



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

Date:Wednesday 19th April 2023, 14.00 – 16.30Venue:Microsoft Teams Conference CallChair: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.
	Welcomed Dr Giovanni Biglino, new Network Research Lead.
2.	Approval of minutes and action tracker
	The minutes of the Network Board on 19 th January 2023 were agreed to be an accurate record.
	The action log was updated as appended. Notable comments:
	<u>170 - Delay of transfers form (Bristol and Cardiff)</u> In progress – project is now in live 'test and learn' phase with Microsoft Form via shared Teams Channel. Closed.
	175 – Communication to families re: the Joint Cardiac Committee process. Published on website and in newsletter. Closed
	<u>179 – Digital storage</u> Logged on Network's issues log. To continue to review with centres. This is particularly an issue in Exeter Paediatrics. Would welcome evidence from elsewhere to understand the extent of the issues Network-wide.
	<u>178, 180 & 181</u> – closed.
	No further actions to report on.
3.	Patient Story
	The Board listened to Jill's story, pre-recorded with live Q&A. Jill introduced herself as a 55-year-old woman who was born with a hole in the heart and coarctation of the aorta. Jill was operated on at birth at the Bristol Royal Hospital for Children and had a full and active childhood.
	Jill was next seen at 14 years and reviewed annually. A concern about her blood pressure led to monitoring and tests, and at 17 years she had a successful re-do of the coarctation of the aorta and aortoplasty. Jill continued to see her paediatric cardiologist as an outpatient until 22 years at which point, she was discharged from long-term follow up (as she believed was common practice in the





1990s). There was no transition/transfer to adult services. Thereafter, Jill had a healthy life, gave birth to two children, and worked as a project manager in the head office of a national bank.

Jill experienced indigestion in 2005 that got progressively worse. In 2007, Jill collapsed and was transferred to the BHI. It was discovered that Jill had an aneurysm in her aorta in the exact location of the coarctation, and she underwent an emergency aorto bronchial fistula. Jill shared how Dr Turner had 'saved her life' and she is 'eternally grateful.'

She went onto explain that she felt fine until 2020/2021 when she began to get breathless and very tired. In autumn 2021, Jill was diagnosed with anomalous vein connected to the left atrium adjacent to the left pulmonary venous confluence. In July 2022, Jill underwent successful keyhole surgery by Dr Turner for closure of the SVC-LA anomalous connection.

Jill described how both surgical procedures in 2007 and 2022 at the Bristol Heart Institute have been life changing and enabled her to live a healthy lifestyle again.

Jill acknowledged the challenges in her ACHD journey, noting that in hindsight she should have received lifelong care from birth. Whilst she recovered extremely well physically from the interventions, following the aneurysm in 2007, Jill shared how this trauma affected her emotionally for about a year after manifesting in several panic attacks and a fear of going out alone. Jill emphasised the importance of offering psychological support for patients.

She also noted how her recent admission to the cardiology ward had been challenging, sharing a bay with elderly patients with dementia.

Jill praised the 'excellent service provided by the NHS, Dr Turner and his team,' and their 'amazing knowledge and expertise' as this saved her life. That the follow-up care is fantastic, and she is glad to have ongoing annual check-ups. She expressed how patients need to understand the need for lifelong follow-up if required.

Key points discussed following the presentation:

The Board thanked Jill for sharing her story in such a clear way, and for her time and contribution. AM acknowledged the psychological stress and agreed with the key message that patients should be offered psychological support when needed. DW reflected that the service has progressed since then and transition services are now available and patients with CHD are encouraged to have life-long follow up.

4. National and regional updates

National update

LH provided a brief national snapshot:

- National CHD Networks of Network monthly virtual meeting refreshed national monthly data return for level 1 surgical centres.
- CHD Clinical Reference Group re-established in April 2023 who will have oversight of the national CHD work programme. Representation includes one of the other CHD Network Managers, together with Susie Gage, Pharmacy Lead, and Andrew Parry, Cardiac Consultant Surgeon.





- o <u>Action</u>: LH to circulate a list of the CHD Clinical Reference Group representatives.
- National CHD work programme has identified three key work strands for 2023/24: workforce, service specification and standards, and data/dashboard development. For workforce, the intention is to produce a national heat map to show workforce pressures nation-wide so the regional Networks will be asking centres for workforce details.
- Delegation of commissioning arrangements from NHSE specialised commissioning to Integrated Care Boards.
- BCCA national annual conference is being held at the Delta Marriot, Bristol, on 13th and 14th November 2023

Commissioner updates

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

• Key updates:

Adult CHD

 Phase 3 ACHD business case was submitted in 2022 by the Level 2 ACHD centre in Cardiff and Vale UHB. This followed funding previously provided by WHSSC in 2015 and 2020 and related specifically to service resilience and improved access to cardiac MRI. The case was initially considered at WHSCC Management Group in November 2022, which highlighted concerns such as delivery of phase 2 and equitable access to CMR. The previous concerns were systematically addressed, and this was considered again by the WHSCC Management Group in March 2023. The business case was supported and subject to issuing a funding release letter (due imminently), the requested service resilience and CMR resources will be made available.

Paediatric CHD

 Continue to monthly monitor cardiac surgery delays and the impact on Welsh patients. Meetings were held recently with Bristol to understand the current position and impact, with positive engagement. Further work is planned to explore flow between Bristol and Cardiff.

AP responded that whilst cardiac surgery delay monitoring is good, there are still issues on the frontline with patient flow and asked whether the commissioners would agree to sending new patients to other surgical centres to help the current backlog.

RD noted that there is ongoing work to improve paediatric cardiac surgery flow in Bristol and that PICU capacity has improved recently (workforce issues were a key challenge over winter). AT commented that the bed base in Cardiff is small so there is little room to repatriate patients – this needs to reflect the capacity of six cardiologists in Cardiff to enable patient flow both ways. He noted paediatric surgical capacity is a national issue.

SC reminded the group of the paediatric delay in transfer audit project between Bristol and Cardiff which aims to identify where the issues are. Both centres were encouraged to submit the Microsoft Form when patient delays occur.

- <u>Action</u>: RP to ask KM to respond to AP comment directly re: sending patients to other surgical centres.
- Action/support required from the Network None noted at the meeting.





• K	(ey up	dates including:
	0	ODN 2023/24 workplans – These were signed off at the February 2023 Network Programme Board. The approach has shifted, and Operational Delivery Networks are now expected to focus on measuring outcomes. A check list has been produced to support wit this. NHSE BI team are working directly with Networks.
	0	Peripheral clinic SLA – With Bristol to progress.
	0	Women and Children's Programme Board – The next meeting is on 16 th May for an upda on workplans (by exception) in case any regional commissioner support is needed.
	0	CYP Elective Recovery – Still a lot of focus on this nationally and regionally. A toolkit has been developed for systems to use. Cardiac waits remain a concern, but hopefully PICU capacity will improve flow.
	0	NHSE – From April 2023, all Integrated Care Boards (ICBs) will take on delegated responsibility from NHS England for the commissioning of pharmaceutical, ophthalmic, a dental functions. Currently reviewing future governance arrangements for Networks whe Specialised Commissioning is delegated (April 2024), however awaiting clarity on future commissioning hubs.
		concerns to be escalated to a national level – Waiting list recovery and restoration – visibi
	of long	est waits and potential harms.
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The South Wales Level 3 University Health Boards self-assessment reviews are being held in May/June





2023 which will provide an opportunity to discuss this further.

DNA rates

LCH shared that the Plymouth ACHD team have targeted the waiting list backlogs and DNA rates, by setting a pathway so all patients are contacted in advance of their appointment to confirm attendance. This is time intensive for the team and involves micromanaging the clinics. It is worth the effort as this has cut DNA rates significantly, from a high of 16-18% to a current rate of 1% and reduced the waiting list backlog as double bookings have been removed. Moreover, this helps to build rapport with patients.

The Board agreed that this was a great effort and so important to support patients in overcoming barriers to accessing care. SC reported that Taunton ACHD have also been working to reduce DNA rate in joint clinics which is yielding good results.

The dashboard showed increasingly high DNA rates for visiting consultants in Royal Glamorgan Paediatric CHD service over the year and high DNA rates for local consultants in Prince Charles Paediatric CHD service.

• Action: AP to check with Royal Glamorgan and Prince Charles Hospitals re: reported high DNA rates, and what is being done to address this. During the meeting, an update memo was received: Local CTM PECSIG is surprised at 40% DNA rate too - will feedback to AP as soon as possible if correct. They are implementing an automated text programme to address the known high rates.

Inpatient report - year to date trends for Level 1 (Bristol)

For surgical, the paediatric waiting list has increased over the year from 61 week waits (Quarter 1) to 83 week waits (Quarter 4), however this did plateau slightly in the summer. The adult waiting list reflected this pattern but in the opposite direction, reducing from 52 weeks a year ago with a plateau in summer to further reduce in Quarter 3 and Quarter 4 to 23 weeks. It is thought that the paediatric bed capacity and workforce issues thwarted paediatric surgery, however enabled more adult surgical flow hence improving the adult service waiting list.

For intervention, the paediatric waiting list digressed from a significant improvement in Quarter 2 (at 57 weeks wait) to 140 weeks in Quarter 4 – a similar level to Quarter 1 at the start of 2022/23. For the adult waiting list, there has been a steady increase over the year with a slight reduction in Quarter 4.

Proposed review of Network Performance Dashboard & draft questionnaire

In summary, the Network collects quarterly data from the Network's centres. This data feeds into the Network's inpatient (level 1) and outpatient (all levels) dashboards, with the key highlights outlined in a performance report presented at Board and the outpatient dashboard published on the Network website. As an aside, to date the inpatient dashboard has not been published on the website – the Board was asked if there is a known reason for this.

The proposal is to conduct a review, initially via an online survey to centres, into both the process and the data collected. The survey questions were shared with the Board. The intention is to also invite any interested Network members to support this via a task and finish project group.

The Board endorsed the recommendation to issue a survey.





6.	Update from Level 3 centre(s)
	The key updates are outlined in the exception report in the papers.
	Adult CHD: SC led an update on behalf of the level 3 South West ACHD centres and HW for South Wales ACHD centres:
	Key themes to note for adults included:
	• Key updates: Included in the papers. LCH reported that Plymouth appointed an experienced registrar in 2022 to support service provision which has increased ACHD clinic capacity and led to significant improvement in the follow up backlog – the service has also had a full review of patients on the waiting lists to validate the data submissions. Also formalised physiologist congenital echocardiography training with one physiologist currently working towards European accreditation. SC reported that Gloucester have successfully received approval for a specialist ACHD nurse and have also been validating their ACHD waiting list and reviewing their clinic structure. Taunton are also seeing extra ACHD patients in joint clinics with their locum consultant, but his contract ends in August 2023.
	For South Wales, Swansea Bay reported that they are running face-to-face consultations and an extra session is provided by HW's job plan, which is slowly improving the waiting list but still a concern. HW reported that Withybush is the only ACHD clinic in South Wales running well within its capacity. DW is now running an additional all-day ACHD clinic in Bridgend (when space is available) and Nav Masani is doing the same in Aneurin Bevan, which is a significant uplift and should address the waiting lists.
	• Key risks/concerns : For the Southwest, Taunton raised that nursing hours are still not funded, and a business case was submitted in April. Musgrove Park Hospital (Taunton) is merging with Yeovil District Hospital in April 2023, and the impact this will have on the service is yet unclear. Gloucester reported concern that they have no specialist ACHD nurse and there is lost to follow up between paediatrics and adults (transition. To address this have been linking in with the local paediatric team to develop relationships.
	Actions/support required from the Network: None reported.
	<u>Paediatric CHD</u> KH led an update for southwest – the key themes to note for paediatric level 3 centres included:
	• Key updates : Included in the papers. For the southwest, some positive and exciting themes in improvement in managing the workload with reduction in patient waiting list in Aneurin Bevan and Exeter, and with more echo machines in Plymouth, Swindon, and Cwm Taf and, a new PEC in Swansea. Moreover, there has been some further service development around the region with link nurses proposed for Gloucester and Taunton, and physiologist clinics being developed in Exeter and Taunton.
	SJ added that a new link nurse with interest in cardiac has been appointed in Hywel Dda, and DW noted that there is also positive progress in Swansea with congenital ultrasound training.
	• Risks/concerns to be escalated: Ongoing concerns are continuity of visiting consultants for Gloucester and Truro. Managing workload, in Taunton and Plymouth with waiting lists. Some
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	service challenges with no ECG cover in Truro and an echo machine coming to end of functional life in Swansea. Jennifer Holman added that Gloucester recently received agreement for a band 6 link nurse focused on transition for 1 day per week, increasing hours over time. Jennifer Holman is retiring in October.
7.	Update from Level 2 centre
	HW presented an update for the Level 2 centre - the key updates are outlined in the exception report in
	the papers. Notable comments included:
	Level 2 adult CHD service:
	• Key updates: Positive news that a new secretary has started so the turnaround time for clinic letters is much faster. Simon MacDonald has co-written and published an article on Melody valve follow-up. Band 7 Clinical Nurse Specialist (15 hours) advertised and awaiting interviews. Submitted a bid for a service improvement grant via the South Wales Cardiac Network for a physio psychological nurse model to enhance wellbeing and encourage CHD patient exercise.
	• Risks/concerns : Key challenge is communication of patient information, particularly around discharge summaries and operation notes from the BHI and improving communication following MDTs. This is being picked up by the Network and a survey has been circulated to the Network to look into this.
	 Level 2 paediatric CHD service: AP presented an update for the Level 2 centre: Key updates: Extra catch-up clinics for Cardiff and Vale have been approved via WHSSC so are looking at space to implement those, and a locum consultant has been appointed to cover long term sickness - with these combined should start to see reduction in waiting list. New psychologist started in March 2023 and a further band 7 appointment in progress. Cardiac Liaison Nurse transition recruitment process underway, and a new General Manager has started covering paediatric cardiology service.
	• Risks/concerns: Third sonographer still not released to paediatric service from adult service – hope this will be addressed by May/June. 'Low intensity' patient transfers between centres not covered by WATch commissioning and challenging to deliver without their assistance – the plan is to put this through a WHSCC business case.
	• Actions/support required from the Network: Network have a meeting scheduled with WATch to discuss cardiac patient transfers across the Network, to inform future commissioning of this activity.
	 <u>Action</u>: Update on cardiac patient transfer/WATch commissioning of service at the July Network Board meet.
8.	Update from Level 1 centre
	The key updates are outlined in the exception report in the papers.
	Level 1 adult CHD service
	SC presented the key updates for the level 1 ACHD centre:





- **Key updates**: Surgery waiting list position has improved for adults (linked to capacity of surgical staff owing to delays in paediatrics). New ACHD CNS recruited to cover maternity leave, and further interviews coming up.
- **Risks/concerns to be escalated**: Rising waiting list for both new patients and follow-ups remains a concern key reasons include staff shortages and delays in recruitment. However, now new fellows and consultant in post, the waiting list should reduce. There is a risk to losing a CHD Cath lab session and a meeting is being held 20th April to discuss this, however BHI are getting a new Cath lab so this may help in time.
- Actions/support required from the Network: None noted.

Level 1 paediatric CHD service

RD shared the key updates to note:

- Key updates: included in the papers.
 - New appointments with Dr Idoia Grange (Consultant Paediatric Cardiologist) joining the BRHC team in May 2023 to cover parental leave vacancy, and Dr Jennifer Shortland starting as Consultant Paediatric EP in September. Looking at progressing with substantive posts imaging consultant post in process of being approved and advertised.
 - Demand and capacity modelling has taken place and currently awaiting the decision on a submitted bid for additional consultant, CNS, and cardiac physiologist time.
 - Received temporary accelerator funding to run additional clinics/waiting list initiatives in the short term. The funds may also support a pilot of ICC CNS clinics to help support paediatric ICC consultants have met as team to look at creating a pathway to hopefully lead to joint clinics. Meeting with the adult ICC CNS too.
 - A transformation project is being undertaken for paediatric cardiology outpatients to look at the patient pathway and ways to increase efficiency first meeting planned in early May with Trust transformation team support.
 - Draft SLA has recently been returned by internal UHBW commissioning team with their comments RD has given some of the South West district general hospital managers the heads up that they will receive this soon for peripheral centre agreement. The funding agreement is similar to current funding arrangements so not anticipating any drastic issues with this.
- **Risks/concern**: Performance and patient flow remain a challenge, mainly due to patient acuity and workforce establishment a detailed critical care action plan has been put together which covers HDU, PICU and cardiology services. The national strikes have affected flow too. Theatre workforce should be fully established by the end of the summer.

• Actions/supports required from Network: Help with understanding future demand from level 3 centres to help shape job plans, and support with rolling out the SLA when finished.

9. Patient representatives update

FC reported that a patient and parent rep meet up was held on 23rd March 2023 with five new interested representatives. Keen to increase the diversity of this group and gain wider perspective. The Cardiff ACHD wellbeing group is continuing and going brilliantly – the new group has enabled a mentor buddy programme. FC also recommended a book by psychologist Dr Lisa Moreton 'Healing Hearts and Minds' – FC and AMC are planning to start a book club. There are two other book reviews in the newly published CHD Network Spring Newsletter with thanks to KH and BL.





	NM shared that she commenced this week as a Heart Heroes family support worker on BRHC Dolphin Ward to support CHD families and signpost to resources available to them – currently this is for one afternoon a week, possibly going to two afternoons. Grateful for ZT support on the ward. This has already been positively received from families and staff. NM updated that following escalating concern about the flurry of comments from families around the BRHC surgical waits and cancellations, this has now settled thanks to BRHC and Network action around communications – with updates posted on the website and letters to patients on the surgical waiting list. RD added that further to the letters sent earlier in the year, the BRHC are following this up with phone calls to update patients. Also, following feedback from cardiac families, an article aiming to demystify the Joint Cardiac Conference (JCC) including a flow chart, has been drafted with the support of the patient representatives, and published on the Network website and in the Spring 2023 Network newsletter. The Board thanked FC, NM, and BN for all their expertise and support to the Network and in developing services. Good to see that comments raised previously have led to actions and outcomes. The Board was reminded that <i>if a project involves patient care, a patient rep should be involved</i> .
10.	Workplan 2022/23 and 2023/24
	LH attached the supporting papers: quarter 4 update (Jan to March 2023); and the work plan 2022/23 closing summary, and the new work plan 2023/24. Please refer to the papers for further detail. <u>Network updated report (Quarter 4) & Workplan 2022/23 summary – achievements and challenges.</u> The key highlight achievements include submission of the South Wales level 3 centres self-assessment to WHSSC and agreement to adopt NHSE's CHD standards, recruiting a new Network Research Lead, progressing the transition pilot project, finalising the 2023/24 workplan, training and education events, patient experience and engagement, and wellbeing support. The key challenges are the paediatric service level agreement (however positive to receive an update during this meeting that this is now progressing forward), the inherited cardiac conditions pathway, support for recovery and restoration, and improving rates of lost to follow up between children and adult services. <u>Current workplan 2023/24 – projects, prioritisation, and delivery</u> The work plan is a Network strategy that is owned and overseen by the CHD Network Board and outlines key projects and timescales for delivery by the core team and Network members. There are several new 'task and finish' project groups that Network members are invited to be involved with. It is important that we focus our resources as a Network to achieve the greatest impact.
	 <u>Board Membership</u> A revised Terms of Reference and membership review will be tabled at the July Board for agreement. DW shared that it is noticeable that whilst there is very good representation from the core Network Board and consistent representation from the PECs, what the Board has recently been missing is attendance from other consultant teams particularly level 1 paediatric and adult cardiologists who are not a clinical lead. DW proposed for agreement, the principle of having core Board members, but also extending the invitation to attend the Board meetings to all the cardiology consultants, cardiac surgical consultants, anaesthetic leads, and psychology consultants, so there is wider clinical representation and more





understanding/exposure to Board action. Whilst avoiding unwieldy meetings, realistically only a few representatives from these staff groups would end up helping the work of the Board in a hands-on manner, but they would gain better insight into the workings and scope of the Network.

Update on key measurable 2023/24 workplan projects.

The proposed reporting mechanism is that key 'task and finish' project groups report into the Network Board. A flow chart of the process is included in the papers for information.

Based on the key issues and risks highlighted by the Network, stakeholder feedback, and aligning to national and regional drivers, the following key workplan projects have been identified. Network members are invited to be involved with projects that are of interest to them and in which they have expertise.

The proposal is that the new reporting process on key projects is via highlight reports (examples were shared during the meeting by project leads). The highlight report is a one slide summary outlining the project aim, the key outcome, recent progress, aims for next quarter and key messages.

Current key workplan projects

- Service review follow up from the South Wales Level 3 Self-Assessment virtual review meets are planned in May/June 2023. Thank you to the centres for their engagement with this process so far.
- Workforce review a national workforce review will require all CHD centres across the country to provide an outline of their workforce so national heatmaps can be developed and to inform future commissioning action.
- Delay of transfers of care between paediatric centres (led by LH with RB support) highlight report to be circulated post-Board. This project is to audit the delay in transfers, to support centres to investigate the barriers to the seamless delivery of care and identify mitigating actions to reduce these. An online Microsoft Form has been developed that can be accessed via a QR code poster or web link, with the responses uploaded to a shared Teams channel for the project this process has been signed off by Information Governance and IM&T. The test and learn phase is currently underway between Cardiff and Bristol to establish a baseline, and the pilot task and finish group are due to meet in early May to review.
- **Transition** (led by JH) highlight report to be circulated post-Board. The aim of the transition project is to improve the provision of transition to patients in Level 1, 2 and 3 centres across the South West and South Wales using a variety of methods.
- Transfer of care (TOC) between paediatric and adult CHD services (led by SC) highlight report to be circulated post-Board. The aim is to identify lost to follow-up between paediatric and adult care, to investigate the causes of this, explore implementation of new TOC system, and ensure adequate TOC. . Proposed outcomes are improved safety and a reduction in unnecessary medical follow-up. Aiming to report on audit at July 2023 Clinical Governance Group. Invite to Network members to join task and finish group to progress this project regionwide.

• Engagement of patient and parent representatives (led by SV) – highlight report to be





	 circulated post-Board. The aim is to recruit more patient and parent representatives, for a more diverse representative group and provide a variety of opportunities for engagement. A recent meeting was held on 23rd March 2023. Communication of patient information across the Network - SC reported that as a Network we are aware of communication issues from level 1 centre (Bristol) to the level 2 centre (Cardiff) and level 3 centres (DGHs) around discharge summaries, and that Cath and operation notes have not always made their way back to the referring teams. This project aims to improve this to ensure better communication and improved patient safety. SC presented the results of a recent Network survey conducted at the end of March 2023 and thanked those who contributed to this. The common features showed that the ideal system is senior-driven, automated, admin-run and independent of staff shortages and individual clinicians' ability to communication information.
	team.
11.	Issues Log
	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. 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. SV presented the top three issues: Delays to and cancellations of appointments and procedures across the Network. Cancellation of paediatric cardiac operations due to PICU capacity. Patients transferring from paediatric to adult care are lost to follow-up between services. Please refer to the paper for the details of actions to mitigate these and share any feedback/comments with Louise.Hudson@uhbw.nhs.uk
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12.	Any Other Business
	 <u>Board membership</u> – Need to ensure members send a nominated deputy if unable to attend. National workforce audit – will be contacting centres with this request.
	 <u>National workforce audit</u> – will be contacting centres with this request. <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>, Thursday 13th July 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.







Name		Job Title	Organisation	19/04/23
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Present
Andy Tometzki	AT	BRHC Clinical Director / Consultant Paediatric Cardiologist	Bristol, University Hospitals Bristol & Weston	Present
Ankita Jain	AJ	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Present
Anna Mcculloch	AM	Consultant Clinical Psychologist	Cardiff, University Hospital of Wales	Present
Becky Nash	BN	Patient Representative		Present
Carys Williams	CW	Cardiac Physiologist	Swansea Bay	Present
Catherine Blakemore	СВ	Consultant Cardiologist with interest in CHD	Torquay, Torbay District General Hospital	Present
Claire Kennedy	СК	Senior Commissioning Manager	NHS England	Present
Daniel Meiring	DM	Fetal&Paediatric Cardiac Physiology Service Manager	Bristol, University Hospitals Bristol & Weston	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Present
Danielle McPeake	DMP	Clinical Nurse Specialist ACHD	Bristol, University Hospitals Bristol & Weston	Present
Frankie Carlin	FC	Patient Representative		Present
Giovanni Biglino	GB	Network Research Lead	Bristol, University Hospitals Bristol & Weston	Present
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Present
Jennifer Holman	JH	Consultant Paediatrician	Gloucestershire, Gloucester Hospital	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present
Jill	J	Patient Representative		Present
Karen Sheehan	KSh	Paediatric Cardiac Research Sister	Bristol, University Hospitals Bristol & Weston	Present
Katy Huxstep	КН	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Present
Louise Hudson	LH	CHD Network Manager	CHD Network Team	Present
Luisa Chicote- Hughes	LCH	Consultant Cardiologist - ACHD	Plymouth, Derriford Hospital	Present
Luisa Wilms	LW	Consultant Paediatrician with interest in cardiology	Taunton, Musgrove Park Hospital	Present
Martin Heatley	MH	Consultant		Present
Nagendra Venkata	NV	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Present
Nicola Morris	NM	Patient Representative		Present
Rachel Burrows	RB	CHD Network Support Manager (note- taker)	CHD Network Team	Present
Rosalie Davies	RD	General Manager (BRHC)	Bristol, University Hospitals Bristol & Weston	Present
Richard Palmer	RP	Senior Commissioner	Welsh Health Specialised Services Committee	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





Name		Job Title	Organisation	19/04/23
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda, Glangwilli Hospital	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
Adam Duffen	AD	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	Apologies
Adrian Wagstaff	AW	Consultant Anaesthetist (Adults)	Bristol, University Hospitals Bristol & Weston	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
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
Chris Gibbs	CG	Consultant - ACHD		Apologies
Claire Logan	CL	Paediatric clinical nurse specialist	Cardiff, University Hospital of Wales	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	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
Faumy Hassan	FH	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	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
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





Name		Job Title	Organisation	19/04/23
Jack Gibb	JG	Paediatric Cardiology ST4 Training	Bristol, University Hospitals Bristol & Weston	Apologies
Joanne Jones	11	Paediatric and Fetal Cardiac Sonographer	Bristol, University Hospitals Bristol & Weston	Apologies
John Madar	JM	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
Karikalan Kandasamy	кк	Consultant ACHD	Truro, Royal Cornwall Hospital	Apologies
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Apologies
Kimberley Meringolo	КМ	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Apologies
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Apologies
Lalit Bhalla	LB	Consultant - ACHD	Aneurin Bevan, 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
Maha Mansour	ММ	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	мс	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
Nicola Johnson	NJ	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Apologies
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Apologies
Orhan Uzan	OU	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Patricia Caldas	РС	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	Cwm Taf	Apologies





Name		Job Title	Organisation	19/04/23
		Cardiology		
Rowan Kerr- Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torquay, Torbay District General Hospital	Apologies
Sally Worfolk	SA	Manager (Adults)	Bristol, University Hospitals Bristol & Weston	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
Sophie Nicholls	SN	General Manager (Adults)	Bristol, University Hospitals Bristol & Weston	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
Tim Murphy	ТМ	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