

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

Date: Thursday 19th January 2023, 14.00 – 16.30

Venue: Microsoft Teams Conference Call

Chair: Dr Dirk Wilson

Minutes

Item	Notes and Actions
1.	Welcome, introductions and apologies
	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.
2.	Approval of minutes and action tracker
	<p>The minutes of the Network Board on 11th October 2022 were agreed to be an accurate record.</p> <p>The action log was updated as appended. Notable comments:</p> <p><u>170 - Delay of transfers form (Bristol and Cardiff)</u> In progress – Currently looking at how this form can be hosted and exchanged, potentially via Microsoft Forms (with support of information governance and IM&T) in a secure way across hospitals in the network, and how this can be monitored.</p> <p><u>173 – Network to work with patient rep to design a sealed envelope for support after a death and look at further resources that may be helpful</u> Ongoing project with patient representative Sophie to progress a sealed envelope project. Also discussed with contacts at the WPCN education day (Nov '22) as the key theme was palliative care.</p> <p><u>175 – Communication to families re: the Joint Cardiac Committee process.</u> In progress - JH has drafted a simple outline of the JCC to demystify this for patients/families. This has been reviewed by patient representatives and is currently with the JCC leads for sign off before publication on the network website.</p> <p><u>176 & 177</u> – closed.</p> <p>No further actions to report on.</p>
3.	Patient Story
	<p>The Board listened to Kal's story pre-recorded with live Q&A. Kal introduced himself as a 50-year-old man with ACHD. After assessment as an infant at Birmingham Children's Hospital, Kal was diagnosed with congenitally corrected transposition of the great arteries (ccTGA), VSD with pulmonary stenosis, and Ebstein's anomaly of tricuspid.</p> <p>Kal outlined his ACHD journey interventions, noting the first phase between 1984 to 2007 involved 'plumbing' issues with a Left valve (LV) to Pulmonary Artery (PA) conduit with Ventricular Septal Defect (VSD) closure at the Harefield Hospital (London) in 1984 and a re-do conduit with placement of</p>

mechanical systemic atrioventricular (AV) valve at The Brompton Hospital (London) in 2007.

The second phase was 'electrical' issues with arrhythmias, atrial tachycardia ablations at the Brompton in 2012 and 2014, a lead replacement and new pacing system in 2014, leading to a ventricular tachycardia (VT) storm with 8 implantable cardioverter-defibrillator (ICD) shocks in September 2020 (non-inducible VT on EP study).

The third phase was heart failure and following assessment by the Freeman Hospital (Newcastle) in September 2021, Kal is currently awaiting a heart transplant. From January 2022 to date, Kal undergoes IV levosimendan infusions every 3 weeks at UHW Cardiff.

Kal acknowledged the challenges he has overcome in living with a cardiac condition, such as fear and isolation around the condition, its effect, the treatment pathways, life expectancy and how to live, particularly around the Covid-19 pandemic. He advocated preparing patients by open two-way holistic conversations in advance (when feeling well) about progression planning and understanding future likely interventions and their impact.

Dovetailing with this, Kal identified his ACHD successes including overcoming fears and uncertainties that he has inherited with having CHD, achieving a full family life (married with two daughters) and a legal career in London. He has also been able to take control of his ACHD condition, navigate multiple interventions and multi-centre care. These successes have been underpinned by a supportive family (who have had to manage together their own fear/anxiety related to Kal's heart journey); as well as being open, honest, and working in partnership with clinical teams and the specialist nursing support.

He found meeting with others with ACHD, particularly outside the hospital setting, to be very helpful in building connections (to avoid feelings of isolation) – Kal praised the Down to Earth ACHD wellbeing project initiated by Dr McCulloch (Cardiff).

In conclusion, Kal recommended that the whole person is seen (symptoms and psychological impact), improving two-way communication, not being afraid of difficult conversations, demystifying and promoting the MDT process and talking about transplant.

The Board thanked Kal for sharing his story in such a clear and constructive way.

Key points discussed following the presentation:

- **Demystifying the JCC/MDT** – As this is often an anxious time for patients requiring intervention and wanting to know next steps, a simple outline including a clear definition of MDT, the purpose, and outcomes, including the reporting/feedback process from the MDT to the patient would be helpful for general understanding. If urgent cases mean a patient's case is postponed to the next MDT, it is important to ensure that this is communicated to the patient to reassure them that they have not been forgotten.

This is an open Board action which is currently in progress – Kal accepted the invitation to comment on the draft script before this is published on the network website to signpost patients to.

- Action (JH): JH to send Kal the draft JCC/MDT script for comments.

- **Importance of psychological support and connecting with others** – in helping patients navigate uncertainty and waiting. Value in wellbeing projects, such as Down to Earth initiative.

4.	National and regional updates
	<p><u>National update</u></p> <p>LH provided a brief national snapshot:</p> <ul style="list-style-type: none"> • Attended the national networks of CHD networks conference held in Birmingham in November '22. Good opportunity to meet other network teams face-to-face. • Monthly national CHD Networks conference calls have been reconvened. There has been focus on the PICU surge and the impact on CHD - there is £15million for investment via paediatric critical care networks with the intention of improving flow. Other common themes include flow, workforce challenges, surgical cancellations, waiting lists, respiratory complexity of patients, plus theatres, ward and PICU capacity. It was noted that the Clinical Reference Group is currently being restructured. • BCCA annual conference is being held at the Delta Marriot, Bristol, on 13th and 14th November 2023 – SV and JH are on the organising board. <p><u>Commissioner updates</u></p> <p>Welsh Health Specialised Services Committee (WHSSC), South Wales - presented by KM.</p> <ul style="list-style-type: none"> • Key updates <p>ACHD – In Nov '22, WHSSC Management Group discussed the phase 3 business case submitted by Cardiff and Vale relating to service resilience and improved access to cardiac MRI.</p> <p>In Dec '22 received a presentation from the CHD network on the NHSE national CHD standards self- assessment of Welsh level 3 centres, and the adoption of the standards in Wales. The presentation was warmly received, and the Management Group advised that it should be discussed by the NHS Wales Collaborative Executive Group, facilitated by the Wales Cardiac Network.</p> <p>Paediatrics – Cardiac surgery delays and the impact on patients is continuing to be monitored monthly with Bristol. Paediatric Cardiology has been tentatively profiled for year 2 of the strategy implementation (2023/24) for a review of outreach and in-reach services ensuring appropriate MDT, equity of access and equity of waiting times.</p> • Action/support required from the network – None noted at the meeting. <p>NHS England, South West Presented by CK</p> <ul style="list-style-type: none"> • Key updates including: <ul style="list-style-type: none"> ○ ODN 2023/24 Workplans are being prepared for submission on 31st January, ready to be reviewed at regional level for sign off at the Women's and Children's Network Programme Board (7th February). Trying to ensure there is more structure to the workplans this year, clearly setting out why the item is on the workplan (the driver behind this such as GIRFT report, national review, identified risk, system priority) and outcome measures. ○ Peripheral clinic SLA is with Bristol to progress.

	<ul style="list-style-type: none"> ○ There is a focus nationally and regionally on CYP elective recovery and the CHD team presented the challenges with cardiac surgery at the December '22 regional meet – positive that there is national attention on this. ○ For NHSE, the operational planning guidance 2023/24 has now been published and each network service specification has been shared with the networks for feedback. <ul style="list-style-type: none"> ● Risks/concerns to be escalated to a national level – waiting list recovery and restoration – visibility of longest waits. <p>Actions/support from the network (LH): ODN intelligence of risks and issues in relation to recovery and restoration to be escalated regionally and nationally.</p>
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5.	Update from Level 3 centre(s)
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	<p>The key updates are outlined in the exception report in the papers.</p> <p>Adult CHD: DL led an update on behalf of the level 3 South West ACHD centres and HW for South Wales ACHD centres:</p> <p>Key themes to note for adults included:</p> <ul style="list-style-type: none"> ● Key updates: Included in the papers. Common themes are: <ul style="list-style-type: none"> ○ Lack of funding restricting service development, including recruitment of CHD nurses etc ○ Management awareness of complexity of CHD patients ○ Demand/capacity data capture issues to help build business cases for staff resource – challenging capturing CHD patient numbers (extracting these from cardiology pool) with lack of quality IT systems that can provide database – SC welcomed ideas on how this could be improved (as a problem in Bristol too) and noted that this also requires review at a national level. <p>Action (LH): To escalate CHD patient numbers and data gathering issues nationally and to report back.</p> <ul style="list-style-type: none"> ○ In Wales, Aneurin Bevan’s new monthly ACHD clinic started in December (Dr Masani - UHW), however there is still no local cardiologist supporting these clinics - service up to where it was pre-Covid. DW is supporting an all-day clinic in Bridgend CTM UHB, which is improving the waiting list. For Hywel Dda, there was an issue with high waiting list (due to Covid-19) and local consultant clinic support – both issues have recently been addressed, however, more clinics will be needed to cope with demand. <ul style="list-style-type: none"> ● Key risks/concerns: For the Southwest, ACHD nurse resource – Taunton done well albeit only half funded post (other half through temporary staffing), but other centres struggling to get this resource. In Wales, Swansea Bay still has no permanent local consultant lead in ACHD and are unable to provide enough clinic space for all sessions to return to face-to-face appointments – ongoing issue. ● Actions/support required from the network: None reported.
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	<p><u>Paediatric CHD</u></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"> • Key updates: Included in the papers. For the southwest, Truro have recruited a part-time cardiac scientist and cardiac nurse (supports CHD standards), as well as a successful capital bid to procure a second echo machine to enable extra clinics. Across the network there are increasing waiting times and follow up waits caused by e.g., capacity, referral and demand, physical space in outpatients, getting hold of equipment e.g., aging echo machines/borrowing from adult services, digital storage is patchy across the network, and continued challenge to get named cardiac link nurse for many centres. For South Wales, appointed a PEC at Swansea so all Health Boards have coverage now. • Risks/concerns to be escalated: For the southwest, NO explained that digital storage is a concern – in Exeter adult ACHD imaging is stored on MedCon that can be accessed by the level 1 centre and for paediatrics ECHOs are stored temporarily on PACs before being deleted so are backed up by an administrator onto CD/DVD with no long-term digital storage solution. Unlike the adult service, Exeter paediatric service do not have the digital storage licences and IT support (would cost around £20k) – this is low priority on the hospital risk registers compared to other specialities risks in hospital. Network support with this would be welcomed. For Wales, there are continued concerns relating to capacity and long waiting lists. <p>Action (LH/SC): To log digital storage as an issue and to follow up with centres.</p>
6.	<p>Update from Level 2 centre</p>
	<p>HW 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><u>Level 2 adult CHD service:</u></p> <ul style="list-style-type: none"> • Key updates: Positive news - new ACHD secretary recruited in early January. Two new clinics set up – day per month in Bridgend (DW) and in Aneurin Bevan. Extra psychology clinic also set up – totals two F2F clinics per week plus a virtual clinic. Held first Cardiff ACHD local mortality meeting in December and plan to continue every 6 months. CNS team have been working closely with disability team to create a booklet that is being translated into Welsh describing outpatient appointments, what ECG is etc. Bethan Shiers is based in West Wales and is now supporting inpatients in Worthybush and Carmarthen Hospitals which is a huge benefit. Presented at BCCA an audit on CNS telephone helpline and poster on reflective practice wellbeing group. • Risks/concerns: Challenges are issues with long waiting list and obtaining discharge summaries and operation notes in a timely way to discuss with patients in clinic. <p><u>Level 2 paediatric CHD service:</u></p> <p>DW presented an update for the Level 2 centre:</p> <ul style="list-style-type: none"> • Key updates: Recent commissioner assurance meeting identified unspent admin resource so looking to create a regional data post to ensure accuracy of data reported and a consistent approach (will require local healthboard agreement). Outpatient department waits recognised and modelled versus clinic capacity (waits mostly due to Covid-19 backlog). Personnel challenges due to long term consultant absences – locum appointment being processed. • Risks/concerns: Temporary Pelican ward closures due to nursing staff shortage and low

	<p>establishment – recruitment in process. Third sonographer still not released by adult services despite being paediatric funded – ongoing discussions.</p> <p>Actions/support required from the network: continued monitoring of transfer and admission delays and the reasons behind this.</p>
7.	Update from Level 1 centre
	<p>The key updates are outlined in the exception report in the papers.</p> <p><u>Level 1 adult CHD service</u></p> <p>GVS presented the key updates for the level 1 ACHD centre:</p> <ul style="list-style-type: none"> • Key updates: Fifth ACHD consultant started full-time in January 2023, currently 6-month post and are pushing for this to be extended and made permanent – this is particularly important for waiting list, and also for maternal medicine cover with SC. This new post has picked up PAs dropped by other consultants, so the service is still at the same consultant capacity. Fourth ACHD CNS (0.6WTE) has been recruited. Significant shortage in middle grade cover, also affecting outpatient clinic numbers – two ACHD fellows are in the pipeline and an ACHD senior cardiology SpR is currently being advertised. • Risks/concerns to be escalated: Increasing backlog of clinics and interventions. Some interventions cancelled due to lack of staff or equipment. • Actions/support required from the network: Facilitate region-wide (Southwest) support for BHI team expansion as provide service for region, particularly for on-call and inpatients. Peripheral visiting clinic sessions are paid for by Level 3 centre. Discussed block contract vs. payment by results. <ul style="list-style-type: none"> ○ <u>Action (CK):</u> CK to ask commissioning colleague to meet with CHD team to discuss funding tariffs for CHD re: block contracts and payment by results. <p><u>Level 1 paediatric CHD service</u></p> <p>ER shared the key updates to note:</p> <ul style="list-style-type: none"> • Key updates: included in the papers. Three new locum consultants recently started covering imaging (Eva Kaprevelou) and intervention (Ines Hribernik and Abdul Salam). Dr David Marini has resigned and are interviewing a replacement next week. Working with the network, transition clinics to be piloted. The CHD SLA has been on hold and is being reinvigorated by the UHBW Commissioning and Planning team. Following a job description/re-banding process, two cardiac physiologists are now running physiologist led fetal cardiac clinics at St Michaels Hospital. • Risks/concern: Waiting list for both inpatient and outpatient cardiology is of concern and is being reported on nationally. PICU position is reported daily to NHS England – local actions around enhanced rates on PICU continuing as pressure is sustained. • Actions/supports required from network: None reported. <p>ER shared that the Business Intelligence team did capacity and demand modelling, which was then reviewed by service managers to cross-check with the operational context, and cardiology was the top speciality in the division where capacity is not meeting demand. It was thought that when return to full establishment and with additional waiting list initiatives (WLIs), there is likely to be a need for another consultant post.</p>

	<p>Surgical SSQD dashboard are in the papers for information.</p>
<p>8.</p>	<p>Patient representatives update</p>
	<p>NM reported that Heart Heroes and Heart Families Southwest have received social media posts from around 15 families raising concerns regarding cancellations/waiting times and shortfalls in communications around this (not about the care). This has resulted in one or two families contacting the Bristol Post. Considering this, NM has been working with JH to develop ‘a guide to the JCC’ (including what to expect) to publish on the network website to signpost patients/families to.</p> <p>FC is a huge advocate of the ‘Down to Earth’ wellbeing course being run by the South Wales ACHD service involving practical outdoor skills and how valuable it is to meet others with ACHD. It was noted that there are several active local paediatric support groups, perhaps there needs to be more support available for adults. The patient rep group has also been involved with the Champion Project, a national initiative.</p> <p>In response, ER noted that there is a plan to send out standardised letters to families about the process of how the waiting list is reviewed and the JCC, and the plans around capacity – this is currently awaiting sign off from the UHBW communication teams. NM suggested that as many families are on social media, whether BRHC can use local support groups such as Heart Heroes to share communication statements as they would be willing to support with this.</p> <p>A CHD network statement has been published on the network website and this has been shared by Heart Heroes and Heart Families Southwest.</p> <p>In addition, ER noted that there is a proposed BRHC plan to set up a central point of contact who can field calls from patients where the clinician’s timescales to surgery have passed (cancelled or otherwise). PA raised that skills training for those that field the calls may be required, with some referrals to psychology to help patients tolerate the distress of the wait.</p> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved.</i></p>
<p>9.</p>	<p>Performance reports with narrative and workplan</p>
	<p>LH attached the supporting papers: quarter 3 update (Sept to Dec 2022); and the work plan 2022/23 update. Please refer to the papers for further detail.</p> <p><u>Draft high level workplan 2023/24</u> The network is reviewing, prioritising, and developing the network work plan for 2023/24. The workplan is owned by the CHD network board and delivered by the core team and network members, providing the direction. The network board has a role in ensuring that the work plan is fit for purpose.</p> <p>The workplan is to align to national drivers (such as the 2023 NHSE priorities and operational planning guidance which articulates new ways of working and acknowledges the complexity of system pressures), regional drivers (ICB commissioning around improving flow and reducing backlogs), and local drivers.</p> <p><u>Network performance report</u> 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 required. Suggested actions or escalations required to</p>

address performance issues are highlighted in the exception reports.

The response rate from centres is positive with 100% for level 1 and level 2, and the level 3 getting close to this. There remain a small proportion of level 3 centres who have routinely not provided the information required. Whilst the return rate is on an upwards trajectory many of the returns are incomplete and the network team are aiming to increase support and will continue to work with centres to understand any barriers and resolve any issues around this.

LH outlined the outpatient waiting times and overdue follow up backlogs. It was noted that Plymouth ACHD has successfully significantly reduced their total overdue follow up backlog (almost halved) between quarter 2 and quarter 3. Particular concern is with the level 1 centres. Support for the Welsh centres will continue through the self-assessment process. She went onto present the regional trends for DNA rates and the inpatient waiting lists. In a national context, the CHD surgical waits by month over the last year for all procedures were shown – this also reflects the extreme operational challenges on paediatric intensive care units. AP highlighted that children are added to the waiting list as P3, and as time goes on these are turning to P2. There is current concern that there are several children with time limited morphologies who are waiting longer than would want.

Risks and issues

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 southwest network risk framework.

The proposed risk management process involves firstly the identification of risks and issues:

- The risk owner (commissioner or provider) identifies a risk/issue for the network to support.
- The network identifies risk and issues via horizon scanning and sharing of intelligence.
- Network members/commissioners maintain risk registers, horizon scan and share risks (rated 12 and over or requiring network support) and serious incidents where action is required.

A flow chart of the process is included in the papers for awareness. Please share any feedback/comments with Louise.Hudson@uhbw.nhs.uk

The networks are also responsible for keeping an issue log with high priority issues reported at the network programme board. These priority issues should inform the network focus and workplan moving forward.

Current workplan 2022/23

The network board has a role in checking progress on the current workplan. The current status is that there are 8 complete work plan areas; 32 work plan areas that are rated green (on track); 4 amber areas (partially progressed but have been delayed by external factors) and there are none currently rated as red. There are 6 areas on hold.

Function of Operational Delivery Networks

LH presented an overview noting that ODNs have three main functions: increasing operational effectiveness and consistency, improving care, and managing patient flows. Within these network functions, for 2023/24 there are six areas of focus (service delivery, resources, workforce, quality, transformation, and population health) which will need to be demonstrated through the new 2023/24 workplan with a project under each.

Suggested projects for 2023/24 workplan

LH presented a draft high level work plan highlighting some suggested areas that could be taken forward as key measurable projects, such as level 3 self-assessments; monitor and support elective

recovery and performance focusing on DNA rates; transition including lost to follow up rate and the peripheral pilot project; focus on paediatric delayed transfers of patients; support improved image sharing and digital storage. She went onto present each suggested pipeline project with a suggested measure and outcome.

The project ‘task and finish’ groups could report into the network board. With this in mind, a new reporting mechanism may be required. These would be driven by network members with the support of the network team.

CK reiterated that the work plan is a network strategy – not about describing what the network does (such as business as usual) - but focuses on a few priority projects with agreed milestones and measurable outcomes that demonstrate ideally improvements for patients or staff, that can be linked back to a national driver such as a national review or identified risk. The importance of network members being signed up to the workplan and projects are key, and so feedback/comments is welcomed.

Live feedback on draft 2023/24 workplan via mentimeter questions:

1. What are your top 3 priority areas from the headlines presented?
 - Fetal
 - Patient flow
 - Transition x2
 - Happy with the priorities presented – cannot think of any key deliverables that we are missing at present
 - Optimising clinic time and templates across the network
 - Improving communication between level 1 and level 2/3 centres ensuring that discharge summaries and op notes and the first post op/intervention letters are automatically sent. Currently this is very patchy, and most are received following request.

2. Are we missing anything?
 - o Action: Please feedback comments of the draft workplan 2023/24 ideas to Louise Hudson

10. Pharmacy: updates on new developments

Susie Gage, Lead Paediatric Cardiac and PICU Pharmacist at the Bristol Royal Hospital for Children, presented a spotlight on new pharmacy updates.

Rivaroxaban for Venous Thromboembolism (VTE)

A new development in paediatric services, is that rivaroxaban is now a licenced treatment option for VTE and prevention of VTE in term neonates, infants, children, and adolescents under 18 years, after at least 5 days of initial parental anticoagulation treatment. The suggestion is that this is tried around the region. There are criteria that patients need to meet, and it is important to note that this is not used for mechanical valve patients.

Several other centres across the country are using rivaroxaban. Nationally, there has been positive outcomes including for those who are needle phobic, children with poor IV access for monitoring, and enables quicker discharges. The challenges are that GP are not prescribing this yet, there is anxiety around the lack of monitoring and no reversal agents. Currently Haematology is involved in the decision making as build experience.

	<p>There are ongoing discussions regarding this and Fontan patients.</p> <p><u>Standardised infusions in PICU</u> Another new development is standardised infusions on PICU, which may also start to be used in HDU, transport service, and in district general hospitals. Currently looking at the standardised intravenous infusion concentrations in children – please see RCPCH UK guidance – and the roll out of this nationally. This will be a change in practise moving from weight based to standardised concentrations. This will be helpful for patients moving to adult services to align practice across the services.</p> <p><u>Pocapavir use in Enterovirus myocarditis</u> There has been a run of enterovirus myocarditis patients – Bristol and Cardiff services have had around 10 patients in the last 3 to 4 months. The collaboration between different teams in the different hospitals, particularly Bristol and Cardiff, has worked really well, with several joint meetings between the cardiologists, the PICU staff, and the infectious diseases teams to discuss the use of pocapavir. This drug has been imported with MHRA approval. Successfully produced guidelines with Bristol and Cardiff, and parent feedback has been positive. It was noted that the number of cases presenting acutely has fallen, however, the disease burden in the 10 patients has been significant.</p>
11.	Any Other Business
	<ul style="list-style-type: none"> • <u>Board membership</u> – It has been noticed that there is no paediatric cardiologist from level 1 and level 2 on the call today and we are missing key representatives. It was raised whether board membership should be extended to all paediatric and adult cardiology consultants. Also, are there individuals that should be on the board that are not on the board. Need to ensure members send a nominated deputy if unable to attend. • <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. • <u>Next Board Meeting</u>, Wednesday 19th April 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.

Attendees

Name		Job Title	Organisation	19/01/23
Andrew Parry	AP	Consultant Cardiac Surgeon	Bristol, University Hospitals Bristol & Weston	Present
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Becky Lambert	BL	ACHD Nurse	Taunton, Musgrove Park Hospital	Present
Carys Williams	CW	Cardiac Physiologist	Swansea Bay	Present
Catherine Blakemore	CB	Consultant Cardiologist with interest in CHD	Torquay, Torbay District General Hospital	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
David Lindsey	DL	Consultant Cardiologist with interest in ACHD	Gloucestershire Hospitals	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Present
Ed Roberts	ER	Assistant General Manager of Paediatric Cardiac Services, Neurosurgery and PICU	Bristol, University Hospitals Bristol & Weston	Present
Gergely Szantho	GS	Consultant cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Jennifer Shortland	JS	Cardiology Registrar	Bristol, University Hospitals Bristol & Weston	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present

Kal	KS	Patient Representative		Present
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Present
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Present
Kimberley Meringolo	KM	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Present
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Present
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	Present
Louise Hudson	LH	CHD Network Manager	CHD Network Team	Present
Luisa Chicote-Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Nicola Morris	NM	Patient Representative		Present
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Present
Pauline Aiston	PA	Psychologist	Bristol, University Hospitals Bristol & Weston	Present
Rachel Burrows	RB	CHD Network Support Manager (note-taker)	CHD Network Team	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
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda, Glangwilli Hospital	Present
Stacey Webb	SW	Assistant General Manager for Cardiology	Gloucester	Present
Stephanie Curtis	SC	Network Clinical Director / Consultant cardiologist	CHD Network Team / Bristol, University Hospitals Bristol & Weston	Present
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol University Hospitals Bristol & Weston	Present
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	Bristol, University Hospitals Bristol & Weston	Present
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Apologies
Andre Clinchant	AC	Lead Nurse	Taunton, Musgrove Park Hospital	Apologies
Andy Arend	AA	Consultant paediatrician	Barnstaple, North Devon District Hospital	Apologies
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
Anthony Goodwin	AG	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Apologies
Anthony Pearce	AP	Commissioner	NHS England	Apologies
Becky Nash	BN	Patient Representative		Apologies
Bill McCrea	BMc	Consultant – ACHD	Swindon, Great Western Hospital	Apologies
Candida Frankham	CF	Cardiac Physiologist	Truro, Royal Cornwall Hospital	Apologies
Chris Gibbs	CG	Consultant - ACHD		Apologies
Claire Logan	CL	Paediatric clinical nurse specialist	Cardiff, University Hospital of Wales	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
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
Gui Rego	GR	Senior Echocardiographer (ACHD)	Bristol, University Hospitals Bristol & Weston	Apologies
Helen Fardy	HF	Medical Director	Welsh Health Specialised Services Committee	Apologies
Helen Liversedge	HL	Consultant Fetal	Exeter, Royal Devon University Hospital	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
Karikalán Kandasamy	KK	Consultant ACHD	Truro, Royal Cornwall Hospital	Apologies
Lalit Bhalla	LB	Consultant - ACHD	Aneurin Bevan, Wales	Apologies
Louise Challis	LC	Link Nurse	Torquay, Torbay District General 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
Mark Dayer	MD	Consultant Cardiologist - ACHD	Taunton, Musgrove Park Hospital	Apologies
Marta Cunha	MC	ACHD clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	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
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	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
Richard Palmer	RP	Senior Commissioner	Welsh Health Specialised Services Committee	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
Shafi Mussa	SM	Consultant Surgeon	Bristol, University Hospitals Bristol & Weston	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
Tatiana Rjabova	TR	Consultant Paediatrician with Expertise in Cardiology	Bath, Royal United Hospital	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