

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

Date: Tuesday 7th December 2021, 14.00 – 16.30

Venue: MS Teams Conference Call

Chair: Dr Dirk Wilson

Minutes

Item	Notes and Actions
1.	Welcome, introductions and apologies - Personnel update
	<p>DW welcomed the attendees to the network’s virtual board meeting via MS Teams. He shared the digital meeting etiquette, noting also that the Microsoft Teams chat question function is available.</p> <p>Steven Pike introduced himself as the interim general manager at the Bristol Royal Hospital for Children, covering while Rosalie Davies is on leave.</p>
2.	Approval of minutes and action tracker
	<p>The minutes of the Network Board on 16th September 2021 were agreed to be an accurate record.</p> <p>The action log was updated as appended. Notable comments:</p> <p><u>161 – Discuss waiting list issues identified in Plymouth and Exeter ACHD services and how network can provide support.</u> Corresponded with ACHD Leads at both centres. A lot of work is going on in both centres on this but there are still big challenges ahead. Network support has been offered where possible. Closed.</p> <p><u>164 – Formal letter to be sent to centres that are not reporting performance quarterly data to the network board</u> Have been discussing with centres individually as issues arise. The centre return rate for the performance data remains an issue - a formal letter is still required.</p> <p><u>166 and 167</u> – all completed and closed.</p> <p><u>168 – BRHC pilot project on DNA rates</u> Project commenced in October 2021. Update to be provided at March 2022 Network Board.</p> <p>No further actions to report on.</p>
3.	Patient Story / Patient Representative Update
	<p>Patient Story</p> <p>The board listened to Amia’s story pre-recorded by her mum, Emma. Amia has various CHD conditions including pulmonary atresia, ventricular septal defect, atrial septal defect and left sided superior vena cava into an unroofed coronary sinus.</p> <p>Soon after Amia was born, she was cared for on Ward 32 (now known as Dolphin Ward) at the Bristol Royal Hospital for Children. Following two cardiac procedures (catheter and a hybrid), Amia then</p>

	<p>needed open heart surgery. Since her first open heart surgery Amia required three more, several catheters and various scans and checks. Emma shared that whilst this has been a tough time, “what is consistent is the amazing team at Bristol Royal Hospital for Children.” Amia and her family have also volunteered to take part in various hospital research studies. Amia is now a healthy and happy 6-year-old. With thanks to the consent of Amia’s parents, Amia’s story is now published on the network website - https://www.swswhd.co.uk/en/page/patient-stories</p> <p>The board discussed this moving story, noting how mum was very positive about what was clearly a difficult journey for them with the uncertainty. The story reflects themes of empathy, reassurance, good communication and kindness throughout their journey. The importance of having a well communicated plan, a team approach with the family being a part of this, and how small normal things can make a big difference to individuals in such circumstances. This story also highlights that whilst research is often for the greater benefit of the patient group, the individual families who volunteer to take part in research trials often receive extra support and opportunities of benefit to them.</p> <p>Patient representative update</p> <p>RT shared that the patient reps had a pre-meet in advance of the Board. The ACHD patient reps are getting involved with an ACHD psychology webinar scoping exercise with Hannah Mustard, and BN is drafting a newsletter article on mental health and open-heart surgery. The patient reps are also getting involved with the network website review project in 2022.</p> <p>NM provided an update on the Heart Heroes charity, which has set up social support hubs for heart families around the region. This included a Christmas Party at Bristol Zoo last weekend. The Gloucester hub has launched an ‘I can...’ project for heart children to attend and take part in practical fun activities (e.g., ‘I can cook’). It was shared that heart children often like to share their scars and their stories. NM has linked in with the BRHC psychologists who are supporting this. Heart Heroes are also linking in with Youth at Heart to support young people.</p> <p>NM raised that communication on consultant changes is so important to patients and families as they often become attached to the clinicians who they see – the support groups are happy to share communications on their social media channels if this would be helpful.</p> <p>Youth at Heart provided a detailed update at the network clinical governance group (07/12) and the work they are doing to support the transition clinics.</p> <p>JGM shared that the patient rep group is really engaged and that their input/support is much appreciated. The network team are looking to expand this group and asked if clinicians are aware of patients that would like to be representatives for the network to let the network team know.</p> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved</i>.</p> <p>DW thanked the patient reps for their time and contributions.</p>
<p>4.</p>	<p>Network Performance exception reporting</p>
	<p>Performance dashboard</p> <p>JGM presented the performance report for review by the board. Focusing on equity of access, the purpose of this visual report is to update the board on performance across the network during the quarter, and to highlight any areas that are performing well or areas that may need support, so that the board may agree any actions or escalations that are required to address any performance issues</p>

highlighted. Please refer to the report for details.

JGM shared the importance of centres submitting the quarterly reports and thanked those that have – the submission rate still has room for improvement. Discussions with individual centres have been really useful but the plan is to send a formal letter to centre leads to help support service teams to access this.

Of key note:

Wait for new patient appointments

Capacity has been a challenge for a lot of centres, particularly in Swansea Singleton Hospital ACHD service with new patient wait being up to 110 weeks. HW has been doing a lot of work to support Swansea with tackling the challenges. She shared that pre-Covid-19 there were 11 clinics per year provided by a combination of four consultants, and then due to Covid-19 since March 2020 and April 2021, the provision became very patchy with one consultant retirement and two consultants being redeployed to cover other areas due to Covid-19 pressures. Since April 2021, the situation has stabilised, but this has generated a huge waiting list.

WHSSC has supported funding for ACHD in Wales and part of this plan was to lift the Swansea Bay service, but the service is currently falling short of these plans. HW explained that the key issue is the local consultant cardiologist vacancy, but also there is a lack of clinic space in Singleton so returning to face-to-face consults is a challenge (mainly running virtual consults). AR raised that in addition to the phase 2 funding, additional funding was also released to support Singleton's backlog, and that she will formally follow up with the Swansea Bay UHB as to how this additional funding is being utilised. HW noted that some of this funding has been used by the local consultant to undertake extensive validation of the waiting lists – this has been beneficial for managing risk and enabled several patients to be referred back to other centres (Carmarthen and Bridgend), referred onto general adult services, and a small number also being removed due to moving outside of area (England).

The board thanked HW for this useful background explanation and felt that the upcoming self-assessment review against CHD standards will be a useful opportunity for more discussion around the Swansea Bay challenges with the key representatives.

Overdue follow up backlogs

Overdue follow ups continue to be more of an issue for ACHD and a support meeting was held in September with Plymouth. Plymouth ACHD service have been working hard to put on extra activity and manage this huge challenge. JGM will continue to link in with the team who plan to attend the next Board meeting in March 2022. The BHI overdue follow up waiting list backlog has also increased dramatically since previous quarter; SC provided the context that she undertook a lot of extra clinics from November 2020 over a 6-month period, which may have temporarily reduced the backlog in the previous quarter report, skewing the position.

Overall, there is some good performance progress across the network, but the volume of backlogs is the primary challenge currently being seen.

Local centre reports

Each individual centre can access their local outpatient performance dashboard via the [CHD network website](#).

Inpatient waits for level 1

Please refer to the report for further details.

	<p><u>NHSE Specialised Services Quality Dashboards (SSQD)</u></p> <p>The Adult Level 1 SSQD Quarter 1 2021/22 dashboard and Paediatrics Level 1 SSQD dashboard for Quarter 1 are included in the papers for information (this is due to the validation timeline). The board noted that for ACHD level 2, the 30-day re-intervention rate following primary catheter intervention procedures is higher than expected again this quarter, which may reflect case mix but the board would like assurance that this has been investigated and any necessary actions taken. AT commented that nationally adult intervention is a challenge due to the complexity of the case mix.</p> <ul style="list-style-type: none"> ○ <u>Action:</u> JGM/AT to follow up with the level 1 ACHD Lead/Interventionists re: 30-day re-intervention rate following primary catheter intervention procedures. <p>The intervention rate for the paediatric service is better than expected.</p> <p><u>Surgical performance update</u></p> <p>For board awareness, it was noted that there are significant challenges with the paediatric surgical programme due to paediatric intensive care capacity, which is currently facing acute pressures.</p>
5.	Update from Level 3 centre(s)
	<p>JGM led an update on the behalf of the level 3 centres and invited representatives present to contribute. The key updates are outlined in the exception report in the papers.</p> <p><u>Adult CHD:</u></p> <p>Key themes to note for adults included:</p> <ul style="list-style-type: none"> ● Key risks/concerns: For the South West, the key concern is the volume of the waiting lists. Gloucester ACHD service had a particular challenge around the withdrawal of nursing support – the latest update is that there has been some progress through the senior nursing channels so hopefully this will be resolved. For South Wales, there are also concerns around waiting times but also high DNA rates in some areas (exploring text reminders as discussed in the last board meeting). There is currently no local cardiologist supporting the clinic in Princess of Wales hospital which is having an impact on the waiting list - this was escalated/discussed at the recent Cwm Taf Morgannwg self-assessment review. As previously noted, Swansea Bay have a ACHD Lead vacancy. ● Actions/support required from the network: Truro identified an increasing workload and need for ACHD nurse support as well – the network can support centres with business cases if this would be helpful or help co-ordinate conversations with others who have had success in this. Prince Charles Hospital raised that the ownership of patients with suspected or actual cardiac disease in Cwm Taf Morgannwg UHB aged 16/17 years still needs to be resolved – it would be helpful to have a regional approach to this. AR confirmed that WHSSC fund ACHD activity, and that the issue with 16/17-year-old age group is a unique operational issue in CTM UHB and this has been previously raised formally with the medical directors who offered a compromise. HF was disappointed to hear that this is still an issue, and the board agreed that this needs re-exploring. <p><u>Paediatric CHD</u></p> <p>Key themes to note for paediatric level 3 centres included:</p> <ul style="list-style-type: none"> ● Key updates: Included in the papers. ● Risks/concerns to be escalated:

	<ul style="list-style-type: none"> ○ NO noted that the consistent challenge/theme across the South West centres is that whilst Covid-19 has pushed back the waiting list, the number of referrals and complexity of these are increasing so the waiting list will continue to rise. Will need innovative working to address this – discussions around capacity planning, job plans, link nurses and innovative use of physiologists have been ongoing over the last year. ○ Swansea – also high volume of waiting list and how this is managed within the Trust. ● Actions/support required from network: <ul style="list-style-type: none"> ○ Ongoing support and understanding whilst work through this difficult period and try to help to ensure that resource is not taken out of CHD services. A theme is that with operational pressures increase across the hospitals, specialist staff are being drawn into general areas. ○ Torbay raised about support in maintaining and scanning current complex cases that would have been seen by visiting specialist. ○ Swansea – would value support with recruitment of a paediatric with a special interest in cardiology. Will link in directly with Swansea about this.
6.	Update from Level 2 centre
	<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: included in the papers. Of note since the last meeting, there are now two new ACHD CNS nurses so the team is at 4.5WTE, supporting the satellite clinics. Appointed two psychologists to start in the new year. ● Risks/concerns: Still haven't fulfilled the hopes of the ACHD phase 2 funding due to a combination of factors including a severe shortage of ACHD trained ECHO support and also capacity in consultant job plans to run clinics in the south east of Wales. Cardiff has persisted with virtual clinics throughout Covid-19 with a plan to continue to August 2022 – there are a few face-to-face consults but otherwise mainly virtual; the ACHD team are opposed to this. ● Actions/supports required from network: None noted at the meeting. <p><u>Level 2 paediatric CHD service:</u></p> <p>AP presented an update for the Level 2 centre:</p> <ul style="list-style-type: none"> ● Key updates: Psychologist due to return in the new year. Are in the process of recruiting an additional psychologist too. ● Risks/concerns: Repatriation of patients from Bristol to Cardiff after procedure. There are some acute risks to the warfarin prescribing service with the liaison nurses being redeployed to general wards to support and mentor new nurses coming into post and getting new liaison nurses training on non-medical prescribing courses. Occasions when availability/accuracy of discharge summaries from Bristol following intervention/surgery – needs looking at from both sides – AP has been in discussion with Bristol Clinical Leads. <ul style="list-style-type: none"> ○ <u>Action</u> – HF asked to be informed of any delays of transfers back from Bristol so support can be provided from WHSSC – AP agreed to add this to the operational procedure for the consultant on-call to escalate. AT and AP to develop a brief template reporting tool to be

	<p>used for this purpose.</p> <ul style="list-style-type: none"> • Actions/support required from the network: None noted at the meeting.
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>In GS absence, JGM shared the key updates on:</p> <ul style="list-style-type: none"> • Key updates: The admin staff is short again as the secretary appointed withdrew. Dr Simon McDonald (Cardiff) contributes now to the ACHD on call service. The BHI have appointed two new consultant cardiologist interventionists. • Risks/concerns to be escalated: <ul style="list-style-type: none"> ○ Have fewer clinical nurse specialists than are needed for the service and are required by both the CHD standards and peer review (currently have 3WTE rather than 5WTE) – MC updated that a big has recently been submitted to again request financial support to address this. ○ Lack of consultant pregnancy clinic support – SC noted that a bid has been submitted for a fifth consultant to support this. Also, NHS England are bringing in a new maternal network so funding arrangements will change, which may provide additional PA/funding for another post, but it is unclear how much this will be. <ul style="list-style-type: none"> ▪ <u>Action:</u> SC to share the fifth consultant business case with the network team to see if support can be provided. <p><u>Level 1 paediatric CHD service</u></p> <p>SP shared the key updates to note:</p> <ul style="list-style-type: none"> ○ Key updates: included in the papers. In addition, a new consultant is starting in January 2022 – SP has emailed the peripheral centres with the changes in consultant arrangements - this will hopefully provide some stability once the clinician changes are implemented in 2022. Network team offered to support/disseminate information if this would be helpful. ○ Risks/concern: <ul style="list-style-type: none"> ○ Current extreme operational pressures are causing challenges to maintain elective activity, particularly due to PIC staffing. This has been escalated at a Trust-level. ○ There have been ongoing staffing shortages on the junior doctor rota (under-recruited), but this group should be over-recruited in the new year. ○ Outpatient capacity has been increased by 20% as part of job planning although this is unlikely to be sufficient to deal with the backlog. • Actions/supports required from network: None noted at the meeting.

8.	Presentation: Research – a feasibility pilot – a personalised physiotherapy-led remote ACHD cardiac rehabilitation programme
	<p>Welcomed Caroline Evans (CE), Clinical Specialist Cardiology Physiotherapist at the Bristol Heart Institute, who presented a pilot to determine the feasibility of physiotherapy led remote cardiac rehabilitation for Adult CHD patients and quantify the impact on physical activity levels and wellbeing. ACHD cardiologists referred 23 sedentary complex ACHD patients for a 12-week physiotherapy-led individualised remote cardiac rehab exercise programme via telephone clinics and apps. 11 patients completed the programme, and all became more active fulfilling the UK physical activity guidelines. In conclusion, the pilot showed that remote cardiac rehab is feasible, allowing patients access to specialised, individualised exercise advice and become more active, improving quality of life. However, further work is needed to improve uptake, extend to larger patient numbers, and look at the long-term adherence post remote cardiac rehabilitation.</p> <p>The next steps would be to try to secure long term funding and start discussions with commissioners and work towards a business case, use attend anywhere consults, and be working towards individualised exercise prescription for all CHD patients (not just sedentary ones). Special thanks to the BHI consultant group.</p> <p>The full journal article can be found at: A feasibility pilot- a personalised physiotherapy led remote ACHD cardiac rehabilitation program - ScienceDirect</p> <p>The board comment was that this is an important piece of work showing that you can encourage patients to be more active, and that hopefully this will go from a pilot to a wider study. The patient representatives were very supportive of this excellent pilot and felt that the roll out of this would be very beneficial for patients, particularly if it's run remotely.</p> <p>JGM asked what existing services would need to start rolling this out. CE advised that to deliver cardiac rehab to CHD patients, specialist knowledge is needed, which is the reason the pilot was run remotely from Bristol. Bristol could potentially run this service for the region; however, there is not currently the staffing capacity to enable this so this would require a business case to be developed as well as commissioning support if this is a viable option.</p>
9.	Research update
	<p>Gemma Dibble and Julie Madden provided an update on the BRHC paediatric research team. Currently the team are funded for 3.7 WTE but unfortunately Bristol has not been shortlisted for the National Institute for Health Research Biomedical Research Centre funding this time round, which would leave only 1 WTE post funded. Massimo Caputo is hoping to obtain British Heart Foundation charitable funding support to enable 2 WTE. This is a risk to the capacity of the team and research portfolio. DW noted that there has been a national reduction in research funds from charitable sources due to the Covid-19 financial challenges, and charities are having to focus on key projects.</p> <p>During the pandemic, the research nurse team were retrained to provide clinical support on the wards but were not called upon so could continue with the Outcomes Monitoring After Cardiac procedures (OMAC) study which covered surgery and catheters. On average have 50-60 patients a month.</p> <p>Due to start another research project named 'Destiny' looking at cardioplegia, and currently running an active study named 'PEACOCK' looking at cortisol levels.</p> <p>Some studies are on hold due to the pandemic as they require follow up appointments with patients</p>

	<p>outside of normal clinical appointments, and this would be a higher risk to patients.</p> <p>DW noted that the plan is to have research on the Board agenda for an update once a year as it is an important part of the network profile.</p>
10.	Network Board update
	<p>JGM attached the supporting papers: quarter 2 update (July to September 2021); and the work plan 2021/22 update. Please refer to the papers for further detail.</p> <p><u>Headlines for Q2/Q3 (September 2021 to date)</u></p> <p>JGM highlighted that the:</p> <ul style="list-style-type: none"> • Annual report 2020/21 was published. • Network autumn 2021 newsletter was published, with thanks to those who submitted articles. • Website homepage updated with new professional photos of CHD patients/staff involved in CHD care. • Education and training, including the third network physiologist meet (DM); PEC education forum (DW); monthly link nurse drop-in sessions (JH); paediatric CHD nurse webinar series (LP); L2&L1 cardiac nurse event; ACHD study day. • Network annual M&M held in September. • Continued to lead the national network of CHD networks regular conference calls. <p>Thank you to network members for their continued work and support.</p> <p><u>Self-assessment against the CHD standards</u></p> <p>Working with WHSSC to carry out a gap analysis with South Wales Health Boards. Health boards have been contacted individually and the first few reviews have been held. The Network team are grateful for the engagement with this process so far.</p> <p><u>Work plan 2021/22</u></p> <p>The network board has a role in ensuring that the work plan is fit for purpose and to check progress on this. The current status is that there are 4 complete work plan areas; 27 work plan areas that are rated green (on track); 6 amber areas (partially progressed but have been delayed by external factors e.g., Covid-19) and 1 currently rated as red (stalled due to capacity in the L1 junior workforce) which AT is addressing. The transition project is about to be re-launched now that SV has returned.</p> <p><u>Future planning: Work plan 2022/23</u></p> <p>Importantly, the network needs to review, prioritise, and develop the network work plan for 2022/23. JGM explained that the workplan is owned by the CHD network board and delivered by the core team and network members. The draft is due with NHS England by the end of January 2022 and sign off at the network board in March 2022. JGM invited input, ideas, and comments from members on what should be included on the workplan. Given the short timeframes, the board agreed that the core network team will begin drafting this and will share with members for input by email.</p>
10.	National and regional updates
	<p><u>National update</u></p> <p>AT provided a brief national snapshot:</p>

- ACHD workforce – this is the main focus for the Clinical Reference Group. Several meetings are being held nationally with PPV and charitable representation too.
- National network of CHD networks meeting – currently being held fortnightly to look at the resilience of CHD services across the UK. Access to critical care is causing high pressures across the country. Recruitment and retention of nursing staff in intensive care is also an issue.
- Post-vaccine myocarditis and pericarditis project for 12–15-year-olds – this is being run by having a registrar to pick up the data. National guidance for all age groups has been released recently: <https://www.gov.uk/government/publications/myocarditis-and-pericarditis-after-covid-19-vaccination>
- The structure of advisory groups, such as the Clinical Reference Group, are being revamped.

(Greg Szanthy joined the meeting following clinical emergencies)

Commissioner updates

Welsh Health Specialised Services Committee (WHSSC), South Wales

- **Key updates**
 - Phase 2 funding has been implemented across South Wales – most staff have been appointed. Are aware of the cardiac physiologist issue and work is ongoing.
 - Awaiting a further business case from Cardiff and Vale UHB to release additional funding for ACHD in relation to increasing access to cardiac MRI. This funding would include a third ACHD consultant post for South Wales, additional admin, and radiology. One of the prerequisites for the admin funding would be to support the submission of the network centre performance data.
 - Paediatric CHD funding has been released and fully implemented.
 - Self-assessment reviews in South Wales – themes are already emerging. After all the review meetings, the plan is to submit an overview report of the gap analysis to the WHSSC management group that asked for this joint working to be undertaken. The aim is that the NHS England standards would be formally adopted in Wales. Recently WHSSC has undertaken consultation on the level 1 and level 2 services for ACHD and this service specification is about to be published. AT thanked AR for her support with this process. Simon MacDonald shared that he is keen to support this as there is a lot of work to develop the services in South Wales.
- **Actions/support required from the network** – To support with the Level 3 Centres baseline assessment against the standards over the next few months. JGM noted that the North Wales network have some staffing issues, so SWSW CHD network will offer support to ensure that an overall position can be determined for Wales.

NHS England, South West

Presented by CK

- **Key updates** including:
 - System working – starting to use CYP system leads to engage with some network pieces of work.
 - Peripheral clinic SLA – has been supported by the region. A lot of work went into this by the CHD network – currently with BRHC to progress.

	<ul style="list-style-type: none"> ○ Paediatric Critical Care Surge Planning – plans approved regionally and nationally, and these continue to be reviewed and updated to support the escalation process. The South West have moved in and out of OPEL 3. Concern was raised about retention of critical care staff. ○ Risk management – specialised comm risk register is now being shared with networks on the last day of each month. Training on the new risk SOP took place through September. <ul style="list-style-type: none"> ▪ <u>Action</u>: CK to send SOP to RB to share with network board for comments. ○ Self-assessment reviews – the plan is to share reviews through the System Partnership Boards. <ul style="list-style-type: none"> ● Risks/concerns to be escalated to a national level <ul style="list-style-type: none"> ○ Alignment of regional waiting list analysis with the ODN efforts to collate waiting list data, to support targeted restoration. ● Actions/support from the network: <ul style="list-style-type: none"> ○ ODN intelligence of risks and issues in relation to restoration.
11.	Network risks – for information
	<p>JGM summarised the network risk report. Please refer to the risk report in the papers. The report includes current risks and their risk rating, what controls are in place and recent actions. There are currently 7 open risks on the network risk register.</p> <p>JGM raised whether should have a risk around the research portfolio.</p> <ul style="list-style-type: none"> ○ <u>Action</u>: JGM to link in with the research team re: the risk around the research portfolio and funding. <p>The Network Board is responsible for managing risks. The Board are asked whether all the relevant network risks are recorded; to check the risk ratings; to check the controls in place are adequate; to decide whether further controls or actions are needed; and whether any other risks need to be escalated.</p>
12.	Evaluation
	<ul style="list-style-type: none"> ● Evaluation forms - Board members were invited to complete the meeting feedback form via the Microsoft Forms link circulated.
13.	Any Other Business
	<ul style="list-style-type: none"> ● Next Board Meeting, Wednesday 9th March 2022, 14:00 – 16:30 (virtual) - Board members were asked to inform the network team of any agenda items for the next network board meeting. ● 2022/23 Board meetings – whether move the dates on a month (April, July, October, January) so receive the most up to date quarterly reports. This was supported.

Attendees

Name	Inits.	Job Title	Organisation	Present/ Apols
Alan Pateman	AP	Paediatric Clinical Lead	University Hospital of Wales	Present
Andrea Richards	AR	Senior Commissioner	Welsh Health Specialised Services Committee	Present
Andy Tometzki	AT	CHD Network Clinical Director / Consultant Paediatric Cardiologist	CHD Network Team	Present
Becky Nash	BN	Patient Representative		Present
Claire Kennedy	CK	Senior Commissioning Manager	NHS England and NHS improvement – South West	Present
Daniel Meiring	DMe	Lead Physiologist	University Hospitals Bristol and Weston	Present
Dirk Wilson	DW	Consultant Paediatric Cardiologist	University Hospital of Wales	Present
Emma Whitton	EW	Commissioner	NHS England South West	Present
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton and Somerset	Present
Helen Fardy	HF			Present
Helen Wallis	HW	Consultant Cardiologist	ABMU Health Board	Present
Jennifer Holman	JH	Consultant Paediatrician	Gloucester Hospital	Present
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Present
John Mills	JGM	CHD Network Manager	CHD Network Team	Present
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals	Present
Lisa Patten	LP	Paediatric clinical nurse specialist	University Hospitals Bristol and Weston	Present
Marta Cunha	MC	ACHD clinical nurse specialist	University Hospitals Bristol and Weston	Present
Matthew Evans		Service Manager	Aneurin Bevan	Present
Nicola Morris	NM	Patient Representative		Present
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Royal Devon and Exeter	Present
Rachel Burrows	RaB	CHD Network Support Manager (note-taker)	CHD Network Team	Present
Rachel Tidcombe	RTi	Patient Representative		Present
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals	Present
Sandeep Ashketar	SA	Consultant paediatrician	Royal Gwent Hospital, Newport	Present
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Present
Simon Dunn	SD	Operational Service Manager	Torbay Hospital	Present
Soha Elbeherly	SE	PEC / Consultant Paediatrician	Nevill Hall Hospital	Present
Sree Nittur	SN	PEC	Swansea	Present
Stephanie Curtis	SC	Consultant cardiologist	University Hospitals Bristol and Weston	Present
Steven Pike	SP	General Manager of Paediatric Cardiac services, Neurosurgery and PICU	University Hospitals Bristol and Weston	Present

Name	Initis.	Job Title	Organisation	Present/ Apols
Susie Gage	SG	Paediatric cardiology and surgical pharmacist	University Hospitals Bristol and Weston	Present
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team	Present
Andre Clinchant	AC	Lead Nurse	Taunton and Somerset	Apologies
Andrew Parry	AP	Consultant	University Hospitals Bristol and Weston	Apologies
Andy Arend	AA	Consultant paediatrician	North Devon District Hospital, Barnstaple	Apologies
Ankita Jain	AJ	PEC	Hywel Dda	Apologies
Anthony Goodwin	AG	PEC	Cwm Taf	Apologies
Anthony Pearce	AP	Commissioner	NHS England and Improvement	Apologies
Becky Lambert	BL	Staff Nurse ACHD	Taunton and Somerset	Apologies
Bill McCrea	BMc	Consultant	Great Western Hospital, Swindon	Apologies
Candida Frankham	CF	Cardiac Physiologist	Royal Cornwall Hospital	Apologies
Catherine Blakemore	CB	ACHD Consultant	Torbay	Apologies
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology	Royal Devon and Exeter	Apologies
Ed Roberts	ER	Assistant General Manager		Apologies
Emma Hulbert Powell	EHP	PEC	Plymouth	Apologies
Faamy Hassan	FH	PEC	Hywel Dda	Apologies
Frankie Carlin	FC	Patient Representative		Apologies
Georgina Ooues	GO	Consultant Cardiologist	Royal Cornwall Hospitals	Apologies
Gergely Szantho	GS	Consultant cardiologist	University Hospitals Bristol and Weston	Apologies
Gerraint Morris	GM	PEC	Swansea	Apologies
Helen Liversedge	HL	Consultant Fetal	Royal Devon and Exeter	Apologies
John Madar	JM	PEC	Plymouth	Apologies
Karen Sheehan	KSh	Paediatric Cardiac Research Sister	University Hospitals Bristol and Weston	Apologies
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff	Apologies
Kimberley Meringolo	KM	Commissioner	Welsh Health Specialised Services Committee	Apologies
Louise Challis	LC	Link Nurse	Torbay	Apologies
Luisa Wilms	LW	Consultant	Taunton and Somerset	Apologies
Luke Harris	LH	Service Manager	Gloucestershire Hospitals	Apologies
Maha Mansour	MM	PEC	Swansea	Apologies
Manish Gandhi	MG	ACHD Consultant cardiologist	Royal Devon and Exeter	Apologies
Marcia Scheller	MSC	PEC	Cwm Taf	Apologies
Marion Schmidt	MS	Consultant Paediatrician	Royal Gwent Hospital, Newport	Apologies
Mark Dayer	MD	Consultant Cardiologist	Taunton and Somerset	Apologies
Matthew Beake	MB	PEC	Gloucestershire Hospitals	Apologies
Max Nathan	MN	Consultant Paediatrician with Expertise in Cardiology	Bridgend, Princess of Wales	Apologies

Name	Inits.	Job Title	Organisation	Present/ Apols
Muhammad Addin	MA	PEC	Royal United Hospital, Bath	Apologies
Nagendra Venkata	NV	PEC	Royal Devon and Exeter	Apologies
Nicola Johnson	NJ	PEC	Taunton and Somerset	Apologies
Orhan Uzan	OU	Consultant Cardiologist	University Hospital of Wales	Apologies
Patricia Caldas	PC	Consultant paediatric cardiologist and Clinical Lead	University Hospitals Bristol and Weston	Apologies
Peter Wilson	PW	Medical Director Commissioning	NHS England and Improvement	Apologies
Poonamallee Govindaraj	PG	Consultant Paediatrician	Royal Glamorgan	Apologies
Pradesh Mappa	PM	Consultant Paediatrician	Great Western Hospital	Apologies
PremKumar Pitchaikani	PP	Consultant	Hywel Dda	Apologies
Rainer Fortner	RF	PEC	Cwm Taf	Apologies
Rowan Kerr-Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torbay Hospital	Apologies
Sarah Finch	SF	ACHD Clinical Nurse Specialist	University Hospital of Wales	Apologies
Shafi Mussa	SM	Consultant Surgeon	University Hospitals Bristol and Weston	Apologies
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Glangwilli Hospital, Wales	Apologies
Simon Macdonald	SM	Consultant Cardiologist	University Hospital of Wales	Apologies
Tatiana Rjabova	TR	Consultant Paediatrician with Expertise in Cardiology	Royal United Hospital, Bath	Apologies
Vishwa Narayan	VN	PEC	Hywel Dda	Apologies
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	University Hospitals Bristol and Weston	Apologies

Also in attendance:

- Caroline Evans, Clinical Specialist Cardiology Physiotherapist (University Hospitals Bristol and Weston)
- Gemma Dibble, Paediatric Research team (University Hospitals Bristol and Weston)
- Julie Madden, Paediatric Research team (University Hospitals Bristol and Weston)
- Kelly Saunders, Paediatric Research team (University Hospitals Bristol and Weston)