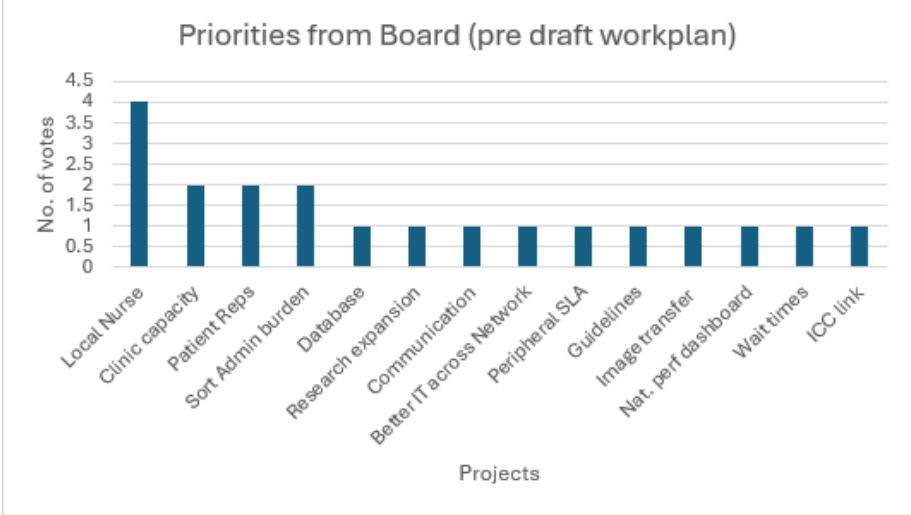


## South Wales and South West Congenital Heart Disease Network Network Board Meeting

**Date:** Thursday 13<sup>th</sup> February 2025, 14.00 – 16.30  
**Venue:** Microsoft Teams Conference Call  
**Chair:** Dr Helen Wallis, ACHD Consultant Cardiologist

### Minutes

Item	Notes and Actions
<b>1.</b>	<b>Welcome, introductions and apologies</b>
	<p>Dr Helen Wallis (HW) 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: Dr Nadia Hajiani, new Consultant Paediatric Clinical Lead in Cardiff; David Blundell, Locum Consultant Cardiff; and Beth Shirt, Director of Nursing at Bristol Royal Hospital for Children.</p>
<b>2.</b>	<b>Approval of minutes and action tracker</b>
	<p>The minutes of the Network Board on 26<sup>th</sup> November 2024 were agreed to be an accurate record.</p> <p><b><u>197 - Hywel Dda Glangwilli paediatric CHD high wait challenges</u></b>  A meeting supported by the Network and local team was held in January to discuss the situation, and a follow up meeting is being planned.</p> <p><b><u>208 – BRHC backlog data breakdown by specialty to provide more clarity</u></b>  ER and MJ have discussed. For new appointment waits we are now able to show the longest wait vs the mean wait, and for the outpatient backlog, we can now show the proportion of the backlog related to ICC. Action closed.</p> <p><b><u>209 – Allocation of paediatric consultant admin work in between peripheral clinics - SLA document</u></b>  This is a challenge to quantify and onerous for some. CA noted that some local centres ask for attendance at local MDTs which helps reduce email traffic – ER noted that Level 1 do ask for this to be formally job planned and paid for. Another challenge is duplication of work due to working across different IT systems, such as Epic and Evolve.  <ul style="list-style-type: none"> <li>○ Action: BRHC and Network to discuss in next tri-to-tri meeting.</li> </ul> </p> <p><b><u>210 – Escalation of Aneurin Bevan and Swansea Bay local ACHD provision concerns</u></b>  HW met with management contacts from Aneurin Bevan and Swansea Bay in early December 2024, and with the Network in January 2025. The Aneurin Bevan major follow up backlog issues are ongoing (2-4 years, rather than months), but the hope is that a local cardiologist will be appointed to support the clinic, dependent on job planning. The clinic will also be revalidated in case there are patients on the list who are being seen elsewhere.</p> <p>For Swansea Bay, the Singleton clinic currently has waits of 12-18 months beyond desired follow up, partly due to staff retirement/lack of succession planning and having only one ECHO machine. The good news is that a new ECHO machine is due to be installed by April.</p>

	<p><b><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></b></p> <p>RP is picking this query up and will report back when able.</p> <p><b>Closed actions: 208, 212</b></p>																														
3.	<p><b>Work plan 2025/26 – virtual ‘live’ poll via Mentimeter</b></p> <p><b>What do you think the top priorities need to be for the Network in 2025/26?</b></p>																														
	 <table border="1"> <caption>Priorities from Board (pre draft workplan)</caption> <thead> <tr> <th>Projects</th> <th>No. of votes</th> </tr> </thead> <tbody> <tr><td>Local Nurse</td><td>4</td></tr> <tr><td>Clinic capacity</td><td>2</td></tr> <tr><td>Patient Reps</td><td>2</td></tr> <tr><td>Sort Admin burden</td><td>2</td></tr> <tr><td>Database expansion</td><td>1</td></tr> <tr><td>Research expansion</td><td>1</td></tr> <tr><td>Communication</td><td>1</td></tr> <tr><td>Better IT across Network</td><td>1</td></tr> <tr><td>Peripheral SLA</td><td>1</td></tr> <tr><td>Guidelines</td><td>1</td></tr> <tr><td>Image transfer</td><td>1</td></tr> <tr><td>Nat. perf dashboard</td><td>1</td></tr> <tr><td>Wait times</td><td>1</td></tr> <tr><td>ICC link</td><td>1</td></tr> </tbody> </table>	Projects	No. of votes	Local Nurse	4	Clinic capacity	2	Patient Reps	2	Sort Admin burden	2	Database expansion	1	Research expansion	1	Communication	1	Better IT across Network	1	Peripheral SLA	1	Guidelines	1	Image transfer	1	Nat. perf dashboard	1	Wait times	1	ICC link	1
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4.	<p><b>Patient Story</b></p> <p>The Board listened to Jack’s story via a pre-recorded interview between his mum, Kareen, and nurse Becky Lambert, based in the Taunton clinic.</p> <p>Jack is a 24-year-old with Down’s Syndrome and Tetralogy of Fallot. He had two emergency BT shunts in 2001 and a total repair in 2024. It was difficult seeing Jack go through surgery. Kareen appreciated the brutal honesty of the Anaesthetist as this in turn saved Jack’s life.</p> <p>There was no transition process at this time, but Kareen advocated for this. Attending the BHI (rather than BRHC) was a challenge due to the unknowns, however being given a hospital passport for those with learning disabilities really helped with communicating Jack’s needs. Kareen emphasised that familiarity and continuity of staff helps build rapport and trust, which is particularly important in supporting those with learning disabilities. Kareen praised Becky Lambert for her Level 3 local cardiac nurse role support.</p> <p>For feedback to the Board, Kareen emphasised that communication is essential, relaying what is happening when. Kareen noted that to have a lay person version of GP letters would be helpful, whether via phone, email or covering letter.</p> <p><u>Key points discussed following the presentation:</u></p> <p>The Board thanked Kareen for sharing her and Jack’s experience so coherently and how this emphasised the power of team work between the patient, family, and healthcare professionals.</p> <p>The Board considered the point about GP medical letters that are copied to patients, yet the medical terminology or meaning of results can sometimes be hard for patients/families to understand. It was acknowledged that to write separately would double the workload, or to write to patient/family would not capture the medical information that the clinicians need to know. Kareen suggested the local nurse is copied in so they can contact the families and support with</p>																														

	<p>interpreting, providing reassurance. AM shared that in psychology she writes to her patients in a way they can understand to empower them, with any additional medical information that she feels the GP may find helpful in brackets.</p> <p>CK noted that with the shift towards the NHS App, patients can access their electronic patient records, yet this can cause a risk with interpretation (and potentially using the internet to source information) which can lead to patient anxiety or misunderstandings.</p> <p>Learning points for the Network – brave communication is key, as are patient passports.</p>
<b>Network performance dashboard and exceptions – key headlines from quarter 3</b>	
<b>5.</b>	<b>Updates from Level 1 (Bristol)</b>
	<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><b><u>Level 1 paediatric CHD service</u></b></p> <p><b><u>Surgical and interventional performance – year to date waiting list trends for Level 1 (Bristol)</u></b></p> <p>For BRHC, the surgical waiting list continues to reduce and is currently at the lowest number on the waiting list in nearly 3 years. It was also noted that 35 more operations were performed in 2024 compared to 2023. The average wait for surgery also continues to reduce further.</p> <p>The interventional waiting list remains relatively stable. The average RTT wait has shown a significant reduction in waiting times seen over the last 6 months.</p> <p><b><u>Outpatient performance for Level 1 paediatrics (Bristol)</u></b></p> <p>This is more challenging, with the longest wait now up to 57 weeks, and the mean wait at 26 weeks (this had improved to 17 weeks within 2023/24). The follow up backlog continues to increase, and growth in referrals is impacting this position with many related to inherited cardiac conditions (25% of the total backlog is ICC related).</p> <p><b>Key updates:</b></p> <ul style="list-style-type: none"> <li>- The CNS team are now fully recruited to establishment and ICC CNS service development continues. Work continues to review the Level 3 pilot project and onward service delivery plan. The Level 1 transition strategy remains in design phase.</li> <li>- Dr Alan Magee has been recruited to the role of paediatric cardiologist with interest in intervention covering for Dr Naychi Lwin during her maternity leave.</li> </ul> <p><b>Risks/concern:</b> Increase in the overdue follow ups.</p> <p><b>Actions/support required from Network:</b> None noted this quarter.</p> <p><b><u>Level 1 adult CHD service</u></b></p> <p><b><u>Surgical and interventional performance - BHI</u></b></p> <p>The adult surgical waiting list shows a slight increase in total patients waiting (relatively stable), however the average length for surgery wait shows a positive position with a significant reduction</p>

	<p>down to 16 weeks. It is believed that the improvement work around the ACHD JCC and the increased throughput of cases discussed has had a positive impact.</p> <p>The adult interventional total waiting list has shown sustained improvement over three quarters. The previous growth over the last 6 months may have been related to expanding interventional treatment options as the average wait for treatment continues to reduce. The average wait for intervention remains static from 2024/25 Quarter 2, now 18 weeks, which is a significant reduction from earlier in the year.</p> <p>SC added that the ACHD team have been fully established with 5 consultants and full quota of Fellows, however interventional Fellow is leaving soon.</p> <p><u>Outpatient performance for Level 1 adults (Bristol)</u></p> <p>There has been an increase in average wait time for new patient consultant appointments, but there has been some excellent progress in relation to the follow up backlog reduction. The backlog has reduced by two thirds since this time last year.</p> <p>The DNA rate is high at 11% this quarter (7% before) and the team are keen to tackle this with targeted work on specific clinics.</p> <p>CM presented the key updates for the level 1 ACHD centre – in addition to the performance data already covered:</p> <p><b>Key updates:</b></p> <ul style="list-style-type: none"> <li>- RUH Bath – positive ongoing discussions re: providing local ACHD specialist clinics in Bath to reduce travel for patients in this area. SC will be the visiting consultant.</li> <li>- Cath lab significant focused work to improve session/list utilisation (to hopefully see intervention waiting list reduce even more)</li> <li>- Cath lab refurbishment scheduled in June to December 2025. This will have minimal impact of ACHD, but useful for awareness.</li> <li>- Thanks was given to Sheena Vernon, who has retired from her part-time BHI CNS Lead role, for the significant part she has played in the development of the ACHD service. SV will continue in her Network Lead Nurse role.</li> </ul> <p><b>Risks/concerns to be escalated:</b> None noted.</p> <p><b>Actions/support required from the Network:</b> Support in launching a physiologist-led clinic.</p> <p><u>Level 1 Surgical update</u></p> <p>On SM behalf, SC updated that in the paediatric CHD service, PICU capacity has been remarkably positive since the new year, and a good volume of elective cases have been completed.</p> <p>In the adult CHD service, there are fewer issues with CICU capacity / throughput and the position is relatively good.</p>
6.	<b>Updates from Level 2 (Cardiff)</b>

## **Level 2 paediatric CHD service:**

### **Performance update**

MJ updated that there are limited updates for this service as no data was provided this quarter for the new patient consultant appointment waits, but previously the wait was static across quarter 1 and 2. There has been further growth in the follow up backlog, now 233 patients, however this is less than this time last year. The was not brought rate (9%) is similar to levels seen across 2023/24.

NH presented an update for the Level 2 centre:

### **Key updates:**

- Dr Nadia Hajiani has taken over as the new Paediatric CHD Clinical Lead. With thanks to Dr Alan Pateman for his support in this role for the last few years.
- Waiting list across level 2 and 3 centres shows demand is much higher than capacity, pointing to the need for another consultant.
- There is currently a vacancy freeze – are expecting a substantive consultant post to be advertised soon (with the Executive team). Currently have two locum consultants.
- Data manager joined team in 2024 to look at outreach capacity and has been developing a high-level dashboard for DGHs to feed into this, to show capacity and demand.

**Risks/concerns:** None noted.

**Actions/support required from the Network:** None noted.

### **Referral pathways**

CA raised about quality of referral pathways, and the need for a more unified process across South Wales and South West – with a working group to address this. HW noted that this is related to GP education. The group went on to discuss heart murmurs and referrals, and whether specialist input is necessary.

## **Level 2 adult CHD service:**

MJ outlined the adult Level 2 position, showing that the new patient consultant waiting list continues to reduce (lowest length of wait since March 2023), which is excellent. The follow up backlog also continues to recover and improve, however a quarter of waiting patients are over 12 months overdue. The DNA rate has jumped back to 8% following 0% in Quarter 2.

HW presented an update for the Level 2 centre.

### **Key updates:**

- Two registrars and clinical fellow have been running a hot clinic, which has helped significantly over the last year with the waiting list position. However, the clinical fellow is leaving in March 2025.
- Congratulations to Elinor O'Neill (current registrar) who has been successfully appointed to the new ACHD consultant post, but this will cause a registrar gap.
- Locum ACHD MRI consultant started end of December providing two sessions of dedicated ACHD MRI.

	<ul style="list-style-type: none"> <li>- Delighted with the new streamlined JCC process with a minimal wait for discussion.</li> <li>- Recent permanent uplift in hours for the ACHD secretary</li> <li>- Moving Hearts Project – commenced in September 2024. Assessed 25 patients and 17 have participated in the programme to date. Early data is encouraging.</li> </ul> <p><b>Risks/concerns:</b></p> <ul style="list-style-type: none"> <li>- Still only able to book routine follow up for 12 months or more. If needed to be seen sooner, then creative reviews in hot clinic / CNS led review / rest and discussion in MDT etc.</li> <li>- Still 8 – 10 months wait for cMRI (hopefully reduce following new appointment)</li> <li>- No local consultant in Aneurin Bevan UHB.</li> </ul> <p><b>Actions/support required from Network:</b> None noted.</p>
<b>7.</b>	<b>Updates from Level 3 centres (District General Hospitals)</b>
	<p><b><u>Paediatrics – South West</u></b></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><b><u>Outpatient performance</u></b></p> <p>MJ highlighted that Barnstaple data has been received for the first time following historical challenges with accessing this. In other positive news, for the follow up backlogs, Bath, Swindon and Taunton all have positions of zero backlog for a mix of local/visiting consultant clinics.</p> <p>Gloucester have seen a further increase in their follow up backlogs for both local and visiting clinics, although have a 0% WNB rate this quarter for all clinics.</p> <p>The key updates are outlined in the exception report in the papers.</p> <p><b>Key updates</b> included:</p> <ul style="list-style-type: none"> <li>- Taunton have reduced their waiting times from over a year to now 10 weeks with no significant long overdue follow-ups. This is with thanks to all the support and hard work from the local team starting with the recognition of the requirement/demand of the cardiology service with investment of money and dedicated time.</li> <li>- Truro – Dr Alan Magee is taking over as the second visiting UHBW consultant.</li> </ul> <p><b>Risks/concerns &amp; actions required from the Network:</b> none noted.</p> <p><b><u>Paediatrics – South Wales</u></b></p> <p><b><u>Outpatient performance</u></b></p> <p>MJ updated that in Glangwilli (Hywell Dda), the visiting consultant waits continue to grow (now at 119 weeks for new patient consultant waits) and this poses a patient safety risk. A meeting was held in January 2025 with the local service, Level 2 service and Network team. Some actions have been agreed to further mitigate the risk (including adjusting the clinic template and data monitoring between the local and Level 2 service); however, this is a capacity and demand issue, and funding is required to manage the backlog and to sustain the ongoing service. A local business</p>

case is being prepared. The commissioners have been approached (NHS Wales Joint Commissioning Committee) and a further meeting is being planned.

The Withybush (Hywell Dda) service continue to struggle with long waits. The team are reviewing the data as this had incorrectly shown as improvement. The service is exploring locum options to cover staff sickness.

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

**Key updates/concerns included:**

- Swansea Bay had a successful capital bid for a new ECHO machine for paediatrics at Morriston Hospital, and their trainee physiologist has successfully achieved EACVI accreditation. Congratulations!

**Actions/support required from the Network:**

- To widely share information about teaching activities at Bristol especially for EACVI preparation. Post-meeting note: contacts have been linked in with the Bristol physiology leads and added to the relevant mailing lists.

**Adult CHD – South West**

The nil returns were for Truro and Gloucester due to workforce changes; and Swindon who have historically not submitted a return and this has been escalated following the self-assessment.

**Outpatient performance**

Exeter ACHD service reported a significant reduction in their long waits for local new appointments, but this data is being validated as the accuracy is questioned. For follow up, Exeter backlogs continue to rise now at 221 with 30% waiting over 12 months (was 142 in 2024/25 quarter 2). The Exeter team are working on a business case to secure additional resource to support the backlog reduction and address the risks around high waiting times for new appointments.

**Key updates:**

- Exeter is working on a business case for an ACHD nurse, with the support of the Network.
- Taunton is actively looking at succession planning for their local nurse post, noting that the outcome report from the self-assessment was very useful to highlight risks of not planning for this.
- Torbay noted that the DNA rate is notably increasing since the service stopped phoning to remind patients (due to saving resources).
- Truro – are submitting a business case for an ACHD nurse.

**Key risks/concerns:**

- Exeter has no ACHD nurse to support the service, and Taunton's local ACHD nurse is due to retire within the next 3 years.

**Actions required from Network:** Support with the ACHD nurse posts.

**Adult CHD – South Wales**

100% of centres provided a data return.

	<p><u>Outpatient performance</u></p> <p>Following increases last month, both Hywel Dda centres (Withybush and Glangwilli) waits have decreased for new patients in the visiting clinics. In Swansea Bay, the local waits continue to rise. HW supported the validity of this.</p> <p>Cwm Taf Princess of Wales service has seen a reduction in their follow up backlog for local consultants. HW queried this as most of the South Wales peripheral clinics have significant waiting list issues for follow ups.</p> <p><b>Key updates</b></p> <ul style="list-style-type: none"> <li>- Cwm Taf YCR clinic is running to time as in the absence of a specialist ACHD appointment, HW has stepped in to help recover the position, as is the Prince Charles service with thanks to DW. All the other clinics are struggling, and this is an ongoing issue.</li> </ul> <p><b>Risks/concerns</b> – none noted.</p>
8.	<p><b>Patient and family representative update</b></p> <p>NM updated that the NHSE CHD Clinical Reference Group recently had some discussions around the information shared with parents at the point of diagnosis, stemming from feedback from new parents who in some cases did not feel fully prepared for the reality of the journey they had started on. The CRG are looking at how information is delivered around e.g., realistic expectations of future pathways / risks / complexity of surgeries / transplant availability, to help families feel better prepared. Kareen added that finding experienced parents who would be willing to be a peer support for new parents, would be a valuable resource.</p> <p>FC continued that the patient representation team have discussed the workplan 2025/26 priorities, and are particularly advocating for transition, cardiac rehab and exercise. FC updated on the 'moving hearts' 6-week course pilot that she has been part of. She emphasised how the course encouraged the change in language from exercise to movement and that this was particularly helpful, together with the psychology reflective side of the course. Learning to distinguish between being breathless due to lack of exercise vs due to heart condition. AM praised FC's involvement.</p> <p>FC has also got involved with reviewing the new year 2025 Network newsletter and promo QR code poster (linking to all the newsletter editions) to display in outpatient areas. The newsletters also have a feedback QR code on the back cover.</p> <p>The Board thanked the patient representatives for their feedback and positive updates.</p> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved</i>.</p>
9.	<p><b>National and regional updates</b></p> <p><u>Commissioner updates</u></p> <p><b>NHS England, Southwest</b> - presented by CK.</p> <p><b>Key updates</b> including:</p> <ul style="list-style-type: none"> <li>- Dominating theme at region has been the publication of operational planning and significant saving plans, with NHSE 15% workforce cut.</li> <li>- Network annual work plans are currently being refined ready to be submitted to the Women's and Children's Programme Board. The focus is to sharpen the language and align these to clear deliverable outcomes and measures against these, to demonstrate the Network impacts and values.</li> </ul>

	<ul style="list-style-type: none"> <li>- Still on track to delegate specialist commissioning into ICBs. ICBs will review Network workplans.</li> <li>- Also looking at whether Networks should have a longer-term strategy of 3-5 years, with stakeholder events to develop this.</li> </ul> <p><b>Risks/concerns:</b></p> <ul style="list-style-type: none"> <li>- Waiting list recovery – visibility of longest waits and potential harms.</li> </ul> <p><b>NHS Wales Joint Commissioning Committee (formerly known as Welsh Health Specialised Services Committee, WHSSC), South Wales – presented by AL.</b></p> <p><b>Key updates</b> including:</p> <p><b>Adult</b></p> <ul style="list-style-type: none"> <li>- The Cardiff and Vale Level 2 service had been carrying two consultant vacancies – one position has been recently appointed to (start date tbc) and the second position is due to be advertised imminently.</li> <li>- Cardiff consultant with interest in MRI is undertaking ACHD MRI scans on Wednesdays.</li> <li>- Cardiff have continued to advise of significant ‘front door’ cardiology service pressures at University Hospitals Wales, noting significant commissioner cost pressures relating to interventional cardiology.</li> </ul> <p><b>Paediatrics</b></p> <ul style="list-style-type: none"> <li>- Plans in place to improve data capture and sharing of weekly waiting list data between Bristol and Cardiff clinical teams, and submission of reports to NWJCC.</li> <li>- Hywel Dda UHB paediatric waiting times for visiting specialists has been escalated as a concern. The Network organised a meeting between Cardiff and Vale UHB and Hywel Dda to understand the issues and seek resolution. Follow up meeting to be held.</li> </ul>
<b>10.</b>	<b>Network Update 2024/25</b>
	<p><u>Network updated report</u></p> <p>BL updated on some key highlight achievements from December 2024 to date, noting that:</p> <ul style="list-style-type: none"> <li>- All 17 of 17 Level 3 South West England self-assessment review sessions have been held, with outcome letters sent to the Executives/decision makers to raise awareness of risks and to advocate for support for services.</li> <li>- Work has progressed to draft a refreshed simple Network dental pathway outlining local support for Level 3 centres for both adult and paediatric patients.</li> <li>- Published a directory of key learning disability staff contacts across the Network.</li> <li>- CNS Level 2 and Level 1 paediatric and adult away day held in Cardiff (January 2025).</li> <li>- Published the New Year 2025 Newsletter.</li> </ul> <p><u>Ongoing project updates</u></p> <p>SC presented on ongoing projects noting the successes and challenges:</p>

1. **The ACHD JCC improvement project** has resulted in significant improvements and the JCC is now working in real-time. Following this, a second survey has been released to measure stakeholder satisfaction and success.
2. Consequently, a **paediatric JCC scoping survey** has been undertaken to gather initial feedback, with the outcome shared.
3. **Communication of patient information across the Network** (to identify gaps in the safe flow of patient information from Level 1 to Level 2 to Level 3 centres). This work included improving the adult patient letters/results/surgical notes being sent too Level 2 & 3 centres; and systems being put in place to inform Level 2 and 3 of adult discharges and adult JCC outcomes. A repeat stakeholder survey to show measurable improvement in adults is currently being circulated. The paediatric work is ongoing as still awaiting an exact plan for the discharge summaries to be disseminated in a reliable way.
4. **Delayed transfers between Level 1 and Level 2 paediatric centres** – to audit and reduce delayed transfers of care. This affects beds and thus the surgical programme. The audit revealed the majority of delays are from Bristol to Cardiff, due to lack of beds in Cardiff (speciality beds being used for general medical patients). An escalation process was put in place in BRHC with the site management team, and this has been discussed with the NWJCC and medical directorate. After two years of the project, a re-audit shows no improvement in terms of the number of children and number of bed days of delays. The next step is for the full project group (Bristol, Cardiff and Network) to meet again to re-address the issues and gain more clarity on bed situation.
5. **Image transfer of all patient images across the Network, particularly ECHO transfer between Wales and England.** Scoped the issue and resolved with IT teams in Swansea and Bristol test centres and set up accounts for users for Welsh systems. Hywel Dda and Aneurin Bevan have come back online following a cyber-attack, and Cwm Taf is in progress. The Bath system is up and running. The long-term Exeter paediatrics ECHO storage has been sorted with the local team and the reporting system is being refined to be complete by mid-2025.
6. **Transfer of care between paediatric and adult services** – primarily looking at the quality of transfer, and checking suitable patients listed/discharged, and aiming to identify patients lost to follow up between paediatric and adult care to ultimately improve safety and reduce unnecessary medical follow up.

The task and finish project group was established with representatives from paediatric and adult services in Level 1 and 3, and the audit for England was presented at the Network Clinical Governance. The audit for Wales is ongoing with HW. In response to the metric to offer advice on who can be discharged from paediatric cardiology, the 'simple lesions to discharge' SOP was drafted, approved at Network Clinical Governance and published. A list of the cardiologists in all hospitals in the Network to refer to for different pathologies was compiled and also disseminated. There is also ongoing work looking into robust electronic transfer and scoping IT systems across the region. NH to scope the Welsh system as this may need a different approach.

#### Paediatric CHD Joint Cardiac Conference (JCC) Meeting – improvement scoping exercise

In summary, SC presented the findings and recommendations in relation to improvement opportunities for the Paediatric CHD JCC meeting following a scoping survey to JCC Network members. The survey results revealed many fervent views covering themes of behaviour, case mix, triaging and listing, meeting flow and post-meeting report outcomes.

The results were disseminated to the Level 1 Paediatric Leads and SC subsequently presented the findings and recommendations at a BRHC paediatric cardiology consultant meeting (February) for discussion and implementation. SC has since been invited by NH to present this at the Cardiff Paediatric CHD consultant meeting in March 2025.

The Level 1 Paediatric service are in the process of appointing a new JCC Lead with allocated job plan time. SC is also supporting by drafting a term of reference for agreement.

The Board thanked the Network team for their support with this transformation project and to the Level 1 teams for their engagement with this. CK praised the JCC projects, noting how recovering waiting lists can seem an insurmountable challenge, however this work along the pathway even with small changes, can significantly impact patients/staff experience, efficiencies and waiting times, making a bigger difference.

#### South West England self-assessments

MJ recapped on the process. Following the individual centres being sent a summary outcome report in the autumn, a consolidated findings benchmarking report for adult and paediatric services was produced.

Letters have since been sent to each Trust Executive teams/decision makers with the reports attached – these highlighted areas of success and celebration in the local CHD teams; provided a supportive escalation from the Network to show where gaps exist leading to areas of risk to patients; and flagged where resourcing or other support is necessary to improve or maintain compliance against the standards and mitigate risk. A key note was the workforce gaps, particularly the lack or limiting resourcing of local CHD nurses within level 3 centres, standalone roles and succession planning. Also, kit requirements, and an inability of time in Level 3 clinicians job plans to enable them to attend the Level 1 centre JCC meetings, both from a shared learning perspective and also for presentation of cases.

The Board celebrated progress centres are already making against the self-assessment action plans, most notably:

- Exeter ACHD service is working on a joint business case with Barnstaple ACHD service for nursing resource.
- Taunton ACHD service is actively reviewing succession planning for a local CHD nurse.
- Truro ACHD service is pulling a business case together for a local ACHD nurse post.
- Plymouth paediatric service have secured funding for a local nurse post.
- Barnstaple paediatric service is now able to provide CHD performance/assurance data for the first time.
- Torbay paediatric service have secured funding for a new ECHO machine.

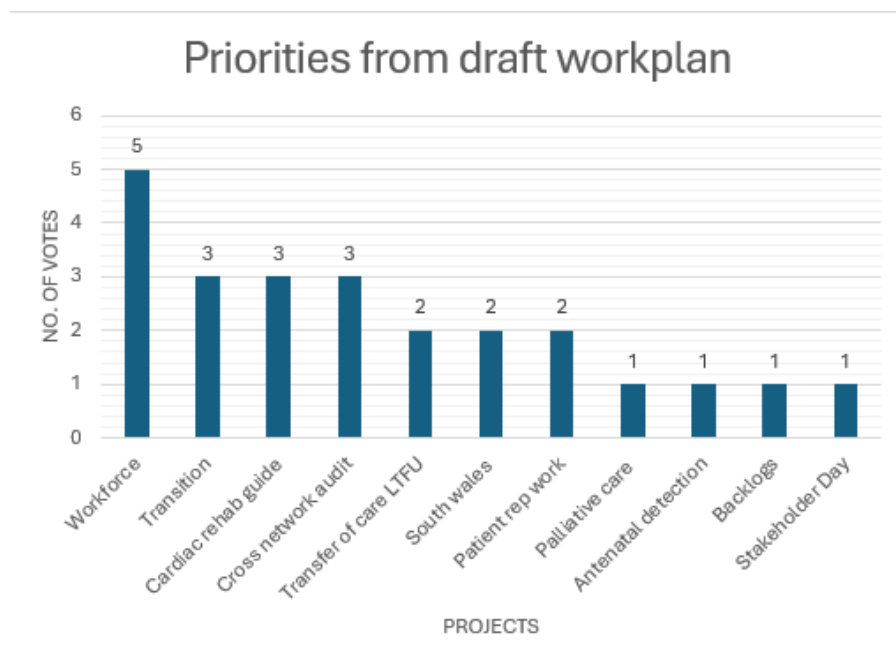
The findings from the self-assessments have been used to draft the workplan projects for 2025/26.

The next steps are to hold the Level 1 specialist paediatric CHD service self-assessment on 13<sup>th</sup> March 2025, and the outputs may support the business case submitted for the 2025/26 planning round. To work with the Level 1 specialist adult CHD service to organise their self-assessment, and then to plan the reviews for the Level 2 Cardiff services. A face-to-face Level 1 and 2 Network stakeholder event is proposed within 2025/26 with a focus on strategy and innovation.

### Network 2025/26 plan

The Network workplan for 2025/26 is being developed, with a continuation of key ongoing projects, and to incorporate recommendations and areas of focus from the 2024 self-assessments and other key priorities identified by Network stakeholders. At the start of the Board meeting, the attendees were asked openly about their top priorities for the workplan to enable a comparison with the draft workplan to ensure these align.

MJ then presented the draft workplan and asked Board members to note the top priorities from the draft list via a menti-meter poll, with the outcomes displayed in a word cloud.



### 11. Any Other Business

- Board membership – Need to ensure members send a nominated deputy if unable to attend.
- Next Board Meeting, Thursday 22<sup>nd</sup> May 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.

### 12. 'Live' feedback on the meeting

### Attendees

Name		Job Title	Organisation	13-02-25
Aisal Khan	AK	ACHD Fellow	Cardiff, University Hospital of Wales	Present
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Becky Lambert	BL	Network Lead Nurse & ACHD Nurse	Taunton, Musgrove Park Hospital	Present
Becky Nash	BN	Patient Representative		Present
Beth Shirt	BS	Director of Nursing BRHC	Bristol, University Hospitals Bristol & Weston	Present

Name		Job Title	Organisation	13-02-25
Cat McElvaney	CME	Deputy Divisional Director (Adults)	Bristol, University Hospitals Bristol & Weston	Present
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Present
David Blundell	DB	Consultant Cardiologist (locum)	Cardiff, Cardiff and Vale	Present
David Lindsey	DL	Consultant Cardiologist with interest in ACHD	Gloucestershire Hospitals	Present
Ed Roberts	ER	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Elinor O'Neill	EON	Registrar/ACHD Consultant Cardiologist	Cardiff, Cardiff and Vale	Present
Frances Cantin	FC	ACHD Specialist Nurse	Plymouth, Derriford Hospital	Present
Frankie Carlin	FC	Patient Representative		Present
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Present
Georgina Ooues	GO	Consultant Cardiologist ACHD	Truro, Royal Cornwall Hospital	Present
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist (Chair)	Cardiff, University Hospital of Wales	Present
Kareen		Patient/family representative		Present
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Present
Laura Mott	LM	Paediatric Service Manager	Cardiff, University Hospital of Wales	Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Muhammad Shahjehan	MS	Consultant	Plymouth, Derriford Hospital	Present
Nicola Morris	NM	Patient Representative		Present
Rachel Burrows	RAB	CHD Network Support Manager (note-taker)	CHD Network Team	Present
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospitals	Present
Samantha Swanson	SS	Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present

Name		Job Title	Organisation	13-02-25
Stephanie Curtis	SC	Network Clinical Director / Consultant cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present