



Newsletter

Updates from
your CHD Network

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Introduction from our Clinical Director Dr Stephanie Curtis

The sun is finally shining again, and we have more good news to share with you in our Network newsletter!

Nursing is centre-stage as we report that Taunton is again ahead of the curve thanks to the leadership of our Network Lead Nurse, Becky Lambert, and the Consultant Paediatricians with Expertise in Cardiology (PECS) in Taunton, running another transfer clinic at Musgrove Park Hospital. Young people were able to benefit from a joint consultation with adult cardiologist and paediatric cardiologist and support from the nursing team and youth worker. Our goal is to ensure that this type of experience is available to all patients throughout the region.

The value of community nursing is highlighted on page 6, illustrating the importance of care in/close to the patient's home. This is one of our aims and is consistent with NHS strategy. We are delighted to report that, as a result of increased funding, a new whole time Specialist Nurse post for Inherited Cardiac Conditions (ICC) at the Bristol Royal Hospital for Children has been approved. Specialist nurses play a key role in the care of children with heart disease; ICC is a rapidly growing area. This post will be invaluable and take pressure off waiting lists and the medical team.

Lastly, on nursing, in May, we said goodbye to our friend and colleague Sheena Vernon, after an unbelievable 48 years in the NHS! Sheena was instrumental in setting up pathways and processes when the Network began and embodies everything that we have come to associate with our Network: a strong patient voice; equitable access to high quality care; a strong workforce; and collaborative working. Her leadership both during her tenure as Network Lead Nurse and prior to that, and at a national level in ACHD nursing, is known to all. Her pioneering spirit, cheerleading for ACHD nursing and various innovations have left their mark on the Bristol ACHD department. We wish Sheena the best in her retirement and will miss her very much. Her legacy will live on in the minds of her friends, colleagues, and patients.

On page 14, you will be able to read about the launch of our new Patient and Public Voice Group, under the leadership of Rebecca Williams, and with new formal meetings and a brand new logo! I for one am really looking forward to the output from this group and thank them all for their time and contributions.

As always, we report on recent and upcoming conferences and teaching events, and you will read that research continues to be strong in our region with more and more individuals producing high-quality work.

Happy reading!

Dr Stephanie Curtis
Clinical Director, South Wales and South West CHD Network

Your South Wales and the South West Congenital Heart Disease Network is here to support CHD patients of all ages throughout their cardiac journey, as well as their families/carers and the staff who are involved in CHD care across your Network.

Your Network connects all of the hospitals, services, staff, and patient/family representatives from across South Wales and the South West of England.

Together we aim to deliver the highest quality care and experience for our patients.

The Network is also part of a national group of congenital heart Networks.

[Network Team Key Contacts](#)

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Pioneering Approaches: Taunton's new transfer clinic

Specialist clinicians from Bristol and Taunton, Paediatric and Adult CHD Services, come together in a shared appointment with patients



By Becky Lambert, CHD Network Lead Nurse

Photo above: Becky, Emily & Xander

In March 2026, we held our second transfer clinic at Somerset Foundation Trust – an exciting development for our service. Transfer clinics bring together the paediatric and adult congenital heart disease teams, enabling a young person's final paediatric appointment and first adult appointment to take place as a single, shared consultation.

We saw six young people during the morning clinic. As a one-stop appointment, each patient had observations, an ECG, and an echocardiogram before meeting with both the paediatric and adult cardiologists together. They were then seen by the adult and paediatric specialist nurses, as well as the youth worker.

This approach ensures that the young person and their family are actively involved in the handover process, rather than it happening behind the scenes. It promotes continuity of care, provides reassurance, supports safer clinical handover, and enables shared decision-making.

Photo below (from left to right): Dr Steph Curtis (Visiting ACHD Consultant Cardiologist), Dr Milly Snook (Visiting Paediatric Cardiologist); Amy Szewiel (Physiologist); Dr Ganga Bharmappanavara (Paediatrician with Expertise in Cardiology); Nelisa Asoy (Physiologist); Becky Lambert (Network Lead Nurse); Dr Louisa Wilms (PEC); Becky Mirams (Paediatric Specialist Nurse); Xander Patel-Cook (Youth Worker).

What do the patients and family think?

"I feel happier, knowing who will be looking after her {daughter} in the future, and that they know what is going on. I was worried that I would have to explain everything to a new group of people." (mum of 17-year-old with CHD and complex needs)

What do the doctors think? We checked-in with Dr Steph Curtis, the Visiting ACHD Consultant from Bristol to hear her thoughts.

"Teenage transfer clinics are difficult to organise but worth it. Having a face-to-face discussion of a patient's care with them and their family in the room is valuable and is the gold standard for any handover."

"Being able to understand the decision-making from the paediatric cardiology perspective has been very useful learning for me and I think it has also been useful for the paediatric team to see how we in ACHD plan long term care and communicate this to the patient and their family."





Sheena Vernon Retires Celebrating 48 years of NHS service in Cardiology



May 2026 marked both a celebratory and sad moment for the Network as we said goodbye to Lead Nurse Sheena Vernon, who retired after an incredible 48 years of NHS service.

- One of the UK's first Adult CHD Specialist Nurses, in Bristol.
- Founding President of the British Adult Congenital Cardiac Nurses Association
- South Wales and South West CHD Network Lead Nurse since 2016

Celebrating an extraordinary career

Sheena was one of the UK's first Adult CHD specialist nurses and helped pioneer our SWSW CHD Network since its inception in 2016. Her vision, drive, and determination have played a pivotal role in shaping CHD care locally and nationally, into the high-quality patient-centred service and Network we are proud of today.

A Pioneer in ACHD Care

Sheena began her nursing career in 1977 as a student nurse in Liverpool, progressing through various cardiology roles, before moving to the Bristol Heart Institute in 1984. In 2002, she set up the ACHD specialist nursing service in Bristol, leading and developing the service until 2025.

Throughout her career, Sheena has supported and mentored countless colleagues while providing exceptional care and advocacy for patients and families across the region. She also established young person clinics and founded the ACHD youth worker role, significantly enhancing support for patients.

A Lasting Legacy

Sheena has also been a passionate advocate for Patient and Public Voice (PPV) involvement, helping establish a thriving and now independent PPV group within the Network, as well as being involved with several cardiac charities.

Her encouragement, leadership and belief in others have inspired colleagues across the CHD community and beyond. She leaves behind an extraordinary legacy of compassion, innovation and commitment to patients, families and staff. And a long-term contribution to strengthened services, developed teams and improved care for those living with CHD across our Network.

We thank Sheena for everything she has contributed and wish her every happiness in her retirement.

National Leadership and Strategic Focus

In 2007, Sheena became one of the eight founding nurses of the British Adult Congenital Cardiac Nurses Association (BACCNA) and served as its first president. Colleagues have described her as "pioneering", "generous with her time, expertise and knowledge", and "instrumental in shaping the future of CHD care".

She also helped develop the NHS England CHD Standards and Specifications, approved in 2016 and still recognised as the national benchmark for CHD care today.



CHD Education

Sheena has extensive clinical expertise and knowledge of caring for patients with CHD and has made a significant contribution to workforce education in the Network, hosting a variety of events.

One of Sheena's greatest achievements is the regions annual ACHD study day, now in its 24th year. What began as a small in-person event for nurses, has grown into a widely valued online educational event attended every year by more than 100 healthcare professionals, including doctors, nurses and AHPs.





Becky Lambert, our Network Lead Nurse who job shared with Sheena since 2024, and is now taking on the role fully, shared her reflections:



Photo: Sheena and Becky at the Little Hearts Matters Charity Conference

"I first met Sheena over ten years ago, before the Network was formally established, when she came to support a Taunton clinic I was working in while I was developing an interest in CHD.

Since then, she has taught, encouraged, inspired, and challenged me. It is almost certainly because of her that I found my place in the incredible world of CHD. I'm grateful for her support, proud to have been her colleague, and even prouder now to call her a friend."



International Representation at Association for European Paediatric & Congenital Cardiology Conference

Members of our Network attended the May 2026 Annual Meeting of the Association for European Paediatric and Congenital Cardiology in Italy.

The event brought together clinicians, researchers, and healthcare professionals from around the world to discuss the latest developments in CHD care.

Representing the Network, our Lead Pharmacist Susie Gage delivered an excellent presentation on a review of pharmacist provision in paediatric ECMO in the UK and Ireland.

Sheena Vernon presented on risky behaviours in teenagers and young adults with CHD, exploring their impact on long-term health outcomes. The presentation was well received and generated lively discussion among delegates.

The conference provided valuable opportunities to share knowledge, learn about advances in paediatric and adult congenital cardiology, and connect with international colleagues.

We thank Susie, Sheena, and all those who represented the Network and contributed to discussions shaping the future of CHD care.

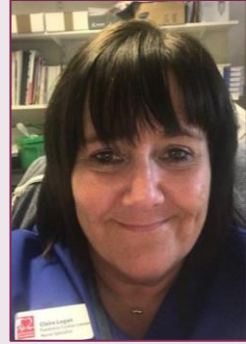


Photo: Alison Wood (Paediatric Nurse Educator), & Lucy Holland (Senior Cardiac Nurse, Bristol)



Photo above: Sheena presenting at AEPC, 2026

Honouring Excellence: Claire Logan, Paediatric CHD CNS in Wales



In March 2026, the CHD Network said farewell to Claire Logan as she retired after decades of dedicated service in paediatric cardiology nursing.

Claire was one of the first paediatric cardiac nurses in the Cardiff paediatric cardiac unit, established in 1990. She later became one of the UK's first Paediatric Clinical Nurse Specialists, and in 1998 went on to develop and lead the Paediatric CHD CNS service across South Wales.

She also led the INR service, and established the paediatric cardiology nurse-led clinic, which has supported patients and families for almost 30 years. This service is invaluable for CHD patients, especially post-operatively.

Fellow CNS team members reflected: *"Claire has been an exceptional source of leadership, dedication and support to both the team and to her patients/families. Claire's forward-thinking approach has driven positive change and continuous improvement within the service, and she always ensures that patient care is at the heart of all we do."*

Reflecting on Claire's contribution, Dr Dirk Wilson, Consultant Cardiologist, said: *"Claire never shirked away from difficult conversations and has been a powerful advocate for our patients and our service."*

Claire also provided valuable support to the Network-led Bristol and Cardiff Clinical Nurse Specialist meetings, promoting collaboration and sharing expertise across the Network.

In recognition of her achievements, Claire was awarded Runner-Up in the 2025 Staff Recognition Awards in Cardiff for Outstanding Contribution to the Nursing Workforce.

We thank Claire for her outstanding service and wish her a happy and well-deserved retirement. We are delighted that Claire's job share, Karina Parsons-Simmonds, has fully taken on the Lead CNS role.



Community Nurses in CHD

By Charlotte Revett, Community Children's Nurse, Bristol Royal Hospital for Children

Who are the children's community nursing team?

The children's community nursing (CCN) team are a team of experienced paediatric nurses with specialist skills and experience in nursing children and young people.

The team provides care to children and young people aged 0 to 17 years, who are registered with a GP in Bristol or South Gloucestershire. The team accept referrals from all specialities based at Bristol Royal Hospital for Children.

Pre discharge planning

Prior to discharge from hospital, the cardiac home monitoring checklist is completed. This includes:

- Frequency of CCN visits
- individualised parameters according to the baby's age and cardiac condition

These agreed parameters enable the CCN team to monitor the baby safely at home and escalate concerns appropriately when required. A named CCN is allocated to each family. Wherever possible, they will visit the family on the ward prior to discharge to introduce the service, explain the monitoring process, and discuss individual needs and expectations.

Cardiac home monitoring programme

A proportion of the caseload consists of infants referred by the cardiology team as part of the home monitoring programme. These babies have complex heart conditions, and have usually undergone surgery or intervention, placing them at higher risk of sudden deterioration at home. The CCN team provides structured support at home until the next stage of cardiac surgery.



Community visits

Home visits are arranged Monday to Friday, typically in the morning. This timing allows effective communication with relevant teams within service hours if additional support is needed.

During each home visit, the CCN team will:

- Monitor and record observations, including heart rate, respiratory rate and oxygen saturations
- Measure and record the baby's weight
- Complete a general wellness assessment, including feeding and oral intake, urine and stool output, medication administration and overall health status

Home visits also provide an opportunity for parents and carers to raise any concerns. The CCN team works closely with the cardiac multidisciplinary teams and will liaise as required. All findings are documented on careflow, enabling supporting teams to access and review the baby's progress.

The CCN team is committed to delivering safe, family centred care within the community, ensuring that children and their families feel supported, informed and confident at home.

Community nurses across the Network are important in the care of patients with CHD because they:

- Monitor patients' health
- Support medication management
- Provide education to patients and families
- Identify complications early
- Co-ordinate care with specialist cardiac teams.

This helps improve quality of life, promotes independence, and reduces hospital admissions.



Refreshing the CHD Standards: National Networks Meeting in Liverpool

By Michelle Jarvis, Network Manager

The Core Network team and Rebecca Williams, Chair of the SWSW PPV representative group, recently attended the National CHD Networks meeting in Liverpool, held at Alder Hey Children's Hospital. Around 70 colleagues attended in person; clinicians and managers across Network teams and services, charities and patient representatives from across all the geographical areas.

The event launched the start of the programme of work to review and refresh the national CHD standards and specifications, covering both adult and paediatric services across Level 1, 2 and 3 centres. With the current standards now approaching 10 years old, there was a clear agreement on a need to update them while maintain the core principles of high quality, equitable care for all CHD patients.



The CHD standards were published by NHS England in 2016 and subsequently adopted in Wales in 2022 aligning specialist cardiac care across both nations. The SWSW Network played a significant role in supporting this process.

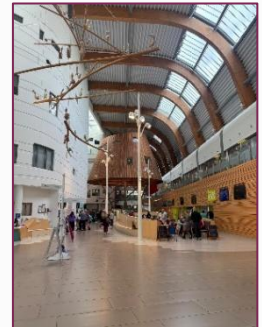
These standards set out requirements for the organisation of specialist congenital heart services, including staffing, and patient pathways, with a focus on improving safety and outcomes through coordinated care.

The day was structured around a series of interactive workshops beginning with a general review of the existing standards followed by a deep dive into section A 'The Network Approach' and concluded with discussions on how the wider review process should be taken forward.

A key strength of the event was the level of engagement across all groups, supporting open and collaborative discussion. It was valuable to come together face to face to share learning and hear a wide range of perspectives including those of patient and public representatives whose lived experience is essential to shaping future standards.

Following the event, as an outcome led by NHSE lead commissioners for CHD, it has been agreed that a lifetime pathway approach will be taken to the national CHD standards. This reflects a move to a more joined up view of care across the patient journey. Delivering this approach will involve a significant programme of work.

We look forward to sharing further updates on this programme of work, alongside any opportunities to be involved, in due course.



Rebecca's reflections from a Patient and Public Voice perspective

By Rebecca Williams, Chair of SWSW CHD Network PPV Group

From a Patient and Public Voice (PPV) perspective, the Liverpool event was inclusive and welcoming. Patient representatives were encouraged to contribute, and lived experience was recognised as a valuable component of the discussion alongside clinical and professional expertise.

This collaborative approach helped to ensure that patient and family perspectives remained central throughout discussions.

The event highlighted the scale and complexity required in reviewing the standards. A whole day event was required to work through one section of the Level 1 paediatric services alone, prompting constructive discussion about how best to approach the remaining standards.

The event was used as an opportunity to explore more effective ways of gathering clinician, patient, family and public views as this work continues.

There was shared recognition that while face-to-face events are invaluable for in-depth discussion, alternative methods of engagement may be required going forward.

Overall, the event demonstrated a strong commitment to improving care standards through inclusive and collaborative working, with patient and public voices firmly embedded at the heart of the process.



National Postgraduate Certificate Pilot launched to Strengthen Congenital Echocardiography Skills

By Owen Burgess, Deputy Head Cardiac Physiologist and Joint Echocardiographer Lead, Bristol Royal Hospital for Children

Funded training initiative strengthening the congenital echo workforce

We are delighted to share the launch of a new national training pilot aimed at strengthening congenital echocardiography expertise across the Network and the UK.

First cohort begins in Bristol

In April 2026, the first students began teaching on the *Postgraduate Certificate in Echocardiography in Congenital Heart Disease* at the University of the West of England (UWE). This six-month pilot programme is the first qualification of its kind in the UK, made possible by funding from NHS England, and represents a significant step forward in developing sustainable, accredited congenital echo capacity.

Programme leadership and alignment

The programme is led by Owen Burgess, Deputy Head Cardiac Physiologist and Echocardiography Lead at Bristol Royal Hospital for Children (Level 1 centre). It is aligned with the British Society of Echocardiography (BSE) congenital syllabus, with the primary aim of supporting participants to progress to BSE congenital accreditation following completion.

Blended learning embedded in clinical practice

The course combines weekly online expert-led teaching from congenital specialists across the UK with practical, workplace-based training. This includes supervised echocardiography, formal assessments and case-based discussions embedded within routine clinical practice. Teaching commenced in April and will continue through to Autumn 2026.

Building a sustainable workforce

This pilot represents a fantastic opportunity for individual clinicians, local services and the Network as a whole. By supporting access to accredited congenital echo training, the programme contributes to workforce development, strengthens service resilience and helps to support high-quality, timely congenital heart care for patients and families across the region.

Why it matters

CHD cases are complex and often require:

- Highly detailed imaging interpretation
- Specialist knowledge of paediatric and adult congenital anatomy
- Close collaboration with cardiology and surgical teams

Network-wide participation expanding skills across the region

Five Cardiac Physiologists (pictured below) from across our CHD Network have now been enrolled, each supported by a named practice educator – we are hugely grateful to Gui Rego, Gemma Wright and Lona Hanzel for taking on this role. The benefits of the programme extend across South West England and the South Wales Cardiff service.



Photos from top left to right:
Liam Davies - Cardiff
Jance Manalo - Bristol
Marie Frost - Bristol
Cameron Blacker – Truro
Sheila Novele - Exeter



Congratulations to Amy Szewiel and Nelisa Sagrado,

Cardiac Physiologists in Taunton, who have recently completed their British Society of Echocardiography accreditation in CHD echocardiography after more than two years of specialist training, supported by Owen Burgess, and the specialist teams in Taunton and Bristol.

The qualification enables more specialist heart scans to be carried out locally, reducing travel for patients and families.

Amy and Nelisa now plan to share their expertise through in-house training to help strengthen CHD services in the region.





A New Approach: Walk, Talk, Think, Feel - Reflective Practice Sessions Outdoors



NHS clinical staff are working in increasingly demanding environments, balancing the emotional intensity of patient care alongside ongoing pressures such as staffing shortages and financial challenges. Reflective practice is an important tool for supporting staff wellbeing and improving patient care, and innovative approaches are helping make this more accessible.

A new approach

Dr Anna McCulloch, Consultant Psychologist in ACHD based in Cardiff, has developed the “walk, talk, think, feel” approach, bringing the South Wales ACHD nursing team together outdoors approximately once a month to reflect while walking in nature.

Based on the Heads and Hearts model of reflective practice, the sessions provide a safe space for staff to share experiences, explore thoughts and feelings, and consider how these influence behaviour and clinical practice. Reflective supervision is now mandated in Wales and is a requirement for nursing and midwifery revalidation.

The impact: powerful and positive feedback

The ACHD nurses report improved wellbeing, stronger team relationships, greater self-awareness, and better coping strategies for managing stressful and emotionally demanding situations. Many describe returning to work feeling calmer, more focused, and better equipped to care for patients.

The outdoor setting played an important role. Walking in nature helped reduce stress and created a calmer, less intense environment where participants felt more comfortable speaking openly. Walking side by side rather than sitting face to face also help reduce feelings of vulnerability during difficult conversations.

Barriers?

Although barriers such as time pressures and staffing challenges remain, participants feel the benefits outweighed the difficulties. Senior management support was also identified as key to encouraging attendance and embedding reflective practice within teams.

Conclusion

Overall, the “walk, talk, think, feel” model highlights the value of integrating wellbeing, reflection, and team support into everyday healthcare practice, reinforcing that resilience is built collectively through connection, support, and shared reflection.

A full article on this new approach has been published in the *Nursing Times*, Volume 121, Issue 11.

“Walking and talking in a park is both active and soothing, which matches the reflective practice in which we are actively discussing a challenging topic, and also [provides] a safe space and support for each other.”

Staff Photographic Competition #9: ‘May scenes across the Network’

Throughout May 2026 we received photos from CHD Network staff, who have taken photos whilst out and about, on a trip away or during their commute to work. To see all the entries and also to peruse the galleries of previous entries, please visit the Network website: <https://www.swswchd.co.uk/en/page/photographic-competition>

The winner is ‘Woodchester Woods Awakens – Nympsfield, Gloucestershire’ - photographed by Lisa Patten, Paediatric Clinical Nurse Specialist





Education and training: Let's keep learning

One of the Network objectives is to support and promote training and education opportunities for our healthcare professionals involved in the care of patients with congenital heart conditions. Details of training and education events can be found on the Network website (www.swswchd.co.uk).

A big thanks to all those who deliver learning and training sessions for colleagues across the Network. These serve to enrich our teams as we continue to strive for excellence in all we do.



Welsh Paediatric Cardiovascular Network Spring Meeting

By Rainer Fortner, Consultant Paediatrician with Expertise in Cardiology

In collaboration with the SWSW CHD Network, our first face-to-face meeting in two years took place at the Multi-Professional Education centre at the Princess of Wales Hospital in Bridgend on 17th April 2026. It was great to see over 30 delegates coming together for their education, professional development and networking.

The day started off with a practical, interactive session showcasing the capabilities and advances in imaging with a new ECHO machine using live scanning. Main themes included coarctation of aorta, basic and advanced cardiac function assessment and pulmonary hypertension. The presentations and discussions involved a variety of speakers, including medical students, neonatologists and paediatric cardiologists.

Feedback received was very positive throughout and clearly showed the delegates appreciating coming together to a friendly and relaxed highly educational face-to-face meeting creating networking opportunities which would not have been possible during a virtual meeting.



What's coming up in 2026?

- ❑ ECHO ACHD webinars, dates throughout the year – online
- ❑ Transition Study Event (focused on CHD) – Thursday 2nd July 2026
- ❑ CNS Away Day – Tuesday 8th September 2026, Cardiff.
- ❑ Annual ACHD study day (for nurses, junior doctors and AHPs) – 13th October 2026.



SWSW CHD Network NHS Future Platform

This platform for healthcare professionals stores training and education resources, and is currently home to the:

- + Transition study event webinars
- + ECHO webinar series
- + Fetal cardiology webinar series
- + Paediatric cardiology nursing webinar series
- + Paediatrician with Expertise in Cardiology (PEC) platform
- + Psychology webinars
- + ACHD study day webinars & resources
- + Research forum webinars

If you think a professionals education page would be useful for your team/staff group, please do let us know.

Contact the Network team if you haven't yet joined:

CHDNetworkSWSW@uhbw.nhs.uk



Exciting Development for the Bristol Paediatric Cardiac Clinical Nurse Specialist Team

By Lisa Patten, Lead Cardiac Clinical Nurse Specialist, Bristol Royal Hospital for Children

A New Role for Autumn 2026

We are delighted to share an exciting development within the Bristol Paediatric Cardiac Clinical Nurse Specialist (CNS) team. Following recent investment in the service, we will be welcoming a full-time Inherited Cardiac Conditions Clinical Nurse Specialist in Autumn 2026.

Understanding Inherited Cardiac Conditions

Inherited cardiac conditions are disorders that can be passed through families and may affect the structure or electrical function of the heart. While distinct from congenital heart disease (CHD), there is important overlap between these areas of paediatric cardiology. Advances in genetics are improving our understanding of some heart conditions and helping to provide more personalised care for patients and families across the Network.

Strengthening Specialist Care Across the Network for Patients

The introduction of this new specialist role marks a significant step forward in strengthening our specialist provision for children, young people, and families affected by inherited cardiac conditions. The role will further service development through enhanced care pathways of care, improved patient and family education, and closer multidisciplinary collaboration.

Enhancing Specialist Expertise

The addition of a dedicated Inherited Cardiac Conditions CNS will bring valuable clinical expertise into the CNS team, complementing our existing skill mix and broadening our capacity to deliver highly personalised, evidence-based care.

Our Commitment to Excellence

Ultimately, this investment reflects our commitment to innovation, quality improvement, and excellence in patient care, ensuring that patients and families continue to receive the highest standard of support throughout their healthcare journey.

We look forward to introducing our new colleague and sharing further updates as the role develops.

The Art of Coaching: Bristol & Cardiff Clinical Nurse Specialist Away Day

The CHD Network Clinical Nurse Specialists (CNS) in Bristol and Cardiff tend to have an Away Day twice a year, to collaborate and share.

The January 2026 event focused on developing coaching skills to support staff development and team working across Bristol and Cardiff.

Emma Haynes from the University Hospital Bristol and Weston Leadership, Management and Coaching team, delivered a session covering key coaching principles. This included effective questioning, active listening, and the benefits of a coaching approach in clinical practice.

The GROW (Goal-Reality-Options-Will) model was introduced as a practical framework to support structured coaching conversations and goal setting.

The session was well received and reinforced the importance of coaching as a tool for supporting professional development, enhancing team performance, and ultimately improving patient care.

“Really great event - empowered us to think outside of the box and engage in conversations with a tool kit”

“Very useful to have the Network updates and to see how we can continue to improve service development”





Network update

By Michelle Jarvis, CHD Network Manager

It has been another busy and productive period across the Network, with a continued focus on collaboration, improvement, and delivering high-quality care for our patients and families.

Driving improvement across the Network: Self-assessments against the CHD Standards

Over the past 18 months, we have completed our current cycle of self-assessments across South West England centres and Level 2 centres in Cardiff covering both paediatric and adult services. As highlighted in previous updates, these reviews have demonstrated a wealth of good practice, innovation, and strong engagement across all services, alongside some shared challenges.

The real value of this work lies in how we take it forward. All of the learning from these self-assessments including areas of excellence and areas for development has been carefully considered and incorporated into our Network workplan for the next year. This means our priorities are based on a clear understanding of where we are now and where we need to focus our efforts.

Beyond Compliance: Our Network Vision for 2025-2035

As mentioned in our last newsletter, we continue to focus on delivering our refreshed Network vision for 2025–2035, *Beyond Compliance*. This vision sets out our ambition not only to meet national standards, but to go further - improving equity of access, strengthening our workforce, enhancing collaboration, and driving innovation across the Network.

Our workplan and priorities are closely aligned with both this vision and the findings from the self-assessment process, ensuring a consistent and strategic approach to improvement.

Refreshing the Network Board Membership

We are also currently refreshing the membership of our Network Board, with the aim of strengthening representation and supporting more inclusive, collaborative decision-making. A key priority is to ensure that the Board continues to reflect the whole of our Network - including all service levels (Level 1, 2 and 3 centres), geographies, and professional groups. We are particularly keen to ensure that all workforce groups and stakeholder voices are represented and able to influence how services are developed in the future.

Growing Strength of the Patient and Public Voice (PPV) Group

Finally, I would like to take a moment to recognise the fantastic progress made by our Patient & Public Voice (PPV) Group. It has been great to see the group develop as a more independent forum, taking the lead in shaping its own agenda and meetings. We are really pleased to support this direction. The patient, carer, and public voice is central to everything we do, and we are extremely grateful for the insight, challenge, and commitment that members of the group continue to bring. Their contribution is vital in helping us ensure that services are planned around the needs and experiences of those we support.



Clinical protocols

Did you know that you can access a wide range of clinical protocols via the CHD Network website?

Go to the clinical information page under the professionals tab here:

www.swswchd.co.uk/en/page/clinical-information

A huge amount of collaborative work has happened recently to update and develop clinical protocols for clinicians within the Network. These are available via MyStaff and on the Network website.

“The guidelines are an incredibly useful tool in clinical settings, to ensure that patient care is safe, consistent, and evidence-based.”

(feedback from CHD clinician)

Network dates for your diary!

Key Network meetings:

Wednesday 19th August 2026:
Network Board

Tuesday 24th November 2026
Network Board and Clinical Governance



Relaunching the Network PPV Group

By Rebecca Williams, Chair of the SWSW CHD Network Patient and Public Voice (PPV) group

Establishing an Independent Group

We are pleased to share that the South Wales and South West Congenital Heart Disease (SWSW CHD) Patient and Public Voice (PPV) group has officially been relaunched, marking an important step forward in strengthening collaboration and ensuring that lived experience continues to shape and influence the work of the Network

The group was restarted after learning from what has worked in the North West, North Wales and Isle of Man CHD Network. This included the importance of PPV groups being led by members and having a real sense of ownership.

The SWSW CHD Network established an independent group with its own chair, alongside ongoing support from the Network team. This gives the group the chance to talk openly about what matters most to them and about the Network issues they want to influence.



Positive Initial Meetings

Our first meeting took place on 5th March 2026 and was a real success, with eight members of the PPV group joining. We spent time getting to know each other, sharing experiences and exploring the skills and strengths within the group. We spoke about personal interests, professional backgrounds and how people feel most confident contributing. A member of the Network team attends to respond to questions from the group or suggest possible actions



How Will The Group Work

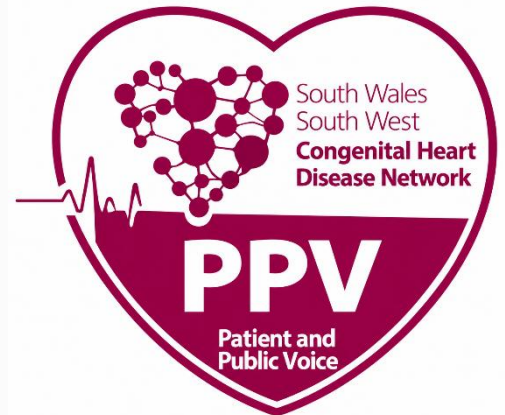
The group have since met monthly and plan to do so on the first Thursday of every month from 7:00-8:30pm. To help keep discussions focused and transparent we agreed there will be an agenda and notes will be shared afterwards by the chairperson, Rebecca Williams.

An action tracker will also be used to keep track of what we are working on and to capture the impact of the group's work. This approach will be reviewed in six months.

Supporting Meaningful Involvement

A key focus of the discussion was how the group can work as a team to support each other, so involvement feels manageable, inclusive and rewarding.

Members also explored how PPV representatives will contribute to Network Board meetings going forward, including what this will look like, and the support available, especially for those attending for their first time. There is always a pre-meet before the Board meeting with PPV representatives, and a post-meet is offered to discuss any sensitive issues.



Looking Ahead & Next Steps

- A regular page in the CHD Network Newsletter updating the Network on the work of the group.
- Recruitment - the next article will describe the role and the aim to have 20 representative members.
- A section on the CHD Network website outlining the roles, activity and support which the group can offer.
- Prepare some resources on aging with CHD for patients, clinicians, the newsletter and website.



Patients at the heart of our Network: Sara's heart-warming story

A striking red bench in Ammanford (Carmarthenshire, Hywel Dda, West Wales) is doing more than offering a place to sit - it is telling a powerful story of survival, courage and hope. The bench, located in Ammanford Park, honours 35 year old Sara Kirby and forms part of a nationwide campaign by the [British Heart Foundation](#) (BHF).

This year marks 65 years since the BHF charity was founded, and to celebrate, 65 red benches are being unveiled across the UK - each one representing someone living with a heart condition. Behind every bench is a real-life story of someone who came from that community. Rather than serving as memorials, these benches turn tradition on its head by celebrating survivors.

A terrifying start

Sara, who was born with Down's syndrome and a congenital heart condition, lives just a short walk from the park. Her mother, Ann, vividly remembers the moment Sara was born in January 1991. *"When you give birth, you expect to hold your baby in your arms, "When Sara was born by caesarean section, she was tiny and blue. I only glimpsed her briefly before she was whisked away, leaving me with empty arms and my heart in my mouth. What was wrong with my little girl? I was absolutely terrified,"* she said.

At just two days old, Sara was diagnosed with Down's syndrome. Six weeks later, doctors discovered she had Tetralogy of Fallot - a serious congenital heart defect. At the age of three, Sara underwent open-heart surgery. What followed was a long and frightening battle. Complications led to organ failure, a mitral valve replacement, endocarditis and months in intensive care. Despite the odds, Sara survived.

"One day, as I helped her, she gave me the biggest, most beautiful smile and I just melted," Ann said. *"Doctors told us she was a total miracle."*

A life full of joy

Sara has since undergone further valve replacements and now has a pacemaker. She lives in assisted accommodation and enjoys bowling and swimming. *"I would like to say thank you for choosing me to represent the British Heart Foundation and for giving me a bench that I, and other people, will enjoy sitting on,"* Sara said.

Her bench is one of 65 placed across the UK to honour people living with heart conditions as part of the BHF's 65th anniversary campaign. Ammanford Town Council has also installed a defibrillator in the park in support of [British Heart Foundation Cymru](#).

Rhodri Thomas, head of BHF Cymru, said: *"Sara's story shows the true reality of living with cardiovascular disease, and we are so grateful that they are courageously sharing their experiences to help others."*

To find out more or support the campaign, visit the [British Heart Foundation](#) website.



**British Heart
Foundation**

The British Heart Foundation funds life-saving research into heart and circulatory diseases while providing trusted health information and community support. Find out more about its work at the BHF website: <https://www.bhf.org.uk>



Useful contacts

We provide life-long support and advice to patients and their families throughout their whole journey with us.



Adult CHD Clinical Nurse Specialist Team
(Bristol)

Available: Mon to Fri, 8am to 4pm

Email: bhiachdnurses@uhbw.nhs.uk

CNS Telephone: 0117 342 6599

BHI Outpatient Department: 0117 342 6638

Cardiac Admissions Office: 0117 342 9444

Pacemaker/ICD advice line: 0117 342 6515

Adult CHD Clinical Nurse Specialist Team
(South Wales)

Available: Mon to Fri, 9am to 4pm

Email: achdnurse.cav@wales.nhs.uk

CNS Telephone: 029 2184 4580

Appointments & non-clinical queries: 029 2184 3892 or via achd.cav@wales.nhs.uk

<https://cavuhb.nhs.wales/our-services/adult-congenital-heart-disease-achd-service/about-the-adult-congenital-heart-disease-achd-service/>



Paediatric CHD Clinical Nurse Specialist
Team (Bristol)

Available: Mon to Fri, 8am to 4pm

Email: cardiacnurses@uhbw.nhs.uk

CNS telephone: 0117 342 8286

Appointment co-ordinator: 0117 3429281

Surgical co-ordinator: 0117 3428977



For any clinical queries and emergencies (out of hours), please contact Dolphin Ward via switchboard (0117 342 0000).

Paediatric CHD Clinical Nurse Specialist Team (South Wales)

Available: Mon to Fri, 8am to 4pm

Email: PaediatricCardiac.Cns@wales.nhs.uk

CNS telephone:

Cardiff & Vale 029 2184 5184

Bridgend, Merthyr, Rhondda 029 2184 7021

Gwent 029 2184 5524

Swansea and West 029 2184 4753

Transition care all areas age 13 to 18 years 029 2184 8046

Fetal care 029 2184 1746

Appointments and non-clinical queries: 029 2184 4749



Want to know more?

The Network website is for patients, families and clinicians.

We have information on:

- Patient leaflets
- Getting support
- Hospitals and clinicians across the Network
- Patient stories
- Patient pathways
- Clinical information
- Network meetings and training events
- Research

Please share your feedback on our newsletter by scanning this QR code with your phone or via the link

<https://forms.office.com/r/dSLx5mAK15>



Thank you for reading!

If you have any stories or ideas, you would like to share for the next edition in

New Year 2027, please contact

CHDNetworkSWSW@uhbw.nhs.uk

We welcome:

- Patient/family/staff/team stories
- Clinical news/updates
- Events
- Network related issues
- Anything else you think might be relevant!

The newsletter will be published twice a year.

Sign up for free

Join our mailing list today to receive the SWSW CHD Network newsletter directly to your inbox.

Send your email address to CHDNetworkSWSW@uhbw.nhs.uk requesting our newsletter.