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

Date: Tuesday 26th November 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 guest speaker, Dr Adam Smith-Collins, South West Neonatal Clinical Director.
2.	**Approval of minutes and action tracker**
	The minutes of the Network Board on 7th August 2024 were agreed to be an accurate record. **197 - Hywel Dda Glangwilli paediatric CHD high waits** The local team are in support of a meeting to discuss this further – a meeting is being planned. **200 – BHI interventionalist waits & cath lab utilisation** CME and RB are reviewing this and can feedback at the next meeting. **204 – BHI DNA rates health inequalities** To be on agenda for future meeting when ready. **Closed actions** 198, 199, 202, 203, 205 & 206.
3.	**Patient Story**
	The Board listened to Oliver's pre-recorded presentation (43-year-old). Oliver had a repaired Tetralogy of Fallot with closure of muscular ventricular septal defects in 1984 and has since undergone a series of other heart interventions on his journey with CHD to support his heart function. Oliver described how he works full time as a corporate finance partner, is bringing up two children with his wife, and is 'extremely happy (he) has made it this far.' Oliver had a cardiac arrest in 2019, which he described as the most difficult experience of his life. He referred to the psychological impact of his heart condition at various times and how it is still challenging to talk issues through. Oliver praised the NHS as 'exceptional people with exceptional mindsets,' specifically naming Dr Graham Stuart and recognising the value of the ACHD Clinical Nurse Specialist service. For feedback to the Board, Oliver suggested that there could be better provision of counselling services at key points and recognising the impact on siblings (one of his siblings felt sidelined and this had a marked impact on her too); improved immediate access to support (as sometimes getting into the system can be an issue); and perhaps the use of reliable technology to monitor outputs in real-time to potentially reduce the likelihood of matters escalating and becoming more costly to deal with.

Key points discussed following the presentation:

The Board thanked Oliver for sharing his journey with so much insight, depth and reflection that was both moving and helpful. The Board discussed Oliver's point about the provision of support and experience of siblings of those with CHD. NM raised that from her parental experience on transfer to adult services, the focus seems to shift to psychological support focused on the patient (rather than family too). SV added that at the recent Little Hearts Matters national conference, support for siblings was raised several times, as a reminder to care for the family not just the patient.

The Board also considered the point about improving the discharge process and managing patient expectations when they are waiting to leave hospital.

Network performance dashboard and exceptions – key headlines from quarter 2

3. Updates from Level 1 (Bristol)

MJ presented an update on the performance and assurance data that is collected on a quarterly basis. A new approach was piloted of merging the data with the exception reporting, with the intention to improve the flow of delivery.

Level 1 paediatric CHD service

Surgical and interventional performance – year to date waiting list trends for Level 1 (Bristol)

The number of patients on the paediatric surgical waiting list has reduced further this quarter, reaching the lowest number in 18 months. However, this is alongside a significant increase in the number of patients waiting for discussion at JCC.

Following discussion at Board in August 2024, the reporting measure switched from longest to average RTT wait. The average wait for paediatric surgery is now down to 20 weeks.

The interventional waiting list continues to show a reducing trend and is the lowest number for 18 months. Additional lists and weekend activity have helped with this.

Outpatient performance for Level 1 paediatrics (Bristol)

The new patient consultant appointment wait has increased to 50 weeks. Improvements had been seen throughout 2023/24 to 17 weeks. The reason for this significant bounce back was questioned as to whether this was an average or a data submission error. ER noted that the waiting list had reduced slightly due to additional evening clinics and noted that NHS England are implementing a push to have no >52 week waits by the end of March 2025.

- **Action**: ER and MJ to verify the data for the BRHC new patient consultant appointment waits.
- **Action**: ER and MJ to look at breaking down the BRHC data by specialty to provide more clarity.

The follow up waiting list for over 2 months, has reduced and is the lowest number for the past year. However, most patients (42%) have shifted from the 6-12 month wait group into the over 12 months wait.

The was not brought (WNB) rate improvement continues with the lowest rate in over 12 months, now sitting at 4%.

ER shared the key exception updates to note:

Key updates:

- Ad hoc EP additional lists (with thanks to GS) have eliminated the 65 week wait patients in September 2024 across paediatric electrophysiology in line with NHS England targets, however ad hoc lists are not as efficient. To address this sustainably, extra lab time and additional PAs are being requested through the business planning round, and it is acknowledged that a second EP consultant is needed.
- New leadership team has started in cardiac services with Tim Murphy as Clinical Director, Patricia Caldas as Lead for Cardiology, and Shafi Mussa as Lead for Cardiac Surgery. Thank you to Dr Tometzki and Mr Parry for their leadership over the past few years.
- New consultant interventional cardiologist (Dr Naychi Lwin) started in September 2024, carrying out peripheral clinics in Truro, however, is going on maternity leave soon – interviews for locum cover are planned at the end of November.

Risks/concern:

- Paediatric JCC significant increase in the number of patients waiting for discussion – the plan is to look at the flow and efficiency of the JCC, and ensure risks are being captured and escalated appropriately.
- Peripheral clinic consultant admin - Consultants are raising concerns around the significant and increasing administrative workload from the peripheral clinics. No funding currently exists for consultant administrative time in between clinics unless agreed by exception and MVF asked if this can be reflected in job plans. PC noted that there is also a disparity in the numbers of patients seen in clinics.

  AP shared that in Wales, admin time is linked to the number of patients seen – each patient has an admin tariff (average) – and this is incorporated in the consultant job plan, which gives a fair allocation. CK went onto suggest that the Service Level Agreement is re-visited. The Network is considering launching an outpatient review project in 2025/26.

  - **Action:** ER to review the peripheral clinic SLA document in relation to the peripheral clinic consultant admin allocation.

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

Level 1 adult CHD service

Surgical and interventional performance - BHI

The adult surgical waiting list has increased over the last 6 months from 18 to 26 patients. Improvement work around the adult JCC and increased throughput of cases discussed could potentially be impacting this. The average wait for surgery has remained status over the last 6 months with a slight decrease to 25 weeks this quarter.

Key service update - the number of patients awaiting interventional procedures continues to report an increasing trend – this could also be due to more patients going through the JCC MDT. However, the average wait for intervention has continued to significantly reduce due to extra ACHD lab time and extra weekend lists. CME and RB are meeting in December to review listings/scheduling to improve intervention throughput further.

	Outpatient performance for Level 1 adults (Bristol) The new patient consultant appointment waits have increased and now up to 32 weeks from 22 weeks last quarter – this is back to the volumes seen through 2023/24. Key update – to help mitigate this, slots for 'new patients' discussed at JCC are being ring-fenced to not delay their pathway to an intervention due to busy clinics. The follow-up backlog for over 2 months has reduced to 407 patients in quarter 2. This is by far the lowest number waiting over the past year and backlogs have halved over the past 9 months. However, over half of patients waiting are waiting over 6 months. The DNA rate was reported for the first time in 18 months, sitting at 7% for quarter 2. RB presented the key updates for the level 1 ACHD centre – in addition to the performance data already covered: **Key updates**: - BHI ACHD Clinical Lead - Dr Radwa Bedair has taken over this role – thank you to Dr Greg Szantho for his leadership over the past 3 years. - Extra cath lab lists - From September extra Saturday lists have been taking place regularly. The longest wait of 62 weeks (up from 54) is for specific patient(s) with individual needs. - Significant progress with the JCC waiting times and number of patients discussed per week, so that the average wait time is now a few weeks at most. - All the fellow and SpR posts are full, but there may be a possible gap from February 2025 to August 2025 which will impact clinic flow. **Risks/concerns to be escalated**: None noted at the meeting. **Actions/support required from the Network**: None noted at the meeting. Deep dive of backlogs - SC raised that for capacity/workforce planning, it would be useful for the BHI to do a deep dive into the backlogs and separate these by specialties to identify the level of non-CHD workload (such as ICC) that each consultant has, and whether support is needed within this. This impacts on CHD patient new referrals. RB agreed that this information would be useful.
4.	**Updates from Level 2 (Cardiff)**
	Level 2 paediatric CHD service: Performance update MJ updated that the new patient consultant appointment waits remain static since quarter 1 now at 33 weeks. This is back up to the length of wait seen in 2023/24 quarter 1 and 2. The follow up backlog over 2 months, has reported an increase (now at 181 patients), but this remains significantly less than 2023/24 Quarter 2 when it was 553 patients. A period of stability has now been achieved in consultant cover which may support improvement in waiting times. In addition, AP noted that many new waiters are about to be moved into the fifth and sixth consultant slots which may reduce the waiting list over the next few months. The was not brought (WNB) data was not available.

AP presented an update for the Level 2 centre:

Key updates:

- Achieved a period of consultant cover stability, however currently running with two locums (one for maternity cover and one covering a substantive post which is due to be advertised in the new year).
- Slow progress to appoint the 3rd sonographer via Child Health - scrutiny panel and advert pending.
- Welsh JCC (formerly WHSCC) funded posts across staff groups remain vacant and are being rejected by scrutiny panel despite central funding, e.g., secretarial support. JCC to take this forward in assurance meetings with Cardiff and Vale Health Board.

Risks/concerns

- Huge JCC discussion list - despite extra sessions to reduce numbers. Risk of catheters needing repeat before Fontan, risk of disease progression or adverse outcomes while awaiting discussion. NB: discussions need to be met with increased operating time to be truly effective in mitigating risks.

  AP noted that JCC monitoring is in a state of flux. PC agreed that the JCC is a recognised concern and that, following SC advice, the plan is to have a substantive consultant who supervises the list and to run a network survey.

  AP also raised the concern that following the JCC, patients are not formally added to the surgical list until they have been seen by a surgeon so are in limbo – this requires attention too.

Actions/support required from the Network: None noted.

Level 2 adult CHD service:

New patient consultant appointments are now down to 20 weeks, which is the lowest length of wait since March 2023. The follow up backlog for >2 months has also improved with 84 patients now waiting. HW noted the caveat that the Cardiff consultant team have made the decision not to book patients for follow up until 12 months as provision is not available – each consultant is responsible to assess patients if they require a follow up appointment sooner via e.g., telephone consult, CNS, 'hot' clinic. The DNA rate is 0%!

HW presented an update for the Level 2 centre.

Key updates:

- Waiting time for clinic remains at a year but new clinic appointments are seen within two months.
- Follow up appointment waits greatly helped by the "HOT Clinic" (see 3 patients every Tuesday) - assessed by ACHD SPR Dr Stephanie Connaire and ACHD clinical fellow Aisal Khan, overseen by Dr Masani.
  - PC asked how the 'hot' clinics work. HW explained that these clinics tend to be run by a middle-grade (meeting their training requirements and experience) and are overseen by a consultant who will attend clinic if needed, otherwise will discuss

the patients after the clinic. RB shared that the BHI also have a dedicated 'hot' clinic for patients who need clinical review within a short time for a specific/defined reason running since 2019 – this is run in the same way as it is in Cardiff.

- Hoping to advertise for 2nd ACHD consultant post to replace Dr Simon Macdonald. 3rd ACHD Consultant recruitment is still ongoing.
- Appointed to the CNS secondment position (started in August).
- BHF 'Moving Hearts Project' started its first sessions in mid-September and is progressing well.
- General cardiologist with expertise in cardiac MRI recently appointed who has two dedicated ACHD sessions for cardiac MRI – starts in January 2025 – hopefully in time will reduce the cardiac MRI waiting list.
- JCC discussion wait time reduced to 0 weeks for discussion which is fantastic - this is with the help of Dr Stephanie Curtis.

Risks/concerns:

- Since Dr Simon MacDonald left the team, the clinics are being managed by Dr Helen Wallis, Dr Nav Masani, Dr Wilson and SPR Dr Elinor O'Neill.
- Right and left heart catheter patients have been referred as appropriate to Bristol via Dr Helen Wallis to Dr Radwa Bedair.

Actions/support required from Network: None noted.

5. Updates from Level 3 centres (District General Hospitals)

Paediatrics – South West

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. The return rate was 78%. The two outstanding centres: Barnstaple have a historic data challenge, but they are working on this, and Exeter who have an excellent track record, currently have a workforce gap causing issues with extracting the data.

Outpatient performance

Taunton have reduced their visiting consultant new patient appointment waits to 0, whilst also reducing the local consultant waits from 35 in Q1 to 15 in Q2. Torbay have halved their wait for new patients to see the local consultant.

For follow up backlogs (>2 months), Taunton have reduced their local consultant backlog to just one patient (from 28 patients in Q1); Torbay now have no local consultant overdue backlog; and Swindon have eradicated the backlog for visiting consultant follow ups. However, there has been an increase in Gloucester for both local and visiting consultant – to mitigate this clinical validation of the waiting list is taking place, new follow up ratios for clinics are being reviewed to best meet demand and additional ad hoc clinics are being funded to support backlog recovery.

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

Key updates included:

- Since the self-assessment reviews, Taunton and Barnstaple have increased the cardiology PAs for their PECs.
- Taunton have appointed a new neonatal consultant (started in September) who has an interest in cardiology, and Swindon welcomed a new PEC in October, Dr Hanlon.
- Taunton are supporting physiologist led echo clinics to help reduce the waiting lists, and several cardiac physiologists across the South West are involved with the network training programme.

Risks/concerns included: Plymouth highlighted lack of fully funded nursing support (a common theme across the region) and issues with the interface of their ultrasound machine. Barnstaple are looking to lease another echo machine to address the waiting lists and are continuing to seek a solution re: parallel booking system.

Paediatrics – South Wales

Cwm Taf Morgannwg data was missing this quarter.

Outpatient performance

Hywel Dda Glangwilli visiting consultant waits continue to grow now at 111 weeks. There are concerns as to patient risk with this significant wait time, and a meeting is planned with the local team, Network and Level 2 centre to discuss further and consider support options. The local consultant waits are much lower at 34 weeks.

For the follow up backlogs (>2 months), Aneurin Bevan have been able to reduce their visiting consultant backlog, and the local consultant backlog remains static. Hywel Dda Glangwilli continue to have no wait for local consultant follow-up, but the visiting consultant remains in a similar position to last quarter with 47 patients waiting, most over 6 months. Swansea Bay have seen a jump in the local consultant backlog from 5 to 20 patients with the majority sitting between 2 to 6 months, however the visiting consultant backlogs have halved from Q1.

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

Key updates/concerns included: Hywel Dda Glangwilli are genuinely concerned about the new patient waiting times to see visiting specialists, as clinic capacity does not meet current demand. Managers are now collaborating with commissioners and hoping for more tertiary support, and the PECs are running extra clinics including at weekends. The plan is to meet with the Network as mentioned earlier to discuss further.

Actions/support required from the Network: Swansea asked for network or national guidance on governance around stand-alone paediatric physiologist-led clinics.

Adult CHD – South West

Most centres provided a return for Q2, except for Barnstaple and Swindon.

Outpatient performance

For the new patient consultant appointment waits, Gloucester's wait has reduced for both local and visiting clinics. Plymouth have seen a jump in local consultant waits to 60 weeks, the highest length in 18 months. Exeter remains concerned at the current length of wait and have noted that the number of new patients entering the service is high. RB (as the visiting consultant for Exeter) added that this is due to paediatric patients transferring, patients receiving follow up in London

being transferred back as the service is more established now, and patients who are re-locating to Devon. The desire is to follow the Truro model and recruit a ACHD consultant.

For the follow up backlog (>2 months), Truro have made good progress in gradually tackling their backlogs over the past year. Exeter backlogs have crept back up following reductions seen a year ago – the service have calculated that much more capacity is required to be able to address the backlog and new to follow up ratios are to be explored.

Key updates:

- Taunton are running two young people clinics per year with a youth worker present and have plans for a ACHD consultant to attend transition clinics.

Key risks/concerns:

- Exeter is significantly behind with ACHD follow up and new outpatient appointments, and the visiting ACHD specialist and local consultants do not have job plan time to increase clinic numbers.
- Torbay reported no visiting consultant clinic in the last quarter, and this is being looked into.
- Taunton need to progress plans for succession of a local nurse post, and Gloucester are facing funding challenges to continue the successful local ACHD CNS post.

Actions required from Network: None noted.

Adult CHD – South Wales

All centres provided a data return.

Outpatient performance

New patient consultant appointment waits for Hywel Dda (Glangwilli and Withybush) have increased. Swansea Bay local waits have doubled since last quarter.

The follow up backlog (>2 months) for Aneurin Bevan have increased for visiting clinics to levels last seen in Q1 2023/24. Swansea Bay has an increasing trend in their local backlog.

Key updates – included in the papers.

- Centres reported low levels of DNA rates, and Princess of Wales Hospital 10% DNA rate equated to two patients due to the cohort size.
- Princess of Wales Hospital (Cwm Taf) – HW updated that this service has a significant backlog (11-month delay beyond desired follow up) but the clinic is well supported by the local consultant who is doing best with this.
- Prince Charles Hospital (Cwm Taf) have successfully introduced two new clinics (4 per year instead of 2) and take up has been good as patients are being seen nearer to home – with thanks to Dirk Wilson.
- Swansea Bay – HW reported that this service is a growing concern as the Associate Specialist (Martin Heatley) who supported the clinic (with DW) has now retired from this and there is no succession plan. HW has escalated to the Clinical Lead that cover is required.

  Swansea ACHD service also only has one decent echo machine available for the Monday afternoon clinic, limiting the number of patients who can be reviewed in clinic (max. 7) – HW has escalated this locally as a governance issue. AP added that the reluctance to share the Singleton paediatric echo machine is that it is for neonates so for infection control reasons is

	kept in the NICU. HW has also offered to increase visiting clinics for a full day (Thursday) but is awaiting clinic space. In good news, DW is now running a transition clinic at Singleton. - <u>Aneurin Bevan</u> only had 25 patients booked this quarter with two clinics. HW has raised concerns about the service being significantly behind on follow ups and has asked the service to validate the waiting list. An ongoing request has been raised with the Health Board for a local consultant to support the clinic. o **Action –** HW, SC and MJ to meet to discuss the escalation of the Aneurin Bevan and Swansea Bay ACHD provision concerns. **Risks/concerns** - Royal Glamorgan (Cwm Taf) visiting ACHD specialist has been absent since June 2024 and HW kindly started supporting this from October on a monthly basis as an all-day clinic until the vacancy is appointed to.
6.	**Patient and family representative update**
	FC updated that the patient representation team were involved with the Network annual report providing their reflections of 2023/24. She praised the 'Moving Hearts' pilot project (a 6-week course in Cardiff with Elinor Mccormac, Anna Mcculloch and the ACHD CNS team) and the confidence this has given patients involved. This also focuses on the psychological side e.g., 'exercise' can have negative connotations for heart patients, yet replacing this with the term 'movement' is more empowering. This involves follow-up too. The Welsh team have also been running patient engagement art classes, which is an opportunity to build connections with others who understand life with a heart condition. NM added that she is a PPV voice on the NHS England Clinical Reference Group – includes ongoing discussions about workforce and a project group with Andrew Parry on equitable access. AD shared her recent patient experience in Withybush when her appointment was partially cancelled due to the consultant and CNS being unavailable, and yet the ECHO checks still went ahead, and the consultant phoned her afterwards to discuss the results. AD really appreciated the flexible way of working and that the appointment was not fully cancelled given the waiting list and the travel/work arrangements already made by her partner. The Board thanked the patient representatives for their feedback and positive updates. The Board was reminded that <u>*if a project involves patient care, a patient rep should be involved*</u>.
7.	**National and regional updates**
	<u>Commissioner updates</u> **NHS England, Southwest** - presented by CK. **Key updates** including: - **Women & Children Network Programme Board (held November)** – the Network reported on their work programme exceptions and value for money framework – looking at the outcomes achieved. Will be expecting the Network 2025/26 plan on a page with a more detailed workplan early next year. - **Commissioning delegation** – continuing to work towards April 2025 for the Specialised Commissioning team to transfer to the Somerset Integrated Care Board (ICB) who will host a collaborative commissioning hub. Networks are seen as a valuable vehicle to deliver

transformation.

- Greater focus on **Paediatric Critical Care pressures** from the national team, with daily reporting of the escalation status. Pressures are already being seen which will unfortunately impact on paediatric cardiac surgery.
- **Engagement day for all Networks** held in November 2024 – focusing on regional and national level activities, such as delegation, and provided the opportunity to scope work projects that span more than one Network e.g., voluntary sector. CK praised the CHD Network for their excellent patient representative work.

Risks/concerns:

- Waiting list recovery – visibility of longest waits and potential harms.

NHS Wales Joint Commissioning Committee (formerly known as Welsh Health Specialised Services Committee, WHSSC), South Wales – presented by AL.

Key updates including:

Adult

- Phase 3 ACHD investment planned recruitment is complete but additional recruitment (separate from investment) is taking place because of recent staff changes. Efforts to secure CMR from private providers is ongoing as of discussion in October 2024
- Cardiff and Vale University Health Board Cardiothoracic Surgery was successfully repatriated from University Hospital Llandough to the University Hospital of Wales during September 2024. This involved a two-week period of scaling back or pausing activity and a small number of emergency procedures being provided by Swansea Bay University Health Board and University Hospitals Bristol NHS Foundation Trust. Some corollary impact on other cardiac services, but all parties agreed that the repatriation had gone extremely well.
- NWJCC continues to undertake Phase 2 of its review of Cardiac Surgery and Interventional Cardiology across South Wales (the 'NWJCC Cardiac Review'), now working in partnership with Cardiff and Vale and Swansea Bay University Health Boards via the Regional Specialised Services Provider Planning Partnership (RSSPPP). CHD provision is not in scope, but clinicians and stakeholders will be advised of progress given possible long-term implications for commissioned services.

Paediatrics

- Cardiac surgery services in Bristol remain at level 0 escalation as reported previously. This routine monitoring involves performance monitoring and submission of the agreed reports monthly to NWJCC. Data has not been received recently and so discussions taking place to progress as this level of assurance is required.

  - **Action:** AL to ask RP to report back on SC query re: commissioner view on Aneurin Bevan (and Swansea) ACHD Health Boards limiting patient support due to financial provision, when other areas Health Boards are providing the service.

<u>**National**</u>

<u>British Congenital Cardiac Association, Dublin (November 2024)</u>

	BL updated that BCCA Dublin national conference was hosted this year by the All-Island CHD Network – like us this network spans two countries providing interesting reflections in this respect. BL presented on 'developing the nurse specialist role in a Level 3 centre' which was well received, and she has since been invited to speak at other Network's meetings who are keen to explore a similar approach. The attendance was lower than usual perhaps due to cost/overseas travel. <u>CHD Network of Networks Annual Meeting (November 2024)</u> MJ and BL attended the National CHD Networks Annual Meeting, with 60 attendees from all England, Wales and Ireland CHD Networks represented. Whilst there was little opportunity for strategic forward planning, this was an excellent informal networking opportunity to discuss shared priorities and challenges.
8.	**Network Update 2024/25**
	<u>Network updated report</u> SV updated on some key highlight achievements from August 2024 to date, noting that the Network have completed the South West England self-assessment reviews and attended a Cardiff site visit hosted by the CNS teams. Following discussions at the self-assessment reviews and the PEC forum held in Exeter (September), SC has created a Network pregnancy and contraception risks and advice guideline for clinicians. A directory of key learning and disability staff contacts across the Network to share learning and best practice is currently being finalised for publication in December. The focus of the website refresh this quarter has been the research and psychology pages. Education opportunities have included the PEC forum held in Exeter (September); the ACHD ECHO webinar series; and the Network ACHD study day (October) focusing on Tetralogy of Fallot. The research forums have continued with good attendance. <u>Annual report 2023/24 - published</u> The annual report has been circulated to Network members and stakeholders and is also tabled at various forums such as the NHSE South West Women's and Children's Programme Board, the UHBW Host Trust Public Board and the BRHC Divisional Management Board. This is an amazing reflection of what has been achieved together as a Network over 2023/24 and was collated with input from members across the Network. Thank you to all involved. <u>JCC</u> In summary, SC reported that 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. The Network team met with the Level 1 ACHD leads to discuss the findings and many recommendations have now been implemented. A revised terms of reference for the JCC has been drafted. Significant improvement to performance has already been identified since changes were made in both the numbers of cases being reviewed and the reduction of the Adult JCC waiting list (reduced by 87% in 4 months!). There has been excellent engagement and much positive feedback. The JCC requires strong leadership to manage this effectively, with allocated job plan time for the preparations required. The Board thanked SC for all her hard work on this significant transformation.

- **Action**: JCC slides to be circulated with the Board minutes.

South West England self-assessments

MJ outlined the purpose of the self-assessment reviews, which are held every 3-5 years to benchmark services against the NHSE 2016 standards and provide assurance. The findings of the reviews help to inform the Network workplan and ongoing priorities.

Since 22nd May 2024, 17 of the 17 review meetings have been completed with all self-assessment returns submitted in advance. Thanks was given for the excellent engagement from centres. The process has celebrated areas of success and high quality, and noted areas of shared challenge and opportunities for supportive improvement.

The Network team agreed a position for some of the Network and Trust infrastructure standards that were open to interpretation to ensure consistency in compliance scoring across the region.

Given the commitment made by members, and to focus any improvement to the process for the future, a quick feedback survey was conducted. The feedback received was positive overall with the majority finding the self-assessment process a beneficial and valuable exercise to review service provision, with the right people in the virtual room. There were a couple of comments that the review meeting felt 'rushed,' and this was due to the over 150 standards to go through during the review.

Visual output documents for each local service have been circulated, which some have found useful to share at their local Trust/governance meetings. The paediatric centres consolidated findings and benchmarking report outlining the overall outputs from the reviews across the South West region has also been circulated.

In summary, the findings showed that the overall compliance for adults is between 80-97% and for paediatrics is 83-96%. There are several examples of excellence and innovation including the cardiac physiologist-led clinics for new paediatric patients; the MDT transition clinics; the JCC referral trackers; local CHD nurse led clinics. Many of these reflect the Welsh reviews too.

There are also several themed areas of Network-wide challenges to support, including the unfunded or inadequate local CHD nursing resource; inadequate time in consultant job plans; risks to local services due to standalone workforce; inconsistent delivery of patient transition. The national challenges are the database, cardiac rehab for ACHD patients and access to community dental.

The next step is to complete the adult findings and benchmarking report now that the last two rescheduled ACHD reviews have been held. A key findings summary and recommendations report for executive decision makers will also be produced as a supportive measure, which is intended to fit well with the business planning timelines for investment proposals. The Network will also prioritise areas for focus for the Network workplan 2025/26 taking a risk-based approach, and consider how innovation and success can be shared, perhaps via Network stakeholder events in 2025/26.

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 contact the core Network team if they would like to discuss the plan further or be involved in any workstreams.

Plans are in place to develop the Network workplan for 2025/26, 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.

9.	**Spotlight on South West Neonatal Service – Dr Adam Smith-Collins**
	Dr Adam Smith-Collins, Clinical Director for the South West Neonatal Network, presented an informative update on working together for neonates with congenital heart disease. He commenced with an overview of the Neonatal Network and the broad areas of their work. Moving onto report that a considerable proportion of congenital cardiac work is relevant to neonatal care. In 2023, 67 infants with CHD were admitted to a neonatal unit in the South West, and 59 of these were admitted to St Michael's Hospital NICU (Bristol). The most common diagnoses were Hypoplastic Left Heart, Tetralogy of Fallot, and Transposition of the Great Arteries. Some of these cases can be incredibly challenging to manage in the first few days of life. A co-ordinated approach through fetal medicine, neonatal care, cardiac intervention, and post op care is of essence, as is sharing learning from outcomes and families' experience of care. There are a considerable number of neonatologists and PECs who undertake some degree of scanning in the region, and there has been an increase in scrutiny and accreditation around this, with consideration on how to work together effectively on this. There has also been a national rollout of pre- and post-ductal saturation screening in neonatal services to identify early diagnosis, but this does cause a screening burden for patients and services. Another approach is neurodevelopment MDT follow up of high-risk cardiac infants. The Board thanked Dr Smith-Collins for his time.
10.	**Any Other Business**
	- Board membership – Need to ensure members send a nominated deputy if unable to attend. - Next Board Meeting, Thursday 13th February 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.
11.	'Live' feedback on the meeting

Attendees

Name		Job Title	Organisation	26-11-24
Adrian Wagstaff	AW	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Present
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Present
Amanda Davies	AD	Patient Representative		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
Becky Nash	BN	Patient Representative		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

Name		Job Title	Organisation	26-11-24
Elinor O'Neill	EON	SpR	Cardiff, University Hospital of Wales	Present
Emma Whitton	EW	Commissioner	NHS England South West	Present
Frankie Carlin	FC	Patient Representative		Present
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Present
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Maria Velasco Forte	MVF	Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Marion Schmidt	MS	Consultant Paediatrician	Newport, Royal Gwent Hospital	Present
Michelle Jarvis	MJ	CHD Network Manager	CHD Network Team	Present
Nicola Morris	NM	Patient Representative		Present
Oliver	ON	Patient		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
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present
Stephanie Curtis	SC	Network Clinical Director / Consultant cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present
Adam Collins-Smith	ASC	Clinical Director, Neonatal Network	SW Neonatal Network	Present