

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

**Date:** Tuesday 12<sup>th</sup> July 2022, 14.00 – 16.30  
**Venue:** Engineers house, Bristol, hybrid event  
**Chair:** Dr Dirk Wilson

### Minutes

Item	Notes and Actions
1.	<b>Welcome, introductions and apologies</b> - Personnel update
	<p>DW welcomed the group to the Network Board. The meeting was held as a hybrid event with some attendees present at Engineers House, and some joining virtually via Microsoft Teams. Meeting etiquette was shared, and it was noted that the meeting is being recorded.</p> <p>DW introduced:</p> <ul style="list-style-type: none"> <li>- Richard Palmer - Senior Specialist at Welsh Health Specialised Services Committee (WHSCC) who has taken over from Andrea Richards</li> </ul> <p>DW noted that:</p> <ul style="list-style-type: none"> <li>- A new CHD Network Manager (Louise Hudson) has been appointed and will be joining in September.</li> <li>- It is Andrew Tometzki's last Network Board meeting as Clinical Director for the CHD ODN – DW expressed thanks to AT for the significant contribution he has made to the network.</li> <li>- A feedback survey for the meeting will be available for attendees to complete.</li> </ul>
2.	<b>Approval of minutes and action tracker</b>
	<p>The minutes from the previous Network Board (held 9<sup>th</sup> March 2022) were approved as an accurate record of the meeting.</p> <p>Updates were provided on the actions currently open on the action tracker:</p> <p><b>168 - Feedback on the BRHC pilot project on DNA rates</b>            SP noted that from the end of October 2021, two full time staff members have been phoning patients with an upcoming clinical appointment (all specialities). As DNA rates have improved as a result, funding for this pilot project has been extended until the end of March 2023. Closed.</p> <p><b>170 - Informing WHSSC of delays of transfers back from Bristol – AT and AP to develop a brief template reporting tool</b>            AT noted that delays around the region should be recorded via an online form - this will be added to the agenda for the BRHC business meeting next week. AP confirmed that a form has been available for some time but is yet to be filled in. The form has been readvertised in recent emails and will be placed centrally for easy access – it may need some tweaks to capture the required information. SV noted that there have been conversations about using a whiteboard in the doctors' office with information being relayed to the relevant managers - it was acknowledged that this would not be a robust process and could be wiped / would not record long-term data.</p> <ul style="list-style-type: none"> <li>o <u>Action</u>: Ensure new 'delay in transfers' form is in use – check in September.</li> </ul>

3.	Patient Story
	<p>Sophie presented the story of her daughter Violet who was diagnosed with Hypoplastic Left Heart Syndrome during her 20-week scan at St Michael’s hospital.</p> <p>Sophie shared the journey from receiving Violet’s diagnosis, detailing the different options her family were given, and the various appointments and experiences (both positive and negative) throughout the pregnancy, and the decision-making process for Violet’s care. Sophie wanted Violet’s life to have a purpose and for her to leave her stamp on the world – after exploring organ donation options, it was realised that this would not be possible, and Sophie expressed her hurt that if she terminated her pregnancy Violet’s birth would not be registered.</p> <p>Sophie and her family elected to follow a comfort care pathway for Violet – plans were put in place for her arrival. During this time, Sophie’s grandmother received a terminal cancer diagnosis.</p> <p>Violet arrived 3 days ahead of her planned induction and was born on Sunday 24<sup>th</sup> May 2020. Sophie described her daughter as completely perfect, other than her heart - an echocardiogram was performed in the delivery room which confirmed the diagnosis.</p> <p>They were transferred to the lavender suite at BRHC, with prints and moulds taken of Violet’s hands and feet, and photos printed to take home. The family were taken home to Wales the following day via ambulance.</p> <p>Sophie expressed her joy that her grandmother was able to meet Violet and have 4 generations at home together. Violet was just like any other baby, and they enjoyed every moment with her for 11 days.</p> <p>After 11 days, Violet’s health began to deteriorate. The community midwife came for a routine visit, and their palliative care nurse arrived, giving medication. Violet passed away in Sophie’s arms at around 8pm that night, just hours after her grandmother passed away – Sophie described her daughter’s death as peaceful and like going to sleep.</p> <p>Sophie explained that everything up until that point had been planned meticulously with the support of multiple different teams, but at the point of Violet’ death there was an abrupt end to contact. She suggested that a sealed envelope of information, leaflets, and support for after her daughter’s death might have provided some comfort.</p> <p>After Violet’s death, Sophie raised over £6,000 to give back to those that helped them. Two years on, Sophie now has a 4-month-old son who is a healthy boy.</p> <p>Sophie thanked medical professionals for their support throughout Violet’s journey, emphasising that it is okay for them to show emotion, to not know the answer to all questions, and feeling listened to is invaluable.</p> <hr/> <p>DW thanked Sophie for sharing her story, acknowledging that learning can be taken from her experiences. Key points discussed following the presentation:</p> <ul style="list-style-type: none"> <li>- The Welsh Paediatric Cardiovascular Network will be looking at palliative care.</li> <li>- Members asked Sophie if her story could be shared with other networks to support their work - Sophie was supportive of this, emphasising that she wants to help other families wherever possible.</li> <li>- DW noted that the points raised during Sophie’s story can be used to further improve palliative care services in England and Wales, such as what happens after death when contact with services ends.</li> <li>- AT noted the importance of planning a post-natal assessment to verify diagnosis, following a case in Exeter where the post-natal scan did not align with the antenatal diagnosis.</li> <li>- HL emphasised that care should be kept local wherever possible. AT noted that these cases are fairly rare, therefore professionals should try to support local care by travelling to the patient if possible.</li> </ul>

	<ul style="list-style-type: none"> <li>- NM noted that as a parent representative, it is powerful to hear a positive story of a palliative care journey, therefore sharing Sophie’s story may help others going through similar situations. JJ suggested Sophie’s story could be shared/printed as a supportive resource. JH will follow up with Sophie.</li> <li>- Detailed symptom management plans often exist for health professionals but not for families – SG suggested this could be considered to support families with managing / understanding symptoms.</li> <li>- It was suggested that Sophie may like to be involved in designing a sealed envelope for support after death and consider what resources might be beneficial. <ul style="list-style-type: none"> <li>o <u>Action:</u> Network to work with Sophie to design a sealed envelope for support after a death and look at further resources for families which may be helpful.</li> </ul> </li> </ul>
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<b>4.</b>	<b>Network Performance exception reporting</b>
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	<p><b><u>Performance dashboard</u></b></p> <p>The CHD Network performance report was tabled 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 highlighted. Please refer to the report for details.</p> <p><u>Local centre reports</u></p> <p>Each individual centre can access their local outpatient performance dashboard via the <a href="#">CHD network website</a>.</p> <p><b><u>NHSE Specialised Services Quality Dashboards (SSQD)</u></b></p> <p>AT presented the Adult Level 1 SSQD Q4 2021/22 report and the Paediatrics Level 1 SSQD Q4 2021/22 report:</p> <ul style="list-style-type: none"> <li>- Paeds L1 CHD: 1 Negative Alert, 5 Positive Alerts</li> </ul> <p>The negative alert for Paediatrics L1 CHD was regarding the proportion of elective congenital heart disease procedures cancelled last-minute for non-clinical reasons – this is being addressed by the team and has been raised with Executives at BRHC in recent weeks.</p> <p>The positive outliers for Paediatrics L1 CHD were highlighted as 30-day re-intervention rate following primary catheter intervention procedures; hospital acquired Clostridium difficile; hospital acquired MRSA; and formal complaints involving inpatients.</p> <ul style="list-style-type: none"> <li>- Adult L1 CHD: 0 Negative Alerts, 1 Positive Alert</li> </ul> <p>The positive alert for Adult L1 CHD was noted as formal complaints involving inpatients.</p> <p>DW noted that a concern was raised 2 quarters ago regarding reintervention rates after CHD interventional procedures – this has not re-featured since, therefore is considered to be at an acceptable rate.</p> <p><b><u>Surgical Performance</u></b></p> <p><b>Paediatric Surgical Performance</b> - this is currently challenging. SP confirmed that the delay is primarily due to nursing staffing across BRHC PICU and theatres due to vacancies and high sickness rates. SP highlighted that staffing challenges in theatre and PICU are being addressed and outlines some of the measures: additional enhancements being paid to PICU staff to encourage nurses to work extra hours; overseas recruitment is taking place (3 nurses joined in February, more to join later this year); there is a permanent rolling advert for PICU nurses; shift patterns are being rearranged to improve staff retention; newly qualified nurses will be starting in September; lists are being reviewed regularly to try and get additional theatre sessions when</p>
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	<p>possible; and the clinical team met with the Medical Director to put forward additional options to consider for improving the programme – a decision has been made to put a bid to HR to pay additional monies to PICU staff to match agency rates in neighbouring hospitals for theatre and PICU staff, to improve availability of beds/theatres.</p> <p>DW noted that recognising these challenges, the Cardiff team have looked at referring to Birmingham as an option when clinically appropriate. This has not yet happened but may be required if challenges remain in delivering surgical dates in Bristol.</p> <p><b>Adult Surgical Performance</b> - SC noted that things are taking slightly longer than usual for adults, but the backlog is being addressed, and that ACHD surgical intervention is often less time critical than paediatric intervention. Some patients were deciding not to have scans and appointments during the pandemic due to the risk of Covid-19 in the hospital.</p> <p>AT provided a national overview – around 5,000 operations for congenital cardiac conditions take place each year. There were approximately 1,600 to 1,800 patients who were not operated on during the Covid-19 pandemic now needing operations while other challenges and pressures (staffing, sickness etc.) continue.</p>
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5.	<b>Update from Level 3 centre(s)</b>
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	<p>SV 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><b>Adult CHD:</b> Key themes to note for adults included:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> Included in the papers. Of note is that Torbay have substantially improved DNA rates by phoning patients 2 days prior to the clinic.</li> <li>• <b>Key risks/concerns:</b> None noted for the South West (only 50% of returns submitted). For South Wales, there are ongoing concerns for Cwm Tag Morgannwg regarding ECHO support for clinics, and for Swansea about the ongoing vacancy for a replacement consultant with an interest in ACHD – this was discussed as part of the self-assessment process and needs to remain a priority.</li> </ul> <p><b>Paediatric CHD:</b> Key themes to note for paediatric level 3 centres included:</p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> included in the papers.</li> </ul> <p>Swansea was delighted to share that funding has been approved (success) for a new consultant paediatrician post with a special interest in cardiology based at Morriston Hospital. Thanks were given to the SWSWCHD network team who helped build a case for this development.</p> <p>AT noted that the merger between Yeovil and Taunton (by April 2023) will need to be managed, as Yeovil traditionally refer to Southampton. GB confirmed that preliminary service-based meetings have taken place – some choice may be given to families where appropriate, but pathways are still to be confirmed. CK offered to follow this up.</p> <p>Barnstaple and Royal Devon and Exeter have been merged since April 2022 as ‘Royal Devon University Healthcare NHS Foundation Trust.’ NO noted that paediatric cardiology is not an early adopter, therefore</p>
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	<p>there has been very little change seen to date.</p> <ul style="list-style-type: none"> <li>• <b>Risks/concerns to be escalated:</b> Image sharing issues escalated by Exeter. Gloucester raised concerns about the overdue follow up waiting list and clinical risk assessments continue. Taunton raised that the change in visiting paediatric cardiologist post is expected to cause some short-term gap and disruption in providing tertiary clinics – AT is looking into this to minimise any disruption.</li> </ul> <p>Swindon had raised about access to ECGs during clinics - PM highlighted at the meeting that this has now been resolved. Clinical capacity is an issue due to limitations of the number of rooms available for tertiary clinics – some progress has been made but they are still behind.</p> <ul style="list-style-type: none"> <li>• <b>Actions/support required from network</b> – Exeter raised about whether the SWSWCHD network CHD standards self-assessment visit could recommence as a way of creating managerial discussion around any service gaps against CHD standards.</li> </ul>
6.	<p><b>Update from Level 2 centre - Cardiff</b></p>
	<p>Updates from the level 2 centres were presented to the group – the key updates are outlined in the exception report in the papers. Notable comments included:</p> <p><b><u>Level 2 adult CHD service</u></b></p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> included in the papers.</li> <li>• <b>Risks/concerns:</b> There are significant challenges with waiting lists for clinic, with 60% of patients waiting 6 months or more for their appointment. Lists are regularly being reviewed, with some being cancelled to fit in urgent cases.</li> <li>• <b>Actions/support required from network:</b> None noted at the meeting.</li> </ul> <p>GS complimented the Wales ACHD team on how much they have achieved since he left Cardiff.</p> <p><b><u>Level 2 paediatric CHD service</u></b></p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> no updated provided this quarter.</li> <li>• <b>Risks/concerns:</b> Outpatient waiting list continues to be a concern, with reduced footprint and social distance restrictions hampering capacity. AP noted that there is an emerging problem where some patients who have had telephone appointments are not having their follow up appointments arranged. There is currently only 1 sonographer as one is on long-term sick.</li> <li>• <b>Actions/support required from network:</b> None noted at the meeting.</li> </ul>
7.	<p><b>Update from Level 1 centre – Bristol</b></p>
	<p>Updates from the Level 1 centre were presented to the group. The key updates are outlined in the exception report in the papers.</p>

	<p><b><u>Level 1 adult CHD service</u></b></p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> No updates reported this quarter.</li> <li>• <b>Risks/concerns:</b> Growing waiting list; need support with getting another full time ACHD consultant and two more CNS posts.</li> <li>• <b>Actions/support required from the network</b> – Continue to support/lobby for a 5<sup>th</sup> ACHD consultant post and two more nurse specialist posts – both these cases have been submitted for prioritisation within the UHBW business planning process.</li> </ul> <p><b><u>Level 1 paediatric CHD service</u></b></p> <ul style="list-style-type: none"> <li>• <b>Key updates:</b> included in the papers. Elective programme continues, however challenging to maintain activity due to extreme operational pressures. AJT noted that he has taken over as clinical director for Level 1 Paediatric cardiac services.</li> <li>• <b>Risks/concerns:</b> Wait for first appointment remains high. Many plans in place to mitigate this. The surgical waiting list is also of significant concern, largely due to reduced theatre lists (staffing) and PICU capacity. This is a moderate risk for BRHC. Lists continue to be reviewed regularly – NHS England and WHSSC are fully sighted on issues. There is also concern around cardiology consultant staffing with the resignation of EP lead – redesigning of the EP service is being considered.</li> <li>• <b>Actions/support required from network:</b> AJT has escalated waiting list issue to Peter Wilson.</li> </ul>
8.	<p><b>Patient representatives update</b></p> <p>BN and NM noted that as patient representatives they found Sophie and Violet’s story very moving and powerful. Patient representative updates:</p> <ul style="list-style-type: none"> <li>- BN wrote an article in the Spring Newsletter highlighting long term mental health implications of surgical intervention and that whilst there has been much progress, further psychological support is required.</li> <li>- NM and BN had the opportunity to be on the new CHD Network Manager interview presentation panel. BN expressed thanks for being included in the process, emphasising how valued it made her feel.</li> <li>- A patient rep article has been included in the 2021/22 CHD Network Annual Report – NM expressed gratitude for patient reps being included in this.</li> <li>- NM has been supporting ‘I can’ with Heart Heroes in Bristol which provides various classes for affected children (and their siblings). PTSD classes have been taking place which have been beneficial, and any ideas for further support or activities for families are welcome. Heart Heroes has now been extended from 16 years old to include young people up to 19 years old to ensure support during transition is maintained. There are now Heart Heroes hubs in Wales (including North Wales).</li> </ul> <p>The Board was reminded that <i>if a project involves patient care, a patient rep should be involved.</i></p>

<b>9.</b>	<b>Presentation: Spotlight on Nursing</b>
	<p>CHD Network Lead Nurses (job share), JFH and SV, provided a presentation on updates across the network from a nursing perspective. This commenced with an overview from the year and included the following key work streams: communicating with nurses across the CHD Network; providing advice and sign posting in clinical situations; education developments and signposting to education opportunities; transition updates; working in collaboration with the national CHD Network Lead Nurses; progressing the network work plan; completing reports in the absence of network manager; and working with patient representatives.</p> <p><b>Level 3 Link Nurse Meeting (held bi-monthly and virtually)</b>  JFH highlighted the purpose of these meetings as an informal space for Level 3 link nurses to:</p> <ul style="list-style-type: none"> <li>▪ Feedback challenges and achievements</li> <li>▪ Collaborate</li> <li>▪ Share resolution</li> <li>▪ Ask for help</li> <li>▪ Learn about education and resources available</li> <li>▪ Website and events</li> </ul> <p>The outcomes of these meeting to date were identified as:</p> <ul style="list-style-type: none"> <li>▪ Taunton visit to observe and support transition clinics</li> <li>▪ Bereavement and complaint facilitation in Torbay</li> <li>▪ Business case support for Gloucester ACHD nurse</li> <li>▪ Support and advice for paediatric nurse post in Taunton</li> <li>▪ Palliative care study morning</li> </ul> <p>LC and BL noted that they have found these meetings beneficial - the opportunity to network with other teams has been useful particularly throughout Covid-19, and sharing challenges, ideas, and best practice is also helpful.</p> <p><b>Level 1 and 2 CNS day, Cardiff</b>  SV highlighted the aims of the CNS day which has been held 6 monthly for around 5 years:</p> <ul style="list-style-type: none"> <li>▪ Promoting collaborative working between L1 and L2 centres</li> <li>▪ Sharing of achievements and challenges by teams</li> <li>▪ Advanced teaching- think aorta, surgical approaches</li> <li>▪ Leadership development</li> <li>▪ SMART targets and actions</li> </ul> <p>Outcomes were presented as:</p> <ul style="list-style-type: none"> <li>▪ Dental audit</li> <li>▪ Tuesday MDT</li> <li>▪ PAC collaboration in Paediatrics and adults</li> <li>▪ Regular ACHD team check-ins</li> <li>▪ Discharge summary communications</li> <li>▪ Leadership training</li> <li>▪ Positive evaluations</li> </ul> <p>LP, KM, CL highlighted the benefit of meeting face to face and sharing challenges between teams, and providing opportunity to discuss collaborative projects.</p> <p><b>Level 1 Link Nurse Meeting (held bi-monthly)</b>  JFH highlighted that the purpose of these meetings is to bring together nurses caring for patients with CHD from across the hospital, including CNS, PICU, NICU, Dolphin ward, learning disability, palliative care,</p>

education, theatres, cath lab, and outpatients.

Outcomes were identified as:

- Improvements in outpatient facilities
- Sharing learning of challenges and achievements
- Promotes collaborative working
- Improvements for the PICU notice board, academic textbooks, survey monkey and improved education for PICU nurses
- Awareness of resources and support
- Teaching on network days
- NICU CNS calling cards

Future areas were highlighted as:

- Training for PICU nurses in assisting chest opening
- ECMO training for theatre nurses
- Theatre teaching slots

**Level 1 Paediatric Cardiac Nurse Specialists 2021/22 joint working with the CHD network:**

LP highlighted areas of focus:

Nursing and education

- CNS webinars (a series of 6 webinars) with plans being considered to repeat these live in the Autumn
- Attending link nurse meetings

Patient support

- Revamping the foetal photobook which can be shared across the network

Clinical

- Dental audit
- L1 and L2 comms

**South Wales Team**

KM highlighted some recent proud moments and achievements from the South Wales Team:

- Supporting all ACHD clinics - 7 local L3 hospitals, presence at each transition clinic (around 12 per year), presence at obstetric clinic (fortnightly), newly started 'hot' clinic to support patients identified as needing a review quickly
- Nurse led clinic initiatives
- Learning Disability champions for all cardiac nurses in Cardiff
- Patient Experience surveys via the obstetric clinic and hot clinic
- Weekly MDT
- Teaching undergraduate pre-registration nurses and post-graduate nurses on the inhouse cardiology course which has received positive feedback
- Psychology support is growing
- Development of the Cardiff websites

**SWSW Lead Nurse Network Support**

KM presented support from the network as:

- Ongoing support with Business case
- Education and training resources
- Patient information
- Networking opportunities / away days
- Governance



## Education

SV highlighted numerous areas of education taking place:

- Engagement with national education initiatives
- BACCNA (ACHD)
- BCCA
- Health Education England Congenital Heart Disease Programme - this went live in May 2022 and is available [here](#)
- Plan and deliver education days in SWSW
- Transition half day rolling programme
- ACHD day October
- BRHC Cardiac course
- Cardiac workbook
- Foetal palliative care
- Support other events (e.g., psychology and physiology)

JFH presented an update on **transition pilot in peripheral clinics**, noting that the pilot project has now moved on to the next phase. Centres were asked to provide honorary contracts, clinic rooms, reimbursement for CNS, and have a link nurse presence - Taunton, Torbay, Gloucester and Truro have confirmed that they would like to be involved. The proposal is to set clinics up by the autumn, with an aim for patients to be seen late autumn.

SV updated the group on **transition study days** – the first event took place on 12th May 2022 with over 30 attendees joining online which focused on adolescent behaviours, HEADSS assessment tool, and mental health. The next event will take place on 6<sup>th</sup> October and will be more CHD focused.

SV noted that a **virtual young people's evening** took place on 29<sup>th</sup> March 2022 during which a new film was shared of a tour of the Bristol Heart Institute for people transitioning to adult services, and the adult team were introduced. This is expected to be rolled out to Level 3 clinics. The next young people's evening will be held on 1<sup>st</sup> November 2022.

Bi-monthly meetings take place with **National CHD Network Lead Nurses** – SV highlighted that the purpose of these meetings is:

- Peer support for new Lead nurses
- Sharing good practice in CHD network leadership
- Collaborative working, protocols, and SOPs
- Teaching on national study days- Tetralogy of Fallot's and Transition

The next education day is planned for 2023, being led by the Leeds network

## Progressing Work Plan – Nursing themes

SV highlighted key nursing themes from the 2022/23 CHD Work Plan:

- Demonstrating the value of the network
- Education, training, and development of the workforce
- Equitable and timely access for patients
- Improvements in quality of care
- Information and communication
- Patient and family experience
- Strategic direction

## Reports

SV noted that they have also been involved in supporting the writing of network reports:

	<ul style="list-style-type: none"> <li>▪ 2022/23 CHD Annual Report</li> <li>▪ CHD National Standards Self-Assessment Report (Wales Level 3 Centres)</li> </ul> <p><b>Patient Representative</b></p> <p>SV and JFH have been supporting the CHD patient representatives with:</p> <ul style="list-style-type: none"> <li>▪ Pre and post Board meeting preparation and support</li> <li>▪ New projects - virtual commenting on patient information for psychology, website feedback, and writing for the newsletter.</li> <li>▪ CHD Network Manager interviews</li> <li>▪ Recruiting new members and diversifying our group</li> <li>▪ Planning a patient rep training day in the Autumn</li> <li>▪ Training and support</li> </ul> <p><b>Future Opportunities</b></p> <p>SV presented future areas of work which are being considered:</p> <ul style="list-style-type: none"> <li>▪ Antenatal classes for parents of cardiac babies</li> <li>▪ Continue expand link nurse meetings to support more link nurses</li> <li>▪ Advocate for link nurses on clinical and service development issues</li> <li>▪ Clinical support</li> <li>▪ Education days (Level 3 study day, transition days, ACHD day, support PEC days etc.)</li> <li>▪ Self-assessment visits across the South West</li> <li>▪ Increasing the membership of the patient representative group</li> <li>▪ Patient representative workshop</li> <li>▪ Cardiac charity meeting 6 monthly for local charities</li> <li>▪ More virtual events for patients</li> </ul> <p>DW acknowledged the significant amount of work which is being undertaken.</p>
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<b>10.</b>	<b>Network Board Update</b>
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	<p>Please refer to the supporting papers for further detail: quarter 1 update (April to June 2022); work plan 2022/23; web strategy.</p> <p><b>Annual report 2021/22</b></p> <p>The final draft annual report was tabled for comments before submission to the NHS England Women’s and Children’s Programme Board in late July. Thank you to those who contributed towards this.</p> <p><b>Web Strategy</b></p> <p>It was highlighted that the CHD network now has two active online platforms – a public-facing website and an NHS Future platform education resource site for healthcare professionals (email RB for access).</p> <p>A draft web strategy document and a user guide for the Future platform have been written by RB and tabled for approval by the Board - these are short documents intended to provide information at a glance. Feedback on these documents has been positive.</p> <p>RB has worked hard to develop a <a href="#">new education events calendar</a> on the network website which is now live. This primarily lists internal events (regional SWSW CHD network), with a filter option to view external events related to CHD too. Please do send the core network team your feedback, or other CHD related events that could be of network interest to add to the calendar. This is a work in progress, and the aim is for this to be as useful a tool to network members as possible.</p>
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Conversations have commenced with a patient (Tom Large) who has recently had open heart surgery and is an expert in comms.

**Work Plan 2021/22**  
 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 52 complete work plan areas; 37 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 staffing capacity) and 0 currently rated as red. Of note, is that some of the psychology work has been put on hold as a result of vacancies in the Bristol service; new recruits are due to start in post in the autumn.

AT noted that achieving some of these ambitions depends on collaboration – it is hoped that enthusiasm for this will increase as we move forwards from the pandemic.

**11. National and regional updates**

**National Updates**  
 AT provided national updates to the Network Board:

- The Health Education England e-learning for health CHD programme is now live.
- During the pandemic, a national network of CHD network meetings was pioneered by the SWSWCHD network – these currently take place monthly and provide a space to share the latest updates. These are jointly Chaired by AJT with admin support from RB.
- Problems are beginning to be seen with medical devices being withdrawn as a result of Brexit and EU legislation, as big companies are taking away a number of devices which have been used for many years. This has been raised as an issue with NHS England and with MPs around the country.
- The Clinical Reference Group (CRG) has been disbanded, and the Clinical Chair post will change to become a National Speciality Advisor. There will be three types of CRG going forwards – adverts have gone out for positions, and it is expected that the groups will begin in September.

**Welsh Health Specialised Services Committee (WHSSC) - South Wales**  
 RP presented an update from South Wales Specialised Commissioning:  
**Adult:**

- A case has been submitted for Phase 3 funding, relating to service resilience and improved access to cardiac MRI; following clarifications, a WHSSC case to secure the release of funding is being drafted.
- The baseline assessment of Level 3 Centres against the NHSE CHD standards has been completed; WHSSC is supportive of findings, subject to concerns with it being allocated responsibility for addressing identified gaps which, owing to it not having responsibility for commissioning Level 3 services, will prove notably challenging.
- WHSSC has commenced the development of a Level 3 service specification based on the NHSE standards, which it had previously agreed to take forward; the work remains in progress.

AT asked RP what the concerns were around the gaps that WHSSC have been allocated responsibility for addressing – RP noted that as WHSSC does not commission Level 3 services, the levers they have are fairly limited therefore the responsibility to close the identified gaps may be better placed elsewhere.

DW commented that the key outcome of the report is that WHSSC adopts the recommended standards, and where there are gaps there needs to be discussion between WHSSC and the health board to establish how gaps can be met. AT noted that the review process was done entirely in tandem with WHSSC and included a meeting with all health boards – there is a process to try and get this achieved to ensure good clinical governance across the whole network. Further discussions around meeting gaps with health boards may be required.

	<p><b>Paediatric:</b></p> <ul style="list-style-type: none"> <li>- The 5-year Specialised Services Commissioning Strategy is in development and will shortly be shared for stakeholder feedback. Key recommendations from strategy will impact on all paediatric services include a review of outreach and in-reach services ensuring appropriate MDT, equity of access, and equity of waiting times.</li> <li>- Outreach funding has been released and fully implemented therefore increased outreach provision now across the south and west region.</li> </ul> <p><b>NHS England, South West</b></p> <p>CK presented an update from NHS England, highlighting:</p> <ul style="list-style-type: none"> <li>- ODN 2022/23 Workplans were approved at the Women’s and Children’s Programme Board in March 2022, recognising that some of the CHD Workplan delivery might be delayed due to the Network Manager vacancy. CK thanked the CHD Network team for their significant efforts to continue to meet requirements despite not having a network manager in post.</li> <li>- The Peripheral Clinic Service Level Agreement (SLA) is still sitting with Bristol to progress.</li> <li>- The Women’s and Children’s Programme Board last met on 24<sup>th</sup> May 2022 which included updates by exception and showcased the great work being done by Networks.</li> <li>- Service review work continues within CHD, Surgery in Children, and Paediatric Critical Care.</li> <li>- On 1<sup>st</sup> July 2022, NHS England and Improvement merged to become one single organisation called NHS England.</li> <li>- ODN Annual Reports are due in August – these are to be signed off by ODN Boards and then the W&amp;C Programme Board.</li> </ul> <p>CK noted the current risks / concerns to be escalated:</p> <ul style="list-style-type: none"> <li>- There is a lot of discussion ongoing at regional level around paediatric waiting lists, and the role of ODNs in this. CK noted that networks should be brought together for these discussions.</li> <li>- The appointment of a new CHD Manager and Clinical Director may delay in some programmes of work</li> </ul>
<p><b>12.</b></p>	<p><b>Network risks – for information</b></p>
	<p>AT summarised the network ‘issues’ report. Please refer to the report in the papers. There is a new process for managing risks and the ODN will no longer hold its own risk register. Risks are instead to be escalated through network boards but held on a commissioner risk register, provider risk register, or managed through the network workplan. The network will instead hold an <i>issues log</i> going forward to record problems which are currently having an impact.</p> <p>AT presented the specialised commissioning risk register form, noting that UHBW is the host Trust, sharing of risks is with NHS England.</p> <p>A new/potential/emerging risks form was also shown, AT noted that some clarity is needed around this.</p> <p>AT highlighted current specific problems as:</p> <ul style="list-style-type: none"> <li>- Workforce</li> <li>- Shared risk with imaging</li> <li>- ICC in paediatrics</li> </ul> <p>The impact of merging of Trusts (Yeovil with Somerset, and Barnstable with Royal Devon &amp; Exeter) on patient</p>

	pathways was noted as an emerging issue.
<b>13.</b>	<b>Evaluation</b>
	Board members were invited to complete the meeting feedback form via the Microsoft Forms link circulated.
<b>14.</b>	<b>Any Other Business</b>
	<ul style="list-style-type: none"> <li>- DW reminded the group that a CAS alert was sent on 4th July for the commencement of a <b>Palivizumab Passive Immunisation Programme against RSV</b> for at-risk infants in England, Scotland and Wales following the rise in rates of RSV in recent weeks.</li> <li>- A question was raised around <b>research funding</b>, asking whether the situation has improved since funding dropped off during the pandemic – DT noted that there are some national constraints, but there are people locally working hard to keep research going.</li> <li>- The <b>next Board Meeting</b> will be held on Tuesday 11th October 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.</li> <li>- The <b>Network Morbidity and Mortality meeting</b> is also being held on Tuesday 11<sup>th</sup> October 2022 at 10:00 until 12noon. Please let the core network team know if you have any 2021/22 M&amp;M cases of network wide interest to present.</li> </ul>

## Attendees

Name		Job Title	Organisation	12/07/22
Alan Pateman	AP	Paediatric Clinical Lead	Cardiff, University Hospital of Wales	Attended
Andy Tometzki	AT	CHD Network Clinical Director / Consultant Paediatric Cardiologist	CHD Network Team	Attended
Ankita Jain	AJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda	Attended
Anna Mcculloch	AM	Lead Consultant Psychologist	Cardiff, University Hospital of Wales	Attended
Becky Lambert	BL	Staff Nurse ACHD	Taunton, Musgrove Park Hospital	Attended
Becky Nash	BN	Patient Representative		Attended
Carys Williams	CW	Cardiac Physiologist	Swansea	Attended
Catherine Blakemore	CB	ACHD Consultant	Torquay, Torbay District General Hospital	Attended
Claire Kennedy	CK	Senior Commissioning Manager	NHS England	Attended
Claire Logan	CL	Paediatric clinical nurse specialist	Cardiff, University Hospital of Wales	Attended
Daniel Meiring	DM	Fetal & Paediatric Cardiac Physiology Service Manager	Bristol, University Hospitals Bristol & Weston	Attended
David Lindsey	DL	Adult Cardiologist	Gloucestershire Hospitals	Attended
Dirk Wilson	DW	Consultant Paediatric Cardiologist	Cardiff, University Hospital of Wales	Attended
Ganga Bharmappanavara	GB	Consultant Paediatrician with Expertise in Cardiology	Taunton, Musgrove Park Hospital	Attended
Gergely Szantho	GS	Consultant cardiologist	Bristol, University Hospitals Bristol & Weston	Attended
Gui Rego	GR	Senior Echocardiographer (ACHD)	Bristol, University Hospitals Bristol & Weston	Attended
Helen Liversedge	HL	Consultant Fetal	Exeter, Royal Devon University Hospital	Attended
Jack Gibb	JG	Paediatric Cardiology ST4 Training	Bristol, University Hospitals Bristol & Weston	Attended
Jessica Hughes	JFH	Network Lead Nurse (joint)	CHD Network Team	Attended
Joanne Jones	JJ	Paediatric and Fetal Cardiac Sonographer	Bristol, University Hospitals Bristol & Weston	Attended
Katy Huxstep	KH	Consultant Paediatrician with Expertise in Cardiology	Truro, Royal Cornwall Hospital	Attended
Kindre Morgan	KM	ACHD clinical nurse specialist	Cardiff, University Hospital of Wales	Attended
Lisa Patten	LP	Paediatric clinical nurse specialist	Bristol, University Hospitals Bristol & Weston	Attended
Louise Challis	LC	Link Nurse	Torquay, Torbay District General Hospital	Attended
Luisa Chicote-Hughes	LCH	ACHD Consultant Cardiologist	Plymouth, Derriford Hospital	Attended

Luisa Wilms	LW	Consultant	Taunton, Musgrove Park Hospital	Attended
Marcia Scheller	MSC	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	Attended
Marion Schmidt	MS	Consultant Paediatrician	Newport, Royal Gwent Hospital	Attended
Mel Gilbert	MG	Matron for Child Health	Truro, Royal Cornwall Hospital	Attended
Nicola Morris	NM	Patient Representative		Attended
Nigel Osborne	NO	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University Hospital	Attended
Pauline Aiston	PA	Psychologist	Bristol, University Hospitals Bristol & Weston	Attended
Pradesh Mappa	PM	Consultant Paediatrician	Swindon, Great Western Hospital	Attended
Richard Palmer	RP	Senior Specialist	Welsh Health Specialised Services Committee	Attended
Rowan Kerr-Liddell	RKL	Consultant Paediatrician with Expertise in Cardiology	Torquay, Torbay District General Hospital	Attended
Sarah Finch	SF	ACHD Clinical Nurse Specialist	Cardiff, University Hospital of Wales	Attended
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team	Attended
Sian Jenkins	SJ	Consultant Paediatrician with Expertise in Cardiology	Hywel Dda, Glangwilli Hospital	Attended
Sophie	S	Parent		Attended
Stephanie Curtis	SC	Consultant cardiologist	Bristol, University Hospitals Bristol & Weston	Attended
Steven Pike	SP	General Manager of Paediatric Cardiac Services, Neurosurgery and PICU	Bristol, University Hospitals Bristol & Weston	Attended
Susie Gage	SG	Paediatric Cardiology and Surgical Pharmacist	Bristol University Hospitals Bristol & Weston	Attended
Andre Clinchant	AC	Lead Nurse	Taunton, Musgrove Park Hospital	Apologies
Andrea Richards	AR	Senior Commissioner	Welsh Health Specialised Services Committee	Apologies
Andrew Parry	AP	Consultant	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
Bill McCrea	BMc	Consultant	Swindon, Great Western Hospital	Apologies
Candida Frankham	CF	Cardiac Physiologist	Truro, Royal Cornwall Hospital	Apologies
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology	Exeter, Royal Devon University 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
Georgina Ooues	GO	Consultant Cardiologist	Truro, Royal Cornwall Hospital	Apologies
Geraint Morris	GM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Helen Fardy	HF	Medical Director	Welsh Health Specialised Services Committee	Apologies
Helen Wallis	HW	Consultant Cardiologist	Cardiff, University Hospital of Wales	Apologies
Jennifer Holman	JH	Consultant Paediatrician	Gloucestershire, Gloucester Hospital	Apologies
John Madar	JM	Consultant Paediatrician with Expertise in Cardiology	Plymouth, Derriford Hospital	Apologies
John Mills	JGM	CHD Network Manager	CHD Network Team	Apologies
Karen Sheehan	KSh	Paediatric Cardiac Research Sister	Bristol, University Hospitals Bristol & Weston	Apologies
Katrina Spielman	KS	ACHD clinical nurse specialist	Cardiff, University Hospitals of Wales	Apologies
Kimberley Meringolo	KM	Specialised Planner (Paediatrics)	Welsh Health Specialised Services Committee	Apologies
Luke Harris	LH	Service Manager	Gloucestershire Hospitals	Apologies
Maha Mansour	MM	Consultant Paediatrician with Expertise in Cardiology	Swansea Bay	Apologies
Manish Gandhi	MG	ACHD Consultant cardiologist	Exeter, Royal Devon University Hospital	Apologies
Mark Dayer	MD	Consultant Cardiologist	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
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
Peter Wilson	PW	Medical Director Commissioning	NHS England	Apologies

Poonamallee Govindaraj	PG	Consultant Paediatrician	Cwm Taf Morgannwg, Royal Glamorgan	Apologies
PremKumar Pitchaikani	PP	Consultant	Hywel Dda	Apologies
Rachel Burrows	RB	CHD Network Support Manager (note-taker)	CHD Network Team	Apologies
Rachel Tidcombe	RTi	Patient Representative		Apologies
Rainer Fortner	RF	Consultant Paediatrician with Expertise in Cardiology	Cwm Taf	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
Zoe Trotman	ZT	Senior Nurse, paediatric cardiology	Bristol, University Hospitals Bristol & Weston	Apologies

**Also in attendance:**

- Tania Sparks, Network Support Manager (South West - Paediatric Critical Care ODN and Surgery in Children ODN) – note taker (notes reviewed by DW and RB)