • Action: SLC agreed to raise with the Somerville Heart Foundation and CRG re: challenges of claiming appropriate benefits for some patients with CHD.
Network performance dashboard and exceptions – key headlines from quarter 1	
3.	<p>Updates from Level 1 (Bristol)</p> <p>MJ presented a summary update on the performance and assurance data that is collected on a quarterly basis. MJ advised that to support meeting timings not all highlights from the quarterly returns will be covered in detail during this section of the agenda. The performance slides will be circulated post meeting for anyone interested in a more detailed review.</p> <p><u>Level 1 paediatric CHD service</u></p> <p><u>Surgical and interventional performance – year to date waiting list trends for Level 1 (Bristol)</u></p> <p>For BRHC, the surgical inpatient waiting list has further decreased. This is at the lowest number it has been in 3 years. The Board praised this positive progress.</p> <p>The average wait for surgery has increased to 15 weeks and is similar to the length of wait seen in quarter 3, but this is much lower than this time last year (26 weeks).</p> <p>The interventional average waiting list has significantly decreased. Improvements are related to additional lists and some weekend activity taking place. However, there can be significant variability on the list so this improvement may not be maintained. The average RTT wait shows a continued improved position with an average wait of 17 weeks for intervention, which is a good achievement.</p> <p><u>Outpatient performance for Level 1 paediatrics (Bristol)</u></p> <p>The new patient consultant appointment longest wait has reduced slightly.</p> <p>The follow up backlogs continue to steadily increase each quarter, and the WNB rate generally hovers between 4 to 7 %. This is currently 5%.</p> <p>Key updates:</p> <ul style="list-style-type: none"> - New appointment of Consultant Cardiologist - Dr Silvia Caroli. Start date August 2025.

- Improvement in interventional RTT performance.
- In the early stages of building a business case for substantive investment into the paediatric cardiology outpatient service

Risks/concern:

- Continued increase in overdue follow up backlog (CA flagged that around 50% are ICC)
- Risk of non-delivery of 52 week wait targets

Actions/support required from Network:

- Will reach out to the Network as would value input with the development of the business case for substantive investment into paediatric cardiology

Level 1 adult CHD service

Surgical and interventional performance - BHI

The gradual increase in the total inpatient surgical waiting list over the last 12 months has reversed and there are currently 29 patients on the waiting list.

The report shows a slight increase in average RTT wait for surgical this quarter, however this remains much lower than this time last year.

The interventional waiting list shows that despite an increase in patients waiting, the average waiting time for intervention continues to reduce, and has significantly reduced compared to this time last year (when it was 25 weeks). The Board praised this achievement.

Outpatient performance for Level 1 adults (Bristol)

The follow up backlog has levelled out with most patients waiting less than 6 months. The backlogs have halved since this time last year and are at levels last seen in June 2021.

DNA rate – CM to update the Board on health equalities DNA project work at the November meeting.

RB presented the key updates for the level 1 ACHD centre – in addition to the performance data already covered:

Key updates:

- The majority of patients overdue follow-up are in the <6-month bracket.
- Sustained improvement in average waiting times for surgery and intervention.
- Funding approved for admin support for CNS team, but withdrawal of first applicant, so re-advertising.
- Danielle McPeake (ACHD CNS) going on a 6-month sabbatical, advertising for 6-month secondment.
- Dr Victoria North returned from maternity leave and Dr Lisa Mcclenaghan completed a 14-month locum consultant post.
- Self -assessment completed July 2025.
- Return of Professor Caputo from sabbatical.

Risks/concerns to be escalated: None noted.

	<p>Actions/support required from the Network: None noted.</p> <p><u>Level 1 Surgical update</u></p> <p>SM updated the Board on a break down of the surgical waiting list for paediatrics and adults. BRHC surgical list shows steady progress and there are no particular concerns with performance/outcomes, however winter is coming. A new imaging cardiologist starts in August 2025 specialising in advanced echo.</p> <p>In BHI the CHD surgical waiting list is also showing steady progress with no particular concerns. There are four surgeons who are picking up extra operating slots when available. The BHI theatre suite refurbishment is taking place but there is a well organised plan and the ACHD lists remain intact.</p>
4.	<p>Updates from Level 2 (Cardiff)</p> <p><u>Level 2 paediatric CHD service:</u></p> <p><u>Performance update</u></p> <p>No return received this quarter to report on – this is related to workforce changes in the team with a changeover of the clinical lead and service manager.</p> <p><u>Level 2 adult CHD service:</u></p> <p>MJ outlined the adult Level 2 position noting that there has been a deterioration in the length of waits for new appointments but an improvement in the follow up backlog position, which has halved from this time last year with most patients waiting between 3-9 months.</p> <p>HW presented an update for the Level 2 centre.</p> <p>Key updates:</p> <ul style="list-style-type: none"> - x2 ACHD consultant appointments: Dr Elinor O'Neill in post and Dr Stephanie Connaire starts on 1st September 2025. - Paper accepted for Nursing Times on "walk, talk, think, feel: Walking reflective practice for ACHD nurses" - BHF Moving Hearts Group ongoing with positive psychological and physical outcomes. - Collaboration and networking with cardiac anaesthetists and anaesthetic colleagues from levels 1 and 2. <p>Risks/concerns:</p> <ul style="list-style-type: none"> - Clinical fellow post gone to advert. - Unfilled clinical psychologist post - recruitment difficulties with current hours and banding. - Still some issues acquiring up to date discharge information from surgical centre post-procedure (has improved, but ongoing work to be done). - Some issues with data collection re patient service user numbers. - Local consultant vacancy (Aneurin Bevan Healthboard) still ongoing

	<p>Actions/support required from Network: None noted.</p>
5.	<p>Updates from Level 3 centres (District General Hospitals)</p> <p><u>Paediatrics – South West</u></p> <p>An ‘at a glance’ chart was displayed to show the data and narrative returns for the Network. It was acknowledged that narrative may not be returned if a centre has no updates to share in quarter.</p> <p><u>Outpatient performance</u></p> <p>MJ highlighted that for the new patient consultant appointments, there has been a continued increase in new referrals for Exeter, exceeding the PEC clinic capacity with the local wait now at 13 weeks. Taunton have made excellent progress in reducing their new appointment waits and the visiting consultant has no waits.</p> <p>For the follow up backlog, Swindon have maintained a positive position in regard to their backlogs again this quarter. For Exeter, Gloucester and Torbay, the backlogs have risen since previous reported quarters.</p> <p>The key updates are outlined in the exception report in the papers.</p> <p>Key updates included:</p> <ul style="list-style-type: none"> - Key highlight - Exeter have had permanent storage of echo images on PACS streamlined since September 2024. - Key highlight - Plymouth have had funding agreed for a specialist children’s cardiac nurse. - Key highlight - Taunton exercise testing for >16 year olds has started; and for <16 year olds this is aiming to start in September 2025. <p>Risks/concerns & actions required from the Network:</p> <ul style="list-style-type: none"> - Exeter has an ongoing significant overdue visiting cardiologist clinic follow-up backlog. This is on the RDUH risk register; however, mitigations are limited within the financial constraints. CA noted that Exeter do have a high number of ICC and other complex patients on their list compared to other surrounding hospitals. - Gloucester overdue follow ups are still a concern - plan to clinically validate the list within next quarter to ensure clinical acuity of patients and safety. - Plymouth have long waits for new patients in visiting consultant clinic. <p>Actions/support required from Network:</p> <ul style="list-style-type: none"> - Exeter requested support for assistance in procuring additional visiting paediatric cardiology clinics. <p><u>Paediatrics – South Wales</u></p> <p>MJ flagged that data has not been submitted by Cwm Taf and Hywel Dda Glangwilli. Glangwilli is</p>

an area of high risk with the significant visiting consultant waits. A progress update is awaited on the agreed actions to mitigate the risk, and also the additional data required to share with the commissioners to match against historic funding arrangements.

Outpatient performance

MJ updated that for Hywel Dda Withybush local and visiting backlogs remain static and low, and the visiting consultant waits remain high. In Swansea Bay, the visiting consultant backlog has doubled since quarter 4 but remains lower than this time last year.

The key updates are outlined in the exception report in the papers.

Key updates/concerns: note noted.

Actions/support required from the Network: None noted.

Adult CHD – South West

The nil returns were for Swindon who have historically not submitted a return and this has been escalated following the self-assessment. A new service manager has started in post who is meeting with the Network as part of their induction.

Outpatient performance

MJ updated that the improvement noted in Exeter's local clinic backlog position last quarter has been maintained, however the previous reduction in Exeter's long wait for local new appointments has deteriorated.

Gloucester continues their progress in relation to all performance measures. Truro reports a similar position to the last return received in quarter 2 (2024/25). Taunton have reported a jump in the local follow up backlog which is now at 43 patients from < 13 across the past year.

Key updates:

- Key highlight – Truro's first scientist-led ACHD clinic has commenced, run by Gemma Wright, Cardiac Clinical Scientist and ACHD echocardiographer. Plus, an ACHD Clinical Fellow has been appointed, who will support service and outpatient clinics.
- Key highlight – Gloucester have seen an improved throughput of patients through the bimonthly ACHD clinic by ensuring a parallel clinic is run by Dr Lindsay alongside visiting consultant in the afternoon. Dr Lindsay is also seeing more ACHD patients in regular cardiology clinics.
- Key highlight – Gloucester CNS post has now been made substantive (0.2WTE) and continues to enthusiastically address the needs of the transition patients/clinics.

Key risks/concerns:

- Truro outpatient waiting times and struggle to obtain ACHD nurse post due to funding restraints.

Actions required from Network: None noted.

Adult CHD – South Wales

86% of centres provided a data return.

	<p><u>Outpatient performance</u></p> <p>MJ updated that Swansea Bay reported no patient on the new appointment waiting list for either local or visiting consultants, and no overdue backlogs for visiting clinics. Hywel Dda Glangwilli visiting backlog has been cleared. Hywel Dda Worthybush reported a 30 week wait for new local appointments.</p> <p>Key updates</p> <ul style="list-style-type: none"> - Royal Glamorgan noted that a substantive visiting ACHD cardiologist is now in post and will start in YCR clinic in August. - Swansea has no new patients on the waiting list. <p>Risks/concerns – none noted.</p>
6.	<p>Patient and family representative update</p> <p>The Board paused marking a moment of respect for some recent sad news on the loss of a patient, Calum Morris (19 years). Calum's mum Nicola is a valued member of the Network and our thoughts are with her and the family at this incredibly sad time.</p> <p>FC updated that the British Heart Foundation 'moving hearts' programme is coming to an end and that as a participant this was a very valuable exercise. The cardiac choir has been successful and is being continued. The book club based on 'healing hearts and minds' book as a springboard is also being re-started in the autumn.</p> <p>The Board thanked the patient representatives for their time and support.</p> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved</i>.</p>
7.	<p>Maturity matrix</p> <p>Board members were invited to undertake an interactive 'live' NHS England self-assessment of the Network as a whole to explore and understand the current level of maturity in how the Network is collectively working.</p> <p>There are eight core areas considered within the matrix: purpose and direction; governance and structure; leadership and facilitation; knowledge capture and reuse; integrity and vitality; learning and improvement; impact and value; sustainability and renewal.</p> <p>Menti-meter was used as a tool to score each area's level of maturity from 1 (lowest) to 5 (highest) and enabled the scoring to be done with anonymity. Comments could also be shared by stakeholders to understand the rationale for scoring and next steps the Network might need to do to further develop over the course of the next 12 months.</p>
8.	<p>Network Update 2025/26</p> <p><u>Network updated report</u></p> <p>SLC updated on some key highlight achievements from June 2025 to date. Of key note:</p> <ul style="list-style-type: none"> - Level 1 adult (Bristol) self-assessment review held (July), plans for findings and next steps review with the Divisional Directors Sep 25 - Progressing plans with Level 2 self-assessment reviews – Cardiff ACHD review planned for September. - Worked with stakeholders at Network Clinical Governance meeting to generate ideas for

Network wide audits for 2025/26

- **Visited Gloucester** adult & paediatric CHD services, met with leads to further discussion re: transition clinics, local nursing support and to revisit self-assessment findings.
- **Network annual report 2024/25** and **Network summer 2025 newsletter** published.
- **Network research forums** held.
- **Network training and education plan 2025/26** published.
- **Network psychology day** (June 2025) thanks to Dr Ness Garratt & Dr Anna McCulloch.
- **Network transition morning** (July 2025).
- **Paediatric Cardiology PEC forum** (July 2025) thanks to Dr Nigel Osborne.

Level 1 (Bristol) and Level 2 (Cardiff) CHD Network Strategy event

A collaborative working event between Bristol and Cardiff adult and paediatric CHD services is being held in September 2025 to consider the future strategy of CHD between these services. This will include problem solving of shared challenges to continue to develop CHD services.

Self-assessments against the National NHS England 2016 CHD standards

Level 1 paediatric review

MJ updated on the outcome of the Level 1 paediatric self-assessment review held in March 2025, with a findings and next steps session with the service and divisional leadership team held in April 2025.

There were many areas of excellence including consistently good outcomes on the surgical and interventional pathways; stable, dedicated and collaborative surgical workforce with plans to extend middle grade tier; development of nursing services including in ICC; pathway changes to improve patient experience and upskill teams; recent delivery of various innovative cath lab interventions; strong relationship and profile with the research and academic departments; consistently high Data Quality Index scores achieved for NICOR submissions; and being recognised as a highly specialist provider of national Barth service.

The key challenges identified cover five main areas: workforce; transition; delivery of pregnancy and contraception advice; fetal services; and outpatient capacity.

Level 1 adult review

The BHI ACHD self-assessment review was held with the local team in July 2025, with a draft outcome report produced and due to be shared with the service for review. The findings and next steps session is planned with the service and divisional leadership team in September 2025. The key findings will be shared at a future Board meeting.

Any actions/areas of Network support as an outcome of the level 1 reviews will be incorporated into the Network workplan. A feedback letter regarding the self-assessment process, highlighting any areas of risk will be sent to the UHBW Executive team.

Level 2 adult review

The Cardiff service team have been meeting weekly to complete their assessment and a review meeting with the service and Network team has been confirmed for Tuesday 16th September 2025.

Level 2 paediatric review

	The service team have started the assessment, and a confirmed date for the review meeting is awaited. Due to a change over of the clinical lead and service manager, this is likely to be delayed.
9.	Any Other Business
	<ul style="list-style-type: none"> - <u>Board membership</u> – Need to ensure members send a nominated deputy if unable to attend. - <u>Next Board Meeting</u>, Tuesday 25th November 2025, 14:00 – 16:30 (virtual) - Board members are asked to inform the Network team of any agenda items for the next Network Board meeting.

Attendees

Name		Job Title	Organisation	06-08-25
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	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
Beth Corris	BC	Support Manager	Cardiff, University Hospitals of Wales	Present
Frankie Carlin	FC	Patient Representative		Present
Georgina Ooues	GO	Consultant Cardiologist ACHD	Truro, Royal Cornwall Hospital	Present
Gui Rego	GR	Senior Echocardiographer (ACHD)	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Megan O'Brien	MOB	General Manager	Bristol, University Hospitals Bristol & Weston	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Nick Davies	ND	Service Manager	Hywel Dda	Present
Orhan Uzan	OU	Consultant Cardiologist	Cardiff, University Hospital of Wales	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
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present

Name		Job Title	Organisation	06-08-25
Shafi Mussa	SM	Consultant Surgeon	Bristol, University Hospitals Bristol & Weston	Present
Stelios Iacovides	SI	Consultant	Exeter, Royal Devon University Hospital	Present
Stephanie Curtis	SC	Network Clinical Director / Consultant Cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present