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

Date: Wednesday 7th August 2024, 14.00 – 16.30
Venue: Microsoft Teams Conference Call
Chair: Dr Radwa Bedair, ACHD Consultant Cardiologist

Minutes

Item	Notes and Actions
1.	**Welcome, introductions and apologies**
	Dr Radwa Bedair (RB) welcomed the attendees to the Network's virtual Board, providing a reminder on the digital meeting etiquette. The Board welcomed Becky Lambert in her role as Network Lead Nurse, working alongside SV, as well as Amy Lewis, NHS Wales Joint Commissioning Committee (paediatrics) who started in post 1st August, taking over from Kimberley Meringolo.
2.	**Approval of minutes and action tracker**
	The minutes of the Network Board on 18th April 2024 were agreed to be an accurate record. No actions to report on.
3.	**Patient Story**
	The Board listened to Sebastian's pre-recorded presentation (35-year-old from Devon). When Sebastian was born, he was transferred to Bristol for an atrial septostomy and diagnosed with Transposition of the Great Arteries (TGA). A successful Senning procedure followed. A few years later, he developed and was treated for atrial fibrillation. On a routine catheterisation, pulmonary hypertension was diagnosed and treated at the Hammersmith London. Sebastian shared that he had an active and positive experience throughout his childhood, and this included regular check-ups with clinicians he built a good rapport with. Sebastian explained that whilst 'having a heart condition did affect [his] life, he didn't let it affect [his] life in the way it could have done.' Referring to sport, he put no pressure on himself. He paced himself, taking his own time to get things done. He described a generally positive experience of transition and transfer to adult services, but reflected that as a young person, it felt strange to share a ward with older people, rather than those of his age, and that his parents could not stay overnight. Sebastian praised Dr Graham Stuart and the cardiac liaison team and expressed that his adult inpatient and outpatient experience and care at the BHI has been incredibly positive. He particularly appreciated how the CNS team are so responsive with advice when needed; that his annual PH clinics are held in Bristol, which saves a lot of time travelling to London; and that he can visit the Exeter service for routine pacer checks. Some of the challenges Sebastian identified due to his heart condition, included not being part of

	the sports team at school; having to explain his condition to people who look at him and see no problems, given it's a hidden condition; having to explain repeatedly to his dentist that antibiotics are needed before treatment; and being more vulnerable to some respiratory illnesses. For feedback to the Board, Sebastian raised that he is pleased to be part of the South West patient team and is grateful for the care he continues to receive in Bristol, Exeter, and London. Sebastian was delighted to share that he now has a son and is enjoying being a dad. Key points discussed following the presentation: The Board thanked Sebastian for sharing his heart-warming story of his journey, and that it was so helpful to hear his reflections on his experience. The Board empathised with Sebastian's feedback on being a young person on an adult ward, noting that whilst the hospital footprint and limited space doesn't enable having a young person designated ward, the BHI have recently opened a young persons' lounge and also, if possible, try to give young people a side room with the option of a parent stay. In response to the repeat explanations to the same dentist, it was suggested that having his condition requirements in writing could be a helpful way forward. The Board praised the effective communication between the centres that provide Sebastian's patient care, and how little acts of kindness and going the extra mile so patients feel valued, clearly makes a significant difference showing the way people feel is what they often remember years later.
4.	**National and regional updates**

	Commissioner updates
	
	Joint Commissioning Committee (formerly known as Welsh Health Specialised Services Committee, WHSSC), South Wales – presented by RP.
	
	WHSCC has joined with the Emergency Ambulance Services Committee (EASC) and the National Collaborative Commissioning Unit (NCCU) to form the NHS Wales Joint Commissioning Committee (NWJCC).
	
	Key updates including:
	
	Adult
	
	• Phase 3 ACHD investment - allocation of resource to Cardiff and Vale University Health Board (C&V UHB) Level 2 ACHD Centre was confirmed in April 2023 and understood to be fully allocated.
	• C&V UHB cardiothoracic surgery is being repatriated from University Hospital Llandough to the University Hospital of Wales (Level 2) from week commencing 26th August 2024, entailing a two-week period of scaling back or pausing activity:
	    o It was reported that Swansea Bay UHB and University Hospitals Bristol & Weston NHS Foundation Trust (UHBW) have been asked to support referrals for surgery during the two-week period 26th August to 6th September, and to support the diverting of emergency cardiac surgery patients over the period 26th August to Monday 9th September.
	    o The knock-on effects on ACHD patient flow are thought to be minimal.
	• C&V UHB have advised of significant 'front door' cardiology service pressures at the University Hospital of Wales, noting also significant system-wide commissioner cost pressures.

	Paediatrics • Cardiac surgery services in Bristol have been formally de-escalated to level 0 following several months of sustained improvements in reporting and the length of time patients are waiting as agreed within the commissioning team. **NHS England, Southwest** Presented by CK **Key updates** including: • **ODN Annual Reports (on a page)** were received at the July 2024 Women & Children's Network Programme Board. • New **Medical Director** for NHSE Commissioning is starting in September 2024 – they are already very impressed by the work of the operating delivery networks. • **Commissioning Delegation for Specialised Services** – continue to work towards April 2025. • **Clinical Genetics** – Whilst there are national workforce issues, currently this is an issue at region. The programme of work focuses on supporting the future of the service. • NHSE Senior Regional Team continue to work with UHBW around fragility of some specialised services (that tend to have workforce and demand challenges). This includes cardiac waits. • New UK government are looking at a 10-year NHS plan. **Risks/concerns:** Continue to work with the ODN on intelligence of risks and issues around cardiac and surgical waiting lists and demand. The ODN have escalated concerns which have fed into the work that the NHSE senior regional team are doing with UHBW.
5.	**Network Performance Dashboard**
	Key headlines from Quarter 1 Network Performance Dashboard The Network Board has a role in monitoring performance of centres within the Network and addressing areas of concern. The Board is asked to review the performance reports included in the papers and agree any actions required to address issues. MJ presented an update on the performance and assurance data that is collected on a quarterly basis, noting that following feedback and a decision by the Board, from Quarter 1 (Q1) 2024/25, the reporting recommenced end of quarter reporting. Data collection The response rate from centres is positive with 100% for all paediatric and ACHD centres returns for level 1 and level 2, as well as South Wales Level 3 paediatric centres. For ACHD level 3, the return rate was lower than usual this quarter at 50% for the South West (perhaps due to the additional work in quarter for the self-assessments) and 71% for South Wales. For paediatric level 3, the return rate was 78% for the South West (same as Q4) and 100% for South Wales. Thank you to centres who submitted these. As part of the South West self-assessments, centres have been asked for their views on the data/frequency. From the 15/17 reviews held to date, no concerns have been raised regarding

continuing with the quarterly data returns, and some centres noted they find this particularly helpful. The South Wales centres will be asked via email for their feedback on this too (completed post-meeting).

As a side note, the Barnstaple paediatric service have struggled to report their local and visiting clinic data historically due to coding and booking system challenges; the Royal Devon University Hospital service manager is currently working with the service to support the resolution of these issues.

Did Not Attend (DNA) or Was Not Brought (WNB)

The variability continues across centres from quarter to quarter. The highest DNA/WNB are seen in centres with low patient numbers, therefore this needs to be taken into consideration. There are high rates reported across Cwm Taf paediatric services (23-32%) which needs further exploration.

Centres with very low rates tend to be those with nurses in place who can contact patients ahead of appointments to manage attendance. Gloucester paediatrics reported 0% DNA rate for Q1 and Gloucester adults at 5% (first time less than 10%). DL concurred that in Gloucester, the ACHD specialist nurse phoning patients ahead of clinics, has significantly reduced the DNA rates.

Waiting time for new patients

Please refer to the performance report for further details.

For paediatrics, there has been a mix in Q1 of centres showing improvements to their new patient waits and other centres facing challenges. In Swansea Bay, local consultant waits have reduced to 5 weeks, and in Cwm Taf Royal Glamorgan with a visiting consultant, new appointment waits are down from 13 weeks to 3 weeks.

BRHC have seen a jump in Q1 new appointment waits following reductions in 2023/24. Cardiff waits have increased back in line with the wait seen in Q1 2023/24. Of keynote to flag, is Hywel Dda Glangwilli as the high wait for new visiting consultant appointments continues – the service has advised that triaging takes place to ensure all urgent and semi-urgent patients are seen within 4 weeks though this impacts the routine wait times. RB queried how patients are allocated between the local and visiting consultant.

- **Action:** MJ to discuss with Hywel Dda Glangwilli paediatrics team the high waits and how patients are allocated between the local and visiting consultant clinic.

For adults, the limited data returns received this quarter make centre patterns difficult to identify. Cardiff have reduced their new patient wait from 42 weeks (Q4) to 32 weeks (Q1), which is good progress. The BHI reduction in new patient waits also continues to reduce and is now at 22 weeks compared to 40 weeks this time last year – this is with thanks to timely recruitment and having a full team of middle-grades and consultants.

Concern was raised last quarter regarding Exeter ACHD services' local consultant waits which were continuing to increase, however data has not yet been submitted for Q1 2024/25 – the team in Exeter previously flagged that the longest waits were directly linked to patient availability.

- **Action:** To discuss Exeter ACHD waiting lists and mitigations at the self-assessment visit planned in early September.

Overdue follow up backlog.

In paediatrics, Taunton and Swansea Bay both reported good progress in reducing their local consultant clinic backlog. Anerin Bevan followed suit, particularly for the visiting consultant line.

	Cardiff's overdue follow up backlog remains static from Q4 following the excellent progress made across 2023/24 in reducing the significant backlogs – currently staffing challenges (ability to appoint) may impact this position moving forward. BRHC have maintained the reduction in this line. In adults, the BHI's excellent progress in backlog reduction continues which is linked to the additional resource in service and extra clinic capacity previously mentioned. Truro have also seen a significant improvement in their local consultant and visiting clinic waits. However, Swansea Bay's noticeable improvement on the backlog position seen in Q3 to Q4, has reversed back to Q3 levels, suggesting there may have been a data error – HW confirmed this is the case. Inpatient report – year to date waiting list trends for Level 1 (Bristol) Please refer to the report in the papers - this data includes patients listed and ready for procedure and excludes those patients awaiting surgical outpatient appointment or JCC discussion. The adult surgical waiting list has reduced from Q4 and is more in line with this time last year. The paediatric surgical waiting list has reduced in Q4, however this remains higher than 2023/24 Q2 and Q3, though lower than this time last year. The longest wait has reduced further with significant improvement across the year. The adult interventional waiting list has increased returning to levels reported in Q3, though not at the peak seen this time last year. The cath lab time for ACHD has increased so the service expect improvement in waiting times for procedures next quarter. The paediatric interventional waiting list has reduced this quarter after a growth in Q4, bringing the list back to the same level as this time last year. HW asked for the average wait for ACHD intervention (rather than longest wait) and CME noted that this is around 40 weeks. The Board suggested that moving to look at the average length of wait would be a preference to the longest length of wait which can be skewed by a single complex patient / patient choice. • **Action:** Review the inpatient data performance measures with a suggested move to look at average length of wait alongside / as a preference to longest length of wait. The Board agreed that the reasons behind the data for this would be useful. For instance, when the waiting list increases, is this due to e.g., listing more patients, or due to resource, cath lab/theatre list utilisation and access. CM shared that system work is underway to reflect the list utilisation more accurately so this potentially could be provided in the future. The sessions are monitored by Level 1 monthly, so a snapshot of the ACHD lab sessions could be given, however uncovered sessions are due to legitimate reason such as leave so it is unclear how useful this would be. • **Action:** MJ and Level 1 leads to consider how can capture the reasons for the surgical and interventional waiting list changes for both adults and paediatrics.
6.	**Update from Level 3 centre(s)**
	The key updates are outlined in the exception report in the papers. 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. As previously noted, the Level 3 South West centres have had a lot of work completing their self-assessments and preparing for the review meetings in Q1 which may have impacted on their capacity for submitting returns this quarter.

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Adult CHD:

Key updates: Included in the papers. BL noted that:

- In Taunton, successful young person clinics and transition clinics have been held, and Mo Mehisen has taken over as the local ACHD consultant.

- In Cwm Taf Morgannwg, Prince Charles Hospital are now running four all-day clinics a year instead of two – this seems to have been popular as the first extra clinic had 100% attendance.

Key risks/concerns:

- In Taunton, succession planning is needed as there is concern regarding the single point of failure for specialist nurse and local consultant. It is also still unclear about the effects of the merger with Yeovil District Hospital on the service.

- The Royal Glamorgan Hospital it was noted that until May 2024, the service was ahead of the follow-up requirements, however the minor slippage since reflects reduced clinics due to annual leave and the resignation of the visiting ACHD consultant. Aneurin Bevan also raised that the loss of the visiting consultant is impacting their waiting lists due to reduced clinics. Thanks was given to the remaining visiting consultants who are providing excellent support given the limited capacity.

- Gloucester – DL raised that funding for their local ACHD nurse is time-limited. The Network are supporting the service to try to get this extended.

Actions required from Network:

- Visiting consultant backfill in Royal Glamorgan.

Paediatric CHD

GB presented the key themes to note for paediatric level 3 centres:

Key updates: Included in the papers.

- For the southwest, Taunton have experienced admin related challenges with retaining secretarial staff - a new cardiology secretary joined the team in late July. Two adult cardiac physiologists have achieved their CHD BSE accreditation (well done), with thanks to the support of the South West training pilot project. Exeter have been making good progress with this project too. In Torbay, sonographer clinics are up and running, and in Gloucester, following Dr Jennifer Holman's retirement, Dr Pradeesh Mappa moved to join the team in early July – the service are grateful that following a period of turnover with the visiting consultant, Dr Grange is providing some continuity.
- For South Wales, Swansea have submitted a business case for a paediatric cardiology specialist nurse and Royal Glamorgan are continuing to scope out a dedicated nursing support for cardiac within Cwm Taf.

Risks/concerns to be escalated:

- Torbay raised issues with the performance of their scanner, and that patients are requiring second appointments in Bristol to acquire adequate imaging prior to surgery.

- Hywel Dda raised that more outreach clinics are needed as there are a lot of urgent

	patients, which is affecting the routine waiting list. **Actions/support required from the Network:** • Swansea asked for guidance with regards to echo machine standards for paediatrics. AP advised that in terms of how often change the machines, published replacement period is 5 years but have found tend to exceed these due to complications with capital bids.
7.	**Update from Level 2 centre**
	HW presented an update for the Level 2 centre - the key updates are outlined in the exception report in the papers. Notable comments included: **<u>Level 2 adult CHD service</u>:** **Key updates:** • ACHD fellow started in March 2024 and the third ACHD consultant recruitment is ongoing. • Additional Singleton face to face clinic has been running successfully since February and is now staffed by HW together with a new Imaging/Heart Failure Consultant Dr Charlotte Thornton. • The ACHD CNS secondment position has been appointed to (maternity cover for Bethan Shiers) and is due to start in early August. • Instituted 'hot clinics' enabling an additional 3 patients per week to be seen at short notice, assessed by ACHD SpR Dr Elinor O'Neill and ACHD Clinical Fellow Dr Aisal Khan, overseen by Dr Masani. • Successful in being one of 5 centres to be awarded funding from the British Heart Foundation to support a Health Innovation Project exercise programme. This has provided funding for 12.5hrs a week of a band 8b Consultant Clinical Psychologist, who has been recruited and starts with the team on 1st September. • Successful in appointing a band 8a psychologist for one day a week - start date tbc. AM is covering the additional hours. • Steph Connaire has joined the Cardiff team. **Risks/concerns**: • Consultant cardiologist SM left in July. Until this post can be recruited to, Dr Masani will be responsible for inpatient care and clinics will be covered by Dr Masani, Dr Wallis, and SpR Elinor O'Neill. • The current JCC waiting time for discussion is about 12 weeks for routine referrals and needs to be < 6 weeks. **Actions/support required from Network**: • Continued support in conversation with Bristol for improving JCC process and waiting times. **<u>Level 2 paediatric CHD service:</u>** AP presented an update for the Level 2 centre: • **Key updates:** There are continued challenges in appointing staff across the team despite

NHS Wales Joint Commissioning Committee (formerly WHSCC) funding.

- **Risks/concerns:** The team are unable to source an answer from Cardiff & Vale UHB or NWJCC with regards to levels of funding for the service. This makes planning delivery of the service challenging.
- **Actions/support required from the Network:** The Cardiff team have requested a reinstatement of what were annual audit meetings facilitated by NWJCC (or then WHSSC) and for one area of discussion to be the funding baseline for the level 2 paediatric service. AP and AL to discuss further when they meet.

8. Update from Level 1 centre

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

Level 1 adult CHD service

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

Key updates:

- Continue to have a 1.4 WTE CNS shortage as per NHSE service standards.
- Been working in collaboration with the CHD Network on the review of the Joint Cardiac Conference (JCC) MDT meeting - this has been completed with draft actions, to be agreed with the clinical team. An MDT coordinator is now attending the JCC meeting and tracking outcomes when further action is required.
- A project on DNA rates linked with health equalities is underway – patients living in more deprived areas are being contacted before their appointment, and this has reduced the DNA rate.
  - **Action**: CME offered to report back to the Board on the DNA rates health equality project at a future meeting (in early 2025).
- ACHD Consultant Victoria North is on planned leave, and Lisa Mcclenaghan is covering her post (locum). The Board celebrated that timely recruitment has maintained activity with no gap – thanks were given to Sally Worfolk and Greg Szantho.

RB added that in the cath lab within the last year, two completely new procedures are now being carried out as routine: sinus venosus defect closure (previously performed surgically and now percutaneously) and a new type of pulmonary valve (previously performed surgically and now in the cath lab). This refers to the question around whether the cath lab waiting times are due to new patients being added to the list or another reason impeding the workflow.

Risks/concerns to be escalated:

- Continued long waits for JCC and procedures.

Actions/support required from the Network:

- None noted this quarter.

Level 1 paediatric CHD service

ER shared the key updates to note:

Key updates:

- Continued reduction in longest waiting patient in cardiac surgery.
- Investment agreed from NHSE England to staff PICU to Paediatric Critical Care standards – already showing reduced cancellations with improvement in nursed PICU beds. Due to be fully recruited by November to hopefully support over winter.
- Appointed two substantive consultant posts, Jennifer Shortland appointed to Arrythmia and ICC post and Naychi Lwin to Interventional post (due to start end September). The Board were very supportive of the move to substantive positions for continuity.
- Also appointed a substantive ICC nurse post via business planning funding.

Risks/concern:

- Paediatric CNS team are facing challenges with vacancies which will affect the service.
- Ongoing issues for patients waiting for paediatric electrophysiology as demand is outweighing capacity resulting in more patients breaching 65 weeks. The team are working hard to find ways to mitigate this in-house. May need to discuss with BHI if can offer 16/17-year-olds the option to be treated in adult services. ER and MJ are looking into whether this is a national issue and if out of region support is an option if the clinicians agree.
    - **Action:** MJ to check with the other CHD networks if the paediatric electrophysiology demand capacity challenges are an issue elsewhere in the UK.

Actions/supports required from Network: None noted this quarter.

9.	Patient representatives update
	The patient rep team had a pre-meet before the Board. On the behalf of the patient reps, SV presented their updates noting that the Somerville Heart Foundation 'living well with CHD' national conference was held in Bristol on 11th May 2024 – many network members attended and presented including patient reps FC, GS and BG who all presented on their lived experience. One patient in attendance approached Giovanni Biglino (CHD Network Research Lead) given her interest in research, and subsequently has reviewed our network website research pages, presenting her recommendations at the second Network research forum (August). Several members of the patient rep team together with other Network members have also got involved with GB's new Network research forum – the first sessions in June outlined the national James Ling Alliance Research Priorities. The Summer CHD Network newsletter featured articles on the patient voice, Rebecca's patient story and FC review of the South Wales book club – with lots of excellent feedback. Following an initial event hosted in Leicester (March 2024), the CHD Networks national patient engagement follow-up event was held online in July 2024 with representatives from around the country – for the South Wales and South West, representation included NM, FC and RW, together with SV, BL and MJ. The Family Support Worker role on Dolphin Ward (BRHC) has been expanded to support PICU cardiac families too. In addition, Heart Heroes hosted a transition day held on 13th July with the support of the clinical teams in Cardiff.

	AM praised the patient rep work and added that RW has also co-wrote an article for Public Health Wales. SV shared that the patient rep group are looking to expand/diversify. Those involved can decide on the level and type of involvement depending on their capacity and interests, and always have the option to step back whenever they need to. The Board thanked the patient representatives for all the time and effort they give to this voluntary role to support the Network – their contributions are very much valued. The Board was reminded that *if a project involves patient care, a patient rep should be involved.*
10.	**Network Update 2024/25**
	Network updated report (Quarter 1 2024/25) SV updated on some key highlight achievements in quarter 1 (April-July 2024), noting that the focus has been the South West self-assessments. She reflected that it has been encouraging to see the considerable progress since the first round of self-assessments when the Network was established. • In June, the Network welcomed Becky Lambert to the Network Lead Nurse role. • The Summer 2024 Newsletter has been launched. • A findings and recommendations report has been produced in relation to improvement opportunities for the Adult JCC meeting following a scoping survey to JCC members. A meeting has been held with the Level 1 ACHD leads to discuss findings (as referred to in item 8) and to implement recommendations. • Work has commenced on a pregnancy and contraception risks and advice guideline for Network clinicians – this is following discussions held at the self-assessment reviews. • Work has progressed to identify key Learning Disability staff contacts across the Network to share learning and best practice. • Work has progressed to draft a refreshed simple Network dental pathway outlining local support for Level 3 centres for both adult and paediatric patients. • The first Network research forums were delivered by Giovanni Biglino, Network Research Lead with a focus on the National Research Strategy 10 priorities for ACHD and paediatric CHD as identified in collaboration with the James Lind alliance – the forum has been well attended. • The Network psychology day was held on 19th June with exceptional feedback from delegates, as well as a Network transition morning. • Continuation of the highly valued ACHD ECHO webinar series – a spotlight update is on the agenda for the Clinical Governance Group in November 2024. South West England self-assessments MJ updated that much Network resource has flowed into delivering the self-assessment and virtual review sessions; 15 South West service self-assessment reviews have been delivered in May-July 2024, with excellent engagement throughout the process. The Board thanked all those involved. The Exeter ACHD review has been postponed to early September and Swindon ACHD review is pending.

	The reviews highlighted areas of success and high quality to be shared and celebrated, and identified areas of shared challenge for our centres, and what support can be put in place to help centres moving forward. Over 200 actions have been generated, including lots of quick wins. The overall compliance rate so far is between 80% and 97% against the national standards for CHD. The Network agreed for some of the Network and Trust infrastructure standards that were open to interpretation to be scored the same to ensure consistency in compliance with the scoring across the region. The next steps are to complete the final two review sessions (Exeter and Swindon ACHD); to collect feedback from the centres on the review sessions to focus any improvements to the process for the future; and for the core network team to generate an output document for each local service and an overall output from the reviews across the South West region. The findings will be shared across the Network and with the commissioners regionally and nationally. Following this, the Network plan to flag any out-of-date standards and those with interpretation queries to the national CHD commissioner. The outputs of the self-assessment reviews will be used to influence the areas of focus and priority for the Network workplan in 2025/26. The plan is to undertake self-assessment reviews with the level 1 centres too. The Board praised the core team and all the centres involved for this impressive amount of work, which has been conducted in such a supportive and collaborative way. The intention is not to compare centres but to work together to share learning and successes. ○ **Action:** To agree appropriate approach on sharing the centre self-assessment outcome reports. Key measurable 2024/25 workplan projects are ongoing. The ongoing projects include the transfer of care between paediatric and adult services; the communication of patient information across the network; and image transfer across the network particularly with echo transfer between Wales and England. Update slides on these will be circulated with the minutes – any queries, please do contact the Network core team. **Network 2024/25 plan** The Network 24/25 plan on a page which describes the priority areas of focus and workstreams is available on the Network website. All Network members are encouraged to get in touch with the core Network team if they would like to discuss the plan further or be involved in any workstreams.
11.	**Update on the adult pulmonary hypertension service**
	RB presented an informative update on the Bristol and Hammersmith (London) joint adult pulmonary hypertension specialist service clinic that has been running since 2010. This is a monthly clinic, with a case mix which is predominantly ACHD. Most investigations are performed locally in Bristol, but sometimes patients are invited for a day case appointment at the Hammersmith if able to meet the wider team. Sebastian who presented his patient story (item 3) referred to the PH service and the value of

	having this closer to home, reflecting how having a joint service in Bristol is greatly beneficial for our regional patients reducing travel further afield. RB highlighted that pulmonary hypertension is an umbrella term covering several types of conditions within the pulmonary artery. Group 1 pulmonary arterial hypertension (PAH) is where CHD is usually associated, however patients with CHD can have any sub-type of PH. Treatment for ACHD PH patients need to be in a specialist setting. Referrals are made via letter for any patient with CHD and known or suspected pulmonary hypertension, and patients with suspected group 1 PAH. When a patient joins the PH service, all investigations will be carried out to help establish the diagnosis. RB presented an outline of the supportive therapeutic options and pathways for targeted treatment (expensive). Advancements in recent years have led to more tablet medications. There is a smooth pathway for the delivery of medications that require ongoing prescription via the Hammersmith Hospital (not GPs) to patients, together with a requirement for regular blood tests. RB noted that a lot of patients remain well with therapies. Could consider a BRHC-Great Ormond Street-Hammersmith paediatric update on the PH service for the future. The Board thanked RB for a high-level update on this fantastic service, and for all her hard work.
12.	**Issues Log**
	SV reminded the Board that the Network no longer owns risks, however, does have a responsibility to keep an issues log with high priority issues reported from centres. The Network Lead Nurse and Manager have completed a review of the current Network issues log with a view to ensure consistency in the process for adding items to the log and the link to the Network workplan. The criteria for these are: - Issues the Network have been made aware of. - Issues leading to a further risk for patients and/or workforce. - Issues leading to non-compliance of national CHD standards which may result in poorer outcomes for patients. Key issues listed (many of which were mentioned during the Board meeting as items being worked on) include lack of investment, some centres not having the recommended staffing establishment, funding for link nurses, medical workforce succession planning, delayed transfers of care, patients and families not being communicated with effectively regarding the process and outcome of the paediatric joint cardiac committee (JCC) meetings, patients and families raising concerns with patient/parent representatives and families regarding surgical cancellations and the impact of re-attending pre-admission clinics. SV advised that a further review of the Network issue log would take place to incorporate the findings of the South West England self-assessment reviews.
13.	**Any Other Business**
	• MyStaff (new UHBW document management system) - HW raised that there are some MyStaff

	access issues in Wales. Will look at having staff manually added. • Concern about infection rates - HW noted that a patient had raised concerns when being referred to the BHI for cardiac surgery as they had heard there was an issue with infection rates. HW also raised that information about this had been posted on a solicitor's website and Facebook page. DL also flagged that there were known issues around infection rates for cardiac surgery in Bristol. CME responded to say that there had been issues identified back in December 2022 when the BHI had identified a small number of patients linked by a bacterium called Staphylococcus warneri in their blood, after undergoing surgery at the BHI. All the cases relate to a specific time period. All patients have been contacted if they were potentially impacted. The BHI have identified the issue, put robust measures in place and have had no cases since. Fletchers, the solicitors who had posted about the BHI, regularly post news stories and social media adverts to attract potential claimants to support potential medical negligence claims. A further letter has been issued to all referring centres that provides information on the situation and offers a contact for people if they have any further queries. ○ **Action:** Letter issued to referring centres to be circulated with the minutes. • Transplant referrals - HW raised a query regarding transplant referrals to the Harefield and Newcastle, and it was clarified that referrals can still be made to multiple centres who will redirect these if required depending on complexity. • Board membership – Need to ensure members send a nominated deputy if unable to attend. • Feedback form - Board members were invited to complete the meeting feedback form via the Microsoft Forms link circulated. Feedback has shown that the majority preference is for the Board meetings to continue to be held virtually. • Next Board Meeting, Tuesday 26th November 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.

Attendees

Name		Job Title	Organisation	07/08/24
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Present
Amy Lewis	AL	Senior Commissioner	NHS Wales Joint Commissioning Committee	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
Cat McElvaney	CME	Deputy Divisional Director (Adults)	Bristol, University Hospitals Bristol & Weston	Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Present
David Lindsey	DL	Consultant Cardiologist with interest in ACHD	Gloucestershire Hospitals	Present

Name		Job Title	Organisation	07/08/24
Ed Roberts	ER	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park 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
Marion Schmidt	MS	Consultant Paediatrician	Newport, Royal Gwent Hospital	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	Bristol, University Hospitals Bristol & Weston	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	NHS Wales Joint Commissioning Committee	Present
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Sebastian	SK	Patient Representative		Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present