

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

**Date:** Thursday 10<sup>th</sup> August 2023, 14.00 – 16.30

**Venue:** Microsoft Teams Conference Call

**Chair:** Dr Dirk Wilson

### Minutes

Item	Notes and Actions
<b>1.</b>	<b>Welcome, introductions and apologies</b>
	<p>DW welcomed the attendees to the Network’s virtual board, sharing the digital meeting etiquette and noting the Microsoft Teams chat question function is available. This meeting was re-arranged from July 2023 due to the doctor strikes.</p> <p>The Board welcomed Beth, Amanda, and Holly, as the new patient representatives and others attending for their first time - Imogen Payne, new Youth Worker for Youth At Heart; Idoia Grange, Consultant Cardiologist at Bristol Royal Hospital for Children; David Withers, ACHD Link Nurse from Gloucester; Sophie Nicholls, General Manager Bristol Heart Institute.</p>
<b>2.</b>	<b>Approval of minutes and action tracker</b>
	<p>The minutes of the Network Board on 19<sup>th</sup> April 2023 were agreed to be an accurate record.</p> <p>The action log was updated as appended. Notable comments:</p> <p><b><u>179 – Digital storage</u></b>            Logged on Network’s issues log. SC has raised this issue with the Exeter paediatric service management who advised that this is due to not having capital funding (around £30k) for the digital archiving of DVD paediatric ECHOs (notably Exeter ACHD has already done this as have the other centres in the South West). SC has been seeking advice from Martin Nelson, an ECHO expert in Bristol, who attached the legal position from the Royal College of Radiologists noting that this a legal necessity. A cloud-based storage system is planned to be initiated throughout the South West of England in 2024 to cover all imaging.</p> <p>Consultants NO, JT and CA who were at the Board meeting reiterated that this is a significant and ongoing problem for local and visiting cardiologists, particularly for JCC presentation, that needs to be addressed. This also raises information governance concerns.</p> <p>The Board agreed that the Trust’s mitigation and timeline to solve the problem was required.</p> <ul style="list-style-type: none"> <li>○ <b>Action:</b> SC to contact Spec Comm Medical Director and draft a joint letter to the Exeter Medical Director re: mitigation and timeline to solve this ECHO storage problem.</li> </ul> <p><b><u>183 – Surgical pressures</u></b> – This is a national issue and discussions are taking place at a national level to understand the capacity for mutual aid. Closed.</p> <p><b><u>182, 184, 185 &amp; 186</u></b>– closed.</p> <p>No further actions to report on.</p>

	<p><b>Board Terms of Reference and membership</b></p> <p>LH outlined that the Board terms of reference were due for review in summer 2023. In 2023, the Network team has increased Network involvement in the delivery of priorities and work streams via task and finish project groups.</p> <p>Amendments noted:</p> <ul style="list-style-type: none"> <li>- Widening of participation – Board membership comprises of ‘core Board membership’ and ‘wider Board membership.’</li> <li>- Network members invited to attend meetings if discussions require input from representatives with expertise.</li> <li>- Performance reporting - to reference both inpatient and outpatient performance.</li> </ul> <p>The Board approved the proposed amends to the Terms of Reference subject to any subsequent national guidance (awaiting publication of national CHD Network specification).</p>
<b>3.</b>	<b>Patient Story</b>
	<p>The Board listened to Bethan’s pre-recorded story, as a 16-year-old born in Wales with complex transposition of the great arteries (TGA) and multiple ventricular septal defects (VSDs). Subsequently over the years, Bethan underwent an atrial septostomy (2007), Mustard procedure (2009), and ablation (March 2023). She experienced exercise intolerance with desaturation, breathlessness, and atrial arrhythmias.</p> <p>Bethan shared her memories of her childhood experience and how she looked forward to seeing her local consultant team as they put her at ease, and her teenage experience in that she was grateful to her caring clinical teams for talking to her directly and taking the time to ensure she fully understand her heart. She recommended that a teenage area on the inpatient ward would have been good and the challenges of living on the periphery of the Network with travel expenses and time to get to appointments (it would take several hours to travel from West Wales to Bristol appointments).</p> <p>Bethan shared the day-to-day struggles living with a heart condition both physically and mentally. School life was hard as she felt treated differently and missed out on normal activities, sometimes being bullied. How she would sometimes struggle with daily activities and have disagreements with others about her physical capabilities and limitations due to her heart condition. Bethan shared the importance of getting children and young people with heart conditions, and their parents, connected via support groups and raising awareness of CHD.</p> <p>Bethan has recently met her new transition clinical nurse specialist to discuss moving to adult services, but doesn’t feel prepared/ready to transfer yet and feels nervous about meeting new doctors and nurses. She recommended that information on this is shared with patients at the younger age of 14, and that ideally transfer appointments are held at patients’ local hospital.</p> <p>Bethan praised the excellent medical care she has received and the communications.</p> <p><u>Key points discussed following the presentation:</u></p> <p>The Board were grateful to Bethan for sharing her story so well (also to Jenni Stirling, Hywel Dda Long Term Conditions Nurse, for her support) - it was very moving to hear. DW reflected that this showed the importance of listening to what patients are saying - it was noted that whilst best efforts were made e.g., letters sent to school and school visits arranged to encourage understanding and support, it is hard when these efforts aren’t fruitful. Travel and financial support for patients to get to appointments further away from their home is also a recognised</p>

	<p>challenge.</p> <p>Amanda and Holly offered to provide patient support.</p>
<b>4.</b>	<b>National and regional updates</b>
	<p><u>National update</u></p> <p>LH provided a brief national snapshot:</p> <ul style="list-style-type: none"> <li>• <b>CHD Clinical Reference Group (CRG)</b> re-established in April 2023 will have oversight of the national CHD work programme meeting on a quarterly basis. Representatives from South Wales and South West: Susie Gage, Pharmacy Lead, Andrew Parry, Cardiac Consultant Surgeon, and Nicola Morris, parent rep. The first meeting held in May 2023 focused on purpose of CRG, NHS priorities, team member expertise and developing vision and strategy. The national areas of focus include CHD workforce, data, modernisation of the service specification and standards.</li> <li>• <b>National CHD network of Networks</b> meet monthly. A face-to-face meeting is being hosted in Bristol in November 2023, which Dirk has agreed to Chair – the agenda is currently being finalised and sponsorship sought. This will include discussions on approaches to research, workforce, and the waiting list challenges.</li> <li>• <b>National CHD work programme</b> is focusing on performance and data collection; national consensus pathways; and workforce. <ul style="list-style-type: none"> <li>○ National consensus pathways – this is being led by the CRG Paediatrician with Expertise in Cardiology representative with the objectives to: recommend evidence based best practice/patient care; collaborate and standardise approach in terms of referral pathways, diagnostic tools and treatment; agreed clinical approach across level 1, 2 and 3 centres; agreed clinical approach across Networks; and to recognise and allow for variations amongst centres. LH gave the heads up that clinical representatives from the regional Networks will be invited to get involved with helping to create or improve pathways. The Network approach will allow feedback on local variations in practice and resource availability, which will help to create ‘fit-for-purpose’ and realistic consensus pathways.</li> </ul> </li> <li>• <b>CHD workforce in England and Wales</b> – had 100% response rate from centres across the South Wales and South West CHD Network – thank you to all who were involved. This national data collection project compared the expected workforce numbers as recommended by the NHSE national CHD standards with the workforce in post (with several caveats). This also helped to inform the South Wales self-assessment reviews. LH presented the key findings, most notably that adult services have a deficit against required workforce numbers.</li> <li>• <b>BCCA national annual conference</b> is being held at the Delta Marriot, Bristol, on 13<sup>th</sup> and 14<sup>th</sup> November 2023.</li> </ul>

### Commissioner updates

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

- **Key updates:**

##### **Adult CHD**

- **Phase 3 ACHD business case** was initially submitted to the WHSSC Management Group in March 2022 by the level 2 ACHD centre (Cardiff), and further to questions, was approved in March 2023. A funding release letter for the requested service resilience and CMR resource has since been issued (dated 26 April 2023), and the required recruitment is understood to be in progress. This is an additional consultant post (50% cardiac imaging and 50% CHD - job plan to be worked out).

##### **Paediatric CHD**

- **Cardiac surgery delays** and the impact on Welsh patients continue to be monitored. Due to lack of reassurance, WHSSC plan to follow formal protocols regarding concerns with the current service provision for paediatric cardiac surgery at Bristol Royal Hospital for Children.
- **Action/support required from the Network** – None noted at the meeting.

#### **NHS England, Southwest**

Presented by CK

- **Key updates** including:

- **ODN 2023/24 workplans** – NHSE Business Intelligent team (data analysts) are working directly with Networks on outcome measures and the development of Operational Delivery Networks dashboards. Looking at how can easily demonstrate the values of Networks – lots of great work.
- **Women's and Children's Programme Board** – next meeting 15<sup>th</sup> August. This will focus on the Network annual reports, value for money, and update on workplans (by exception).
- **Children and Young People elective recovery** – there have been additional challenges such as medical strikes. Several tools have been developed to support prioritisation at a regional level to focus on system plans.
- **Cardiac waits** – similar challenges across the country. Request for mutual aid but very few providers in a position to support this. National CHD Networks group meeting regularly and share good practice from across the country.
- **NHSE** – Further to consultation, Specialised Commissioning are moving into a Collaborative Commissioning Hub from April 2024, drawing together expertise.
- **Risks/concerns to be escalated to a national level** – Waiting list recovery and restoration – visibility of longest waits and potential harms.
- **Actions/support from the network:** ODN intelligence of risks and issues in relation to recovery and restoration to be escalated regionally and nationally.

5.	Network Performance Dashboard
	<p><u>Key headlines from Quarter 1 Network Performance Dashboard</u></p> <p>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.</p> <p><u>Response rate</u></p> <p>The response rate from centres is positive with 100% for all paediatric and ACHD centres returns for level 1 and level 2, and slightly lower for level 3. Thank you to centres who submitted these. There remain a couple of ACHD level 3 centres who have routinely not provided the information required, and we work with centres to explore any barriers.</p> <p><u>Outpatient performance</u></p> <p>LH outlined the outpatient performance, notably for waiting times for new patients and overdue follow up backlogs (please refer to the paper for details). Of note is that the Bristol Heart Institute shows a significant increase in overdue follow up backlogs over the last year, however hopefully new fellows and additional consultant post will help turn this around. Positive downward trends in the follow up backlog are being seen in Bristol Royal Hospital for Children, Cardiff, Aneurin Bevan, Swansea Bay and Plymouth.</p> <p>SM mentioned that waiting times in Bristol paediatrics is still a challenge and there is a working group looking at patient flow through outpatients. A key change is the development of cardiac physiology led clinics, which is more time-efficient and parent feedback is positive. CA reported that the significant challenges at Bristol Royal Hospital for Children is lack of space to run outpatient clinics and the waiting list. Retired consultant colleague Alison Hayes returned to help reduce waiting list in the short term. Been temporarily granted some funding to appoint Inherited Cardiac Conditions (ICC) band 7 nurses to help screen high risk patients – in the meantime waiting to see whether NHSE will commission ICC services separately.</p> <p><u>Did Not Attend (DNA)</u></p> <p>High DNA rates in paediatric CHD in Royal Glamorgan (CTM Health Board). Prince Charles Hospital, also part of the Cwm Taf Morgannwg Health Board, shared positive practice on this at the recent self-assessment review.</p> <p><u>Inpatient report – year to date trends for Level 1 (Bristol)</u></p> <p>For surgical, the key headline is the increase in the paediatric surgical waiting list – to be discussed under item 8. The adult waiting list remains static, and a wider theatre utilisation project is underway.</p> <p>For intervention, whilst there is an upward trend in paediatrics, for adult services the trend data is reducing. SN noted that a new cardiology cath lab has been opened, which includes an additional weekly session for CHD.</p> <p><u>Review of Network Performance Dashboard – online survey results</u></p> <p>Following Board endorsement in April 2023, service leads were invited to feedback on the Network performance dashboard and data collection process, via an online survey in May-June 2023. This</p>

coincided with the workforce strikes and other information requests, so the response rate was lower than expected.

The results and feedback showed that overall centres found the Network performance data requests easy to extract and felt this data was accurate. It noted that no guidance is required; however, the Network remains open to provide support if service leads need it.

The Network performance outpatient dashboard is published on the Network website on a quarterly basis and enables centres to access their own centres' submitted data, with trend graphs displaying the submitted data over the quarters. As part of a quality improvement project, Swansea Bay paediatric CHD centre have used the data to assess the impact of the physiologist-led clinics on the waiting list which showed a significant reduction. This data has also been used to support business cases for recruitment, for example the successful bid and appointment of a consultant paediatrician with expertise in cardiology in Swansea. Following feedback and consent from the Level 1 centres and as there are no information governance concerns, the Network will look to publish the CHD inpatient dashboard in the future too.

Most feedback from the survey, and also from the recent self-assessment review, was around the data timeframes and the value in presenting full data sets i.e., end-of-quarter reporting. The options presented to Board was therefore to either continue with mid-quarter snap shots or shift back to end of quarter reporting but bring the Board dates forward from April 2024 to avoid a 'data-lag' – this would mean centres providing returns in a more-timely way (after the 10<sup>th</sup> of the month when data is usually available).

**The Board agreed to revert to end of quarter reporting and pilot the new proposed Board dates from April 2024.**

Dates for CHD Network Performance Reporting – 2024/25					
Quarter	Months	Data requested	Data return deadline (2 weeks later)	Dashboard populated & finalised – report drafted	CHD Network Board
Quarter 1	Apr-Jun 2024	Mid July	End July	Early Aug	Late Aug
Quarter 2	July-Sept 2024	Mid Oct	End Oct	Early Nov	Late Nov
Quarter 3	Oct-Dec 2024	Mid Jan	End Jan	Early Feb	Late Feb
Quarter 4	Jan-Mar 2025	Mid April	End April	Early May	Late May

National data collection developments

Level 1 (Bristol) has provided monthly national returns via the Network to NHSE since 2020. This includes the number of patients waiting and capacity calculations; a count broken down into CHD surgical and catheter intervention; and the number of hospital-initiated cancellations. NHSE shares the results via monthly presentations to the CHD network of Networks group.

- **Action:** LH to circulate the NHSE monthly level 1 presentation to the Board.

Recently NHSE have asked Networks to comment on a new 'under development' data collection template for this (produced by Birmingham). The stated purpose is to facilitate meaningful

	<p>benchmarking to prove need for investment regionally and nationally. The Board raised concerns about the significant level of extra data required and the time this would take to retrieve for the level 1 centre that are already facing staff time/capacity pressures.</p>
<b>6.</b>	<b>Update from Level 3 centre(s)</b>
	<p>The key updates are outlined in the exception report in the papers.</p> <p><b><u>Adult CHD:</u></b></p> <p>Key themes to note for adults included:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> Included in the papers. <ul style="list-style-type: none"> <li>○ Business plan still in progress for permanent funding for ACHD nurse hours (Taunton).</li> </ul> </li> <li>• <b>Key risks/concerns:</b> <ul style="list-style-type: none"> <li>○ Waiting lists continue to be a concern across South Wales.</li> <li>○ Succession planning with future retirements (Exeter).</li> </ul> </li> <li>• <b>Actions/support required from the Network:</b> <ul style="list-style-type: none"> <li>○ Support for ACHD echos whilst waiting for substantive appointment – asked about possibility of a Bristol visiting echocardiographer (Truro).</li> <li>○ Funding to support recruiting an ACHD nurse (Barnstaple)</li> </ul> </li> </ul> <p><b><u>Paediatric CHD</u></b></p> <p>NO led an update for southwest – the key themes to note for paediatric level 3 centres included:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> Included in the papers. <ul style="list-style-type: none"> <li>○ For the southwest, there are ongoing issues of increasing referral numbers, difficulties with new patient and follow up capacity, and increasing innovation of different ways to meet these needs with e.g., physiologist-led clinics in Exeter. DNA rates remain stable between 4-6% despite efforts to reduce these.</li> <li>○ Taunton held their first pilot cardiology transition clinic in June 2023 with positive feedback from patients/families and a few learning points to implement. Swindon are planning a quality improvement project to improve transition arrangements locally.</li> <li>○ Barnstaple and Taunton both grateful for level 1 led physiologist training support with Owen Burgess teaching programme, notably training adult cardiac physiologist in developing paediatric skills.</li> <li>○ For South Wales, improved clinic utilisation in Glangwili. Swansea Bay updated that there has been excellent progress since the self-assessment review (held May 2023) and a business case written for paediatric ward refurbishment.</li> </ul> </li> <li>• <b>Risks/concerns to be escalated:</b> <ul style="list-style-type: none"> <li>○ Digital storage in Exeter (please see agenda item 2).</li> <li>○ Waiting list backlog issues and lack of psychology support for complex patients in Hywel Dda (Glangwili and Withybush).</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>● <b>Actions/support required from the Network:</b> <ul style="list-style-type: none"> <li>○ Continuing with encouraging SLA roll out, communications project group, and transition pilot to improve services network-wide.</li> <li>○ For South Wales, acknowledging the risks of waiting list backlog issues in Hywel Dda and lack of psychology support for complex patients.</li> </ul> </li> </ul>
<b>7.</b>	<b>Update from Level 2 centre</b>
	<p>SF presented an update for the Level 2 centre - the key updates are outlined in the exception report in the papers. Notable comments included:</p> <p><b><u>Level 2 adult CHD service:</u></b></p> <ul style="list-style-type: none"> <li>● <b>Key updates:</b> <ul style="list-style-type: none"> <li>○ Good news that Clinical Fellow post currently being advertised on NHS jobs and BMJ careers site.</li> <li>○ ACHD physiologist led/CNS supported ECHO clinic starting in early September for simple lesions initially to try and reduce the wait for routine follow up.</li> <li>○ Additional ACHD outreach clinics in Cwm Taf Morgannwg and Aneurin Bevan are being run by Dr Masani and Dr Wilson to try to tackle waiting lists.</li> <li>○ Additional funding for wellbeing support group to run until December 2023 with an assistant psychologist from the Covid-19 rehab team to support.</li> <li>○ Xander (Youth at Heart Youth Worker) is attending transition clinic appointments in level 2 and 3.</li> </ul> </li> <li>● <b>Risks/concerns:</b> <ul style="list-style-type: none"> <li>○ Still significant waiting list backlog in Aneurin Bevan Health Board – currently there is no ACHD local cardiologist, and this concern has been escalated.</li> <li>○ Lack of space in Swansea for HW clinic so still being held virtually.</li> </ul> </li> </ul> <p><b><u>Level 2 paediatric CHD service:</u></b></p> <p>DW presented an update for the Level 2 centre:</p> <ul style="list-style-type: none"> <li>● <b>Key updates:</b> A funding opportunity for waiting list clinics lapsed and this request will need to be re-submitted.</li> <li>● <b>Risks/concerns:</b> None noted.</li> <li>● <b>Actions/support required from the Network:</b> None noted.</li> </ul>
<b>8.</b>	<b>Update from Level 1 centre</b>
	<p>The key updates are outlined in the exception report in the papers.</p> <p><b><u>Level 1 adult CHD service</u></b></p> <p>SC presented the key updates for the level 1 ACHD centre:</p> <ul style="list-style-type: none"> <li>● <b>Key updates:</b> Funding secured for substantive 5<sup>th</sup> consultant post which is out for advert.</li> <li>● <b>Risks/concerns to be escalated:</b> None reported.</li> </ul>

- **Actions/support required from the Network:** None reported.

### Level 1 paediatric CHD service

SM shared the key updates to note:

- **Key updates:** included in the papers.
  - Ed Roberts, new General Manager covering cardiology.
  - New appointments with Dr Jennifer Shortland starting as Consultant Paediatric EP in September 2023 (mainly Bristol-based but will also have some sessions in Cardiff). Dr Idoia Grange joined the team in May 2023 as a locum until May 2024 and is leading on transition.
  - Dr Camilla Snook, consultant fetal cardiologist, is returning from planned maternity leave in September 2023.
  - Dr Ines Hribernik, locum interventional cardiology consultant, is leaving in October 2023 to take a substantive post elsewhere. This will leave two substantive interventional cardiologists and one locum.
  - Potential retirements of two out of three senior consultant paediatric cardiologists.
  - Substantive imaging and interventional posts to be advertised/recruited.
  - CNS supported Inherited Cardiac Conditions (ICC) clinics are being piloted until September 2023, and a bid for further funding to extend this is being progressed.
- **Risks/concern:** Still facing significant challenges with outpatient waiting times – an established working group is looking at how to improve patient flow. A cardiac physiologist led echo clinic is being piloted with subsequent telephone follow-up by a consultant which seems to be working well from a patient perspective. Unsure what impact the clinics are having on waiting times as yet.
- **Actions/supports required from Network:**
  - Further discussion re: transfer of patients between Cardiff and Bristol.
  - Awareness of situation in other Networks in terms of operational performance and backlogs.
  - Support with rolling out the SLA when finished.

### Surgical waiting list

SM presented the surgical waiting list and the key concerns. The surgical waiting list is reviewed at a performance meeting held before the paediatric JCC every week. This covers the total number of elective patients waiting for cardiac surgery; the total number of patients in breach of the recommended treatment time; the total number of patients within 4 weeks of breaching the recommended treatment time; longest waiters; and the number of elective patients accepted for surgery within the last calendar month.

In addition to the historical challenges of Covid-19 etc, the current main challenges centre around staffing with PICU nursing and impact on bed availability, theatre staffing and perfusionist staffing vs. commitments. Also, urgent/emergency surgery (30-40% of the total paediatric workload)

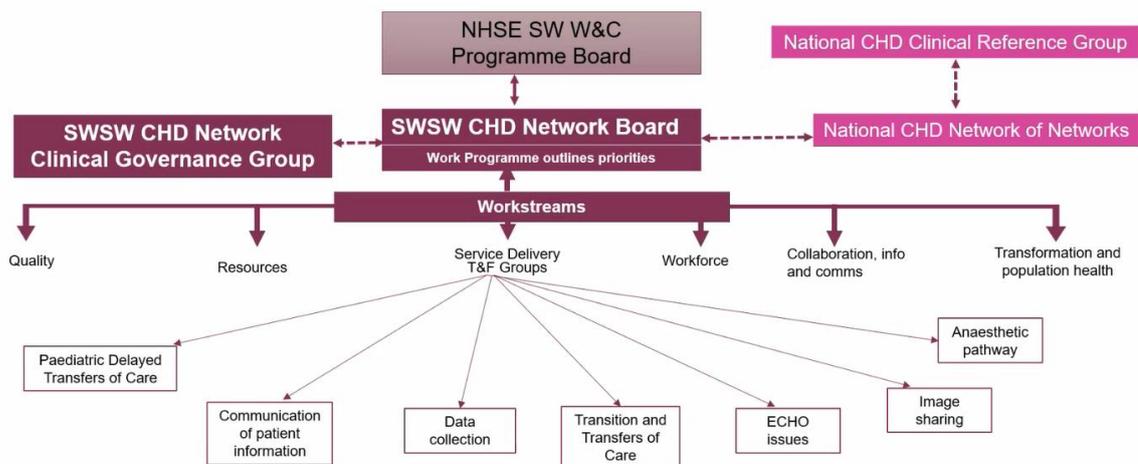
	<p>impacts the capacity for planning elective surgery. Recent strike action has also impacted the ability to deliver operating lists.</p> <p>The potential solutions include the aim to fully recruit the cardiac scrub team by the autumn; the plan to recruit additional PICU nurses such that BRHC PICU is staffed to 18 beds per shift; three additional High Dependency Unit (HDU) beds to improve patient flow out of PICU.</p> <p>Following a meeting with WHSSC, SM reported that BRHC have been providing fortnightly updates to the Welsh commissioning team on the Welsh patients that are undergoing surgery – they are being offered equal priority and treated the same as the patients from the South West. A further meeting with Kimberley Meringolo (WHSSC) is planned at the end of August.</p> <p>NO raised about the inefficiencies of having a long surgical waiting list in relation to the number of pre-admission appointments or diagnostic tests that time-expire and need to be repeated as a result. SM confirmed that data is collected on this with the aim of supporting the economic case for investment and increasing capacity so surgery can be delivered.</p> <p>SC referred to the delay in transfer project between Cardiff and Bristol which will also provide evidence on the wider issues impacting patient flow.</p>
<p><b>9.</b></p>	<p><b>Patient representatives update</b></p>
	<p>NM reported that she has been appointed as a parent representative on the NHS England Clinical Reference Group for CHD and can feedback at future Board meetings. She also works as a Heart Heroes Family Support Worker regularly visiting BRHC Dolphin Ward to support patient/families. NM explained that this also gives her much insight into issues families are experiencing – particularly around cancellations and the waiting list. NM highlighted that communication is key - when families are aware of what is going on and can understand the processes, they are generally more tolerant of changes. Families are very supportive of the efforts of hospital teams.</p> <p>NM and her son Callum who has CHD and has recently transitioned from paediatrics to adult services at the BHI with the support of Xander, did a recorded interview on their experience as a patient and parent for the Network transition study day in May 2023. It was noted that the Youth At Heart youth workers play a valuable role in transition by supporting the young person and their families through this. They will also be interviewed at the National British Congenital Cardiac Association (BCCA) conference with Dr Taliotis, being hosted in Bristol in November 2023.</p> <p>On FC behalf, NM shared that a book club is being set up for patients based in Cardiff and it is being looked at whether this approach can be rolled out in the wider Network. FC also created her own patient experience film for the Network psychology study day in June 2023 to give staff a better understanding of how patients feel, and this was very well received. In addition, FC has been involved with reviewing/commenting on an advanced care clinic letter.</p> <p>The Board thanked NM for the updates, and the new patient reps for joining the group. The Board was reminded that <i>if a project involves patient care, a patient rep should be involved</i>.</p>
<p><b>10.</b></p>	<p><b>Workplan 2023/24</b></p>
	<p><u>Research update</u> On the behalf of Dr Giovanni Biglino, LH presented his update slide noting areas that he would like</p>

to take forward as Network Research Lead:

1. To introduce a monthly research forum: part journal club, part forum for discussion; proposed launch October 2023.
  2. Projects being discussed with Dr Georgia Spentzou (survey on vaping habits amongst CHD adolescents and young adults) and Dr Katy Huxstep (neurodevelopment in cyanotic CHD) with intention/potential to extend across Network.
  3. To liaise with existing patient book club and contribute (liaise with Frankie Carlin).
  4. To launch a simple research repository (spreadsheet) to capture research outputs and facilitate reporting.
  5. A Bristol Heart Festival is being planned for February 2024: opportunity for public engagement including promoting and sharing CHD research.
  6. A major application is being prepared for a British Heart Foundation (BHF) Research Excellence Award building on current BHF Accelerator Award, around maternal health (Prof Deborah Lawlor) and CHD (Prof Massimo Caputo).
- **Action:** Dr Biglino plans to email the Network outlining the above and inviting those interested to contact him.

Network Workplan 2023/24 - structure and priorities

LH provided a recap of the Network reporting structure and how the work being undertaken fits into the workstreams and reflects the Network’s vision and objectives.



Network updated report (Quarter 1)

Please refer to the papers for further detail: quarter 1 update (April-June 2023); and the work plan 2023/24.

In addition to the key highlight achievements covered in the project updates, the Network published a Spring 2023 Newsletter, the 2022/23 Annual Report and undertook a nationally led network-wide workforce audit.

Annual report 2022/23

This was published and circulated in July 2023, and is also available on the [Network website](#). The report includes updates from centres and staffing groups, and the focus for 2023/24. Feedback is welcomed.

### CHD National Standards Self-Assessment Review in South Wales

Further to NHSE publishing the National CHD standards in 2016, the CHD Network proposed for these to be formally adopted in Wales with a vision of providing equity of access and seamless care across the Network. Following a request by the WHSSC Management Board, the CHD Network carried out a first round of self-assessment reviews for each of the Welsh Health Boards against the standards in 2021-22 (eight reviews in total with paediatric and adult CHD services reviewed separately).

A recommendation report (including the action plans for each Health Board) was presented back to the WHSSC Management Group in December 2022, and subsequently Wales agreed to formally adopt the NHSE CHD standards. They accepted the findings of the reviews but recommended these were revisited with the Health Boards as most of the actions sat locally.

A second round of progress review follow-up meetings with each of the Health Boards were subsequently held in May-July 2023 in collaboration with the Wales Cardiac Network. The eight services were asked to highlight where their RAG rating against the CHD standards had changed since the original 2021-22 self-assessment review and to consider what actions might be appropriately taken in response to any standards rated as red or amber. There was a high level of engagement from all providers with self-assessments completed thoroughly leading to constructive conversations about services – the Board thanked all those involved.

The common themes were reviewed on 9<sup>th</sup> August 2023 with the Wales Cardiac Network. Across both adults and paediatric CHD services the common themes included: time in consultant job plans; audit and research; physiology training and education; image sharing; nursing support; network-wide database (risk of lost to follow up and lack of appropriate business planning for services); dental services.

The next steps are:

- To produce a summary report to highlight issues, progress, and good practice and to write to the Health Board Executives and Service Leads with the key actions and request a timeline for implementation.
- To share the findings with WHSSC and maintain momentum and dialogue with centres.

South West England Self-Assessment Reviews - The plan is to consider re-visiting these in Spring 2024 (to avoid winter).

### Update on key measurable 2023/24 workplan projects.

The new Board reporting mechanism is that key 'task and finish' project groups report into the Network Board via highlight reports (one slide summary).

Current key workplan projects

- 1. Communication of patient information across Network project (led by SC)** – SC updated that a survey was carried out in the Spring 2023 which showed much dissatisfaction with the communications of patient information from Level 1 to Level 2 and Level 3 centres and the aim is to improve this.

**Recent Progress**

- Change in JCC form ACHD and training of co-ordinator, all outcomes to go onto WCP
- JCC tracker in Wales (tbc in Bristol, maybe a Band 4 role)
- Sec training and master email list – all ACHD letters to have L2/L3 centres cc'd and Welsh to Welsh email for WCP
- New field to be added to all documents from L1 ACHD (exploring in L1 paed) – see challenge below\*
- CNSs to inform local teams about IP medical discharges and send d/c summaries

**Aims for Next Quarter**

- Have a paed meeting and tackle in similar way
- ACHD Intervention pathway audit
- Approach surgical ANPs to inform local teams about IP surgical discharges and send d/c summary

**Key Messages (Challenges, Risks, Awareness, Discussion)**

- Need L1 paed engagement
- Digital noting challenge
- \*IT too busy to implement agreed changes, limiting automated systems (will have to rely on staff training and culture)
- Will be difficult to implement in d/c summaries, JDs change all the time

- 2. Engagement of patient and parent representatives (led by SV)** – the key outcome is a representative group of patient and parent representatives engaged and involved in the Network in a variety of ways:

**Recent Progress**

- Patient and parent representative meeting held March 23<sup>rd</sup>
- Six new members GS, RW, BG, JM, AD, informal telephone interview lasting an hour and signed a contract which also identifies how long they would like to be involved 1yr, 2yr, 3yr
- A wide range of skills in the group including cardiac experience, working with young people, engagement in other national non cardiac patient representative groups, project management, national cardiac groups-CHD Standards, working with disengaged young people and in public health

**Aims for the next quarter**

- Recruit young people and those with additional needs

**Key Messages (Challenges, Risks, Awareness, Discussion)**

- Ensuring a representative group of patient and parent representatives including young people and those with learning disabilities and additional needs and a balance of male and female members

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

Recent Progress
Mapping all centres for paed and adult started Breakthrough with new portal to Swansea (firewall crossed), up and running, all users have accounts (Dec to July) Progressing in Aneurin Bevan (James Stevens) and Stephen Morris supporting Hywel Dda (Catrin Williams and Nerys James) and Cwm Taf (Matthew Jones)
Aims for Next Quarter
Ensure all Welsh echoes have links to Bristol Chase Bath ECHOPAC upgrade Chase Cardiff and Vale new system and set up link Finalise mapping of all centres Sort Exeter paed storage issue
Key Messages (Challenges, Risks, Awareness, Discussion)
Different HBs/trusts using different systems Paed/adult issues separate systems/requirements England/Wales firewall Financial restraints if capital investment required

**4. Delay of transfers of care between paediatric centres – Cardiff and Bristol (led by LH with RB support) – the key outcome is to reduce delayed transfers of care between paediatric centres. The pilot project launched in March 2023.**

Recent Progress
<ul style="list-style-type: none"> <li>13 submissions received (6 patients). 11 recorded delays from Bristol to Cardiff and 2 recorded delays from Cardiff to Bristol</li> <li>Task and finish group met to refine form and implemented changes based upon feedback and to provide more granular detail around location of delay</li> <li>Continue to report weekly</li> <li>Raised awareness of project – Cardiff management and Bristol PICU</li> </ul>
Aims for Next Quarter
<ul style="list-style-type: none"> <li>T&amp;F Group to review results</li> <li>Collate results and present to commissioners</li> </ul>
Key Messages (Challenges, Risks, Awareness, Discussion)
<ul style="list-style-type: none"> <li>Completion of baseline data and audit information to accurate levels</li> </ul>

Bristol and Cardiff paediatric teams to encourage forms to be submitted so have evidence. CA has reminded her team and suggested that to see wider scope of how delays impact hospital flow to also document the delays from PICU to HDU to the Ward so document the full journey and unpick the reasons for the delays.

- **Action:** CA/Ward Clerk to display QR codes posters in more locations e.g., PICU fridge.

**5. Transfer of care (TOC) between paediatric and adult CHD services (led by SC) – key outcome is to reduce the risk/and hopefully end the loss of patients between services.**

**Recent Progress**

- Task and Finish Group met June and July
- TOC document presented to L1 paed cardiologists
- Audit of lost to FU patient cohort 2018. 114 px, 54% not seen at correct time (median 7m [3.2m to 48m!]), 46% tbs in Bristol, range of complexity, not seen at all 9.6%, full report Oct
- Guideline “who needs lifelong care” complete – for approval at NW CG group
- Transition leaflet (who to transfer to) for each centre being done, list 90% complete for centres

**Aims for Next Quarter**

- Scoping pathway in each centre plus ideal pathway
- Full report on lost to FU audit and explore causes
- Finalise leaflets for each centre
- To start using TOC document in L1 (meeting with IT to improve) and explore roll-out to L3 centres – progressing in Taunton
- To disseminate “who needs lifelong care” document to paed cardiologists and PECs

**Key Messages (Challenges, Risks, Awareness, Discussion)**

- Diversity of IT systems unable to emulate TOC document in L3 centres – not sure if an issue yet – tbd at Board
- If audit suggests that lost to FU due to lack of ACHD staff – not sure yet!
- Nature of paed/adult handover tbd

Next project group meeting in September.

**6. Transition pilot project (led by JH) – aim to deliver transition consultations to young people aged 12-16 in three participating centres (Taunton, Torbay, and Gloucester).**

**Recent Progress**

First pilot clinic held in Taunton June 23  
Transition Network SOP in progress

**Aims for Next Quarter**

Date to be confirmed for first Torbay clinic, key stakeholders engaged, likely November  
Link nurse role in Gloucester has been advertised, awaiting recruitment, next steps to plan for first clinic  
Transition letter to be re-written based on patient feedback

**Key Messages (Challenges, Risks, Awareness, Discussion)**

Lead nurse time limitations  
Education for link nurses  
CNS resource to support clinic  
Recruitment of link nurses

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

Nursing business cases / roles / Network support

SV presented an update that there is slow and steady progress in gaining more formal nurse representation in level 3 clinics.

- Truro - Nina Worrin was appointed as paediatric CNS in January 2023 (b7).
- Exeter – Grace Pye was appointed as paediatric cardiac transition nurse in June 2023 (b7).

	<ul style="list-style-type: none"> <li>○ Glangwili – Jenni Sterling, long-term conditions nurse for CHD (b7).</li> <li>○ Gloucester – David Withers, ACHD CNS (b6).</li> </ul> <p>Pending</p> <ul style="list-style-type: none"> <li>○ Gloucester – paediatric cardiac link nurse (b6).</li> <li>○ Taunton – business case submitted to support permanent ACHD and paediatric posts.</li> <li>○ Plymouth – business cases and job description shared.</li> </ul> <p>SV and JFH noted centres that had paid and unpaid link nurse roles. Support available from the Network includes making the case and meeting with senior teams to explain the need and role for nurses; supporting business cases; job description advice; education opportunities and access to resources on the CHD Network website and NHS Future Platform; nursing competencies; bi-monthly virtual meetings for level 3; and 1:1 support.</p>
<b>11.</b>	<b>Issues Log</b>
	<p>Operational Delivery Networks no longer own risks but have a role in oversight and supporting risk reduction via mitigating action. This new process aligns with the NHSE southwest risk framework for ODNs.</p> <p>The Networks are responsible for keeping an issue log with high priority issues reported at the Regional Network Programme Board. These priority issues should inform the Network focus and workplan moving forward.</p> <p>In quarter 1 (2023/24), no new issues were added to the log, and one issue was closed which related to patients’ cardiac operations being cancelled due to PICU capacity pressures – the decision to close was taken after discussion with level 1 management who reported an improvement in PICU capacity during quarter 1 (April to June 2023).</p> <p>SV presented the top two priority issues:</p> <ul style="list-style-type: none"> <li>• Delays to and cancellations of appointments and procedures across the Network.</li> <li>• Patients transferring from paediatric to adult care are lost to follow-up between services.</li> </ul> <p>Please refer to the paper for the details of actions to mitigate these and share any feedback/comments with <a href="mailto:Louise.Hudson@uhbw.nhs.uk">Louise.Hudson@uhbw.nhs.uk</a></p>
<b>12.</b>	<b>Any Other Business</b>
	<ul style="list-style-type: none"> <li>• <u>Network Manager post</u> – LH has decided to step down in mid-October and the post is currently out to advert on NHS jobs.</li> <li>• <u>National Network of CHD Networks</u> - meeting being hosted in Bristol, 15<sup>th</sup> November 2023. Let the Network team know if you are interested in attending (there are limited spaces available).</li> <li>• <u>Board membership</u> – Need to ensure members send a nominated deputy if unable to attend.</li> <li>• <u>Feedback form</u> - Board members were invited to complete the meeting feedback form via the Microsoft Forms link circulated. Feedback has shown that the majority preference is for the Board meetings to continue to be held virtually.</li> <li>• <u>Next Board Meeting</u>, Thursday 12<sup>th</sup> October 2023, 14:00 – 16:30 (virtual) - Board members were asked to inform the Network team of any agenda items for the next Network Board meeting.</li> </ul>

### Attendees

Name		Job Title	Organisation	10/08/23
Amanda Davies	AD	Patient Representative		Present
Becky Nash	BN	Patient Representative		Present
Beth Greenway	BG	Patient Representative		Present
Catherine Armstrong	CA	Consultant Paediatric Cardiologist	Bristol	Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Present
David Withers	DW	ACHD Link Nurse	Gloucester	Present
Debasis Biswas	DB	Consultant	Hywel Dda	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Present
Holly Jones	HJ	Patient Representative		Present
Idoia Grange		Consultant Paediatrician Cardiologist	Bristol	Present
Imogen Payne		Youth Worker	Youth At Heart	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present
Justin Thuraisingham		Consultant Paediatrician with Expertise in Cardiology (newly appointed)	Exeter	Present
Louise Hudson	LH	CHD Network Manager	CHD Network Team	Present
Mark Dayer	MD	Consultant Cardiologist - ACHD	Taunton, Musgrove Park Hospital	Present
Nicola Morris	NM	Patient Representative		Present
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Present
Rachel Burrows	RB	CHD Network Support Manager (note-taker)	CHD Network Team	Present
Richard Palmer	RP	Senior Planner Commissioner	Welsh Health Specialised Services Committee	Present
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Present
Shafi Mussa	SM	Consultant Surgeon	Bristol, University Hospitals Bristol & Weston	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present
Sophie Nicholls	SN	General Manager (Adults)	Bristol, University Hospitals Bristol & Weston	Present
Stephanie Curtis	SC	Network Clinical Director / Consultant cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present
Adam Duffen	AD	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Adrian Wagstaff	AW	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Apologies
Andre Clinchant	AC	Lead Nurse	Taunton, Musgrove Park Hospital	Apologies
Andrew Parry	AP	Consultant Cardiac Surgeon	Bristol, University Hospitals Bristol & Weston	Apologies
Andy Arend	AA	Consultant paediatrician	Barnstaple, North Devon District Hospital	Apologies

Name		Job Title	Organisation	10/08/23
Andy Tometzki	AT	BRHC Clinical Director / Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Apologies
Ankita Jain	AJ	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Anna McCulloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Apologies
Anthony Goodwin	AG	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Anthony Pearce	AP	Commissioner	NHS England	Apologies
Becky Lambert	BL	ACHD Nurse	Taunton, Musgrove Park Hospital	Apologies
Bill McCrea	BMc	Consultant – ACHD	Swindon, Great Western Hospital	Apologies
Carys Williams	CW	Cardiac Physiologist	Swansea Bay	Apologies
Catherine Blakemore	CB	Consultant Cardiologist with interest in CHD	Torquay, Torbay District General Hospital	Apologies
Chris Gibbs	CG	Consultant - ACHD		Apologies
Claire Logan	CL	Paediatric clinical nurse specialist	Cardiff, University Hospital of Wales	Apologies
Daniel Meiring	DM	Fetal & Paediatric Cardiac Physiology Service Manager	Bristol, University Hospitals Bristol & Weston	Apologies
Danielle McPeake	DMP	Clinical Nurse Specialist ACHD	Bristol, University Hospitals Bristol & Weston	Apologies
David Lindsey	DL	Consultant Cardiologist with interest in ACHD	Gloucestershire Hospitals	Apologies
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Apologies
Dushen Tharmaratnam	DT	Consultant ACHD	Barnstaple, North Devon District Hospital	Apologies
Ed Roberts	ER	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Apologies
Ed Roberts	ER	Assistant General Manager of Paediatric Cardiac Services, Neurosurgery and PICU	Bristol, University Hospitals Bristol & Weston	Apologies
Emma Hulbert Powell	EHP	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
Emma Whitton	EW	Commissioner	NHS England South West	Apologies
Faamy Hassan	FH	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Apologies
Frankie Carlin	FC	Patient Representative		Apologies
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Georgina Ooues	GO	Consultant Cardiologist ACHD	Truro, Royal Cornwall Hospital	Apologies
Geraint Morris	GM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Gergely Szantho	GS	Consultant cardiologist	Bristol, University Hospitals Bristol & Weston	Apologies
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Apologies
Gui Rego	GR	Senior Echocardiographer (ACHD)	Bristol, University Hospitals Bristol & Weston	Apologies
Helen Fardy	HF	Medical Director	Welsh Health Specialised Services Committee	Apologies

Name		Job Title	Organisation	10/08/23
Helen Liversedge	HL	Consultant Fetal	Exeter, Royal Devon University Hospital	Apologies
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Jack Gibb	JG	Paediatric Cardiology ST4 Training	Bristol, University Hospitals Bristol & Weston	Apologies
Jennifer Holman	JH	Consultant Paediatrician	Gloucestershire, Gloucester Hospital	Apologies
Joanne Jones	JJ	Paediatric and Fetal Cardiac Sonographer	Bristol, University Hospitals Bristol & Weston	Apologies
John Madar	JM	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
Karen Sheehan	KSh	Paediatric Cardiac Research Sister	Bristol, University Hospitals Bristol & Weston	Apologies
Karikalan Kandasamy	KK	Consultant ACHD	Truro, Royal Cornwall Hospital	Apologies
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Apologies
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Apologies
Kimberley Meringolo	KM	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Apologies
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Apologies
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	Apologies
Louise Challis	LC	Link Nurse	Torquay, Torbay District General Hospital	Apologies
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Apologies
Luisa Wilms	LW	Consultant Paediatrician with interest in cardiology	Taunton, Musgrove Park Hospital	Apologies
Maha Mansour	MM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Manish Gandhi	MG	Consultant cardiologist - ACHD	Exeter, Royal Devon University Hospital	Apologies
Marcia Scheller	MSC	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Marion Schmidt	MS	Consultant Paediatrician	Newport, Royal Gwent Hospital	Apologies
Martin Heatley	MH	Consultant		Apologies
Matthew Beake	MB	Consultant Paediatrician with Expertise in Cardiology	Gloucestershire Hospitals	Apologies
Max Nathan	MN	Consultant Paediatrician with Expertise in Cardiology	Bridgend, Princess of Wales	Apologies
Mel Gilbert	MG	Matron for Child Health	Truro, Royal Cornwall Hospital	Apologies
Muhammad Addin	MA	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	Apologies
Nagendra Venkata	NV	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Apologies
Nicola Johnson	NJ	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Orhan Uzan	OU	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies

Name		Job Title	Organisation	10/08/23
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	Bristol, University Hospitals Bristol & Weston	Apologies
Pauline Aiston	PA	Psychologist	Bristol, University Hospitals Bristol & Weston	Apologies
Poonamallee Govindaraj	PG	Consultant Paediatrician	Cwm Taf Morgannwg, Royal Glamorgan	Apologies
Pradesh Mappa	PM	Consultant Paediatrician	Swindon, Great Western Hospital	Apologies
PremKumar Pitchaikani	PP	Consultant	Hywel Dda	Apologies
Rainer Fortner	RF	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Rowan Kerr-Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torquay, Torbay District General Hospital	Apologies
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospitals	Apologies
Sandeep Ashketar	SA	Consultant paediatrician	Aneurin Bevan, Royal Gwent Hospital	Apologies
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda, Glangwilli Hospital	Apologies
Simon Dunn	SD	Operational Service Manager	Torquay, Torbay District General Hospital	Apologies
Simon Macdonald	SM	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Soha Elbehery	SE	Consultant Paediatrician with Expertise in Cardiology	Aneurin Bevan, Nevill Hall Hospital	Apologies
Sree Nittur	SN	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol University Hospitals Bristol & Weston	Apologies
Tatiana Rjabova	TR	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	Apologies
Tim Murphy	TM	Consultant Anaesthetist (Paediatrics)	Bristol, University Hospitals Bristol & Weston	Apologies
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team	Apologies
Vishwa Narayan	VN	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Apologies
Yusf Museji	YM	Consultant – ACHD	Glangwilli	Apologies
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	Bristol, University Hospitals Bristol & Weston	Apologies