South Wales and South West Congenital Heart Disease Network

South Wales and South West Congenital Heart Disease Operational Delivery Network

Annual Report 2025/2026

GIG CYMRU NHS WALES

NHS England

Contents

Foreword

By Dr Stephanie Curtis, Clinical Director, South Wales and South West Congenital Heart Disease Network

2025/26 has been a year of change. In many ways, it feels like a point of transition: a before and after as we move into the next phase of our refreshed Network strategy.

We have refreshed our 10-year strategy and vision to ensure that we continue to move with the times. Alongside our commitment to maintaining high standards of care with minimal unwarranted variation, we are embracing digital integration, artificial intelligence, innovation and research. A particular priority is strengthening communication between Levels 1, 2 and 3, recognising that effective communication is fundamental to reducing variation and delivering consistently high-quality care.

Our Level 1 and 2 strategy event in September was an important part of this work. Bringing senior colleagues from across England and Wales together to consider the national and Network picture, followed by collaborative workshops, was extremely well received. The opportunity to build relationships face-to-face was particularly valued, and we plan to build on this with further Level 3 events scheduled for this coming autumn, focusing on developing the cardiac physiology and specialist nursing workforce and extending psychological support beyond our Level 1 and 2 centres.

Our new Patient and Public Voice group, led by patients and families, has also been a great success. I am particularly keen that we continue to strengthen their involvement in shaping and driving our strategy.

There remain significant challenges. Long outpatient waits persist across the region, while workforce growth is necessarily slow and constrained by funding. Yet colleagues continue to find creative solutions. Remote specialist nurse and youth worker support is helping patients in more isolated areas; relatively modest investment has transformed the Gloucester ACHD service; and two new consultants have brought additional specialist expertise to patients in South Wales.

Whilst digitalisation is welcomed in many ways, there are challenges. Systems introduced without sufficient user involvement, training or ongoing support can create barriers rather than solutions. However, there are also real opportunities. The rollout of Epic across Devon promises more seamless communication, while providing Level 2 teams with laptops giving direct access to bookings and results has already improved collaboration, tackling a longstanding thorny issue. Similarly, transformation of the JCC with clinical leadership has allowed reduction in waiting lists and improved efficiency of meetings that will be sustainable and our cross-Network imaging work aims to reduce unnecessary repeat scanning and variation in practice that has been longstanding.

Looking ahead, we need to be creative in how we use specialist nurses, cardiac physiologists and other members of the multidisciplinary team to increase capacity and release consultant time. Most importantly, we need to focus on the last 10% — understanding why some patients struggle to access care, reducing DNAs and developing psychological services, which are increasingly recognised as essential to supporting patients and families.

Despite uncertainty about the future of Networks and the wider NHS, I remain immensely proud of what we have achieved together. Our standards of care remain high, and surgical and interventional outcomes are excellent. Alongside our strategic work, education, training, research and updated clinical guidelines continue to underpin everything we do.

Some things change quickly; others require persistence and incremental progress. What matters is that we continue to move forward together, with our patients and families at the centre of what we do.

Meet the Core Network Team (2025/26)

Radwa Bedair
Network Board Chair

Michelle Jarvis
Network Manager

Steph Curtis
Clinical Director

Sheena Vernon
Lead Nurse

Becky Lambert
Lead Nurse

Rachel Burrows
Support Manager

Our Vision

The Network vision was refreshed within 2025/26 through the development of *Beyond Compliance: Vision 2025–2035*, setting out an updated strategic direction for the next decade. The Network's 2025-2035 vision is to be a Network whereby:

#1	High quality standardised care is delivered in all centres, led by the latest clinical developments, including seamless care between paediatric and adult services.
#2	There is equity of access to services and equitable outcomes, regardless of geography.
#3	There is a strong and sustainable CHD workforce across the Network.
#4	There is a strong patient and parent partnership with representation from a variety of socio-economic and ethnic groups.
#5	There is a strong and collective voice for Network Stakeholders
#6	A culture exists of fostering research, innovation, and digital integration.

Network Aims & Objectives

(refreshed for 2025/26 in line with our updated strategic vision)

- Deliver equitable access and outcomes for all CHD patients
- Improve quality of care and reduce variation through innovation and best practice
- Support seamless and lifelong pathways across paediatric and adult services
- Sustain and enhance a skilled workforce and strengthen patient and public partnership
- Provide strategic leadership across the Network and monitor compliance with national CHD standards

About Us

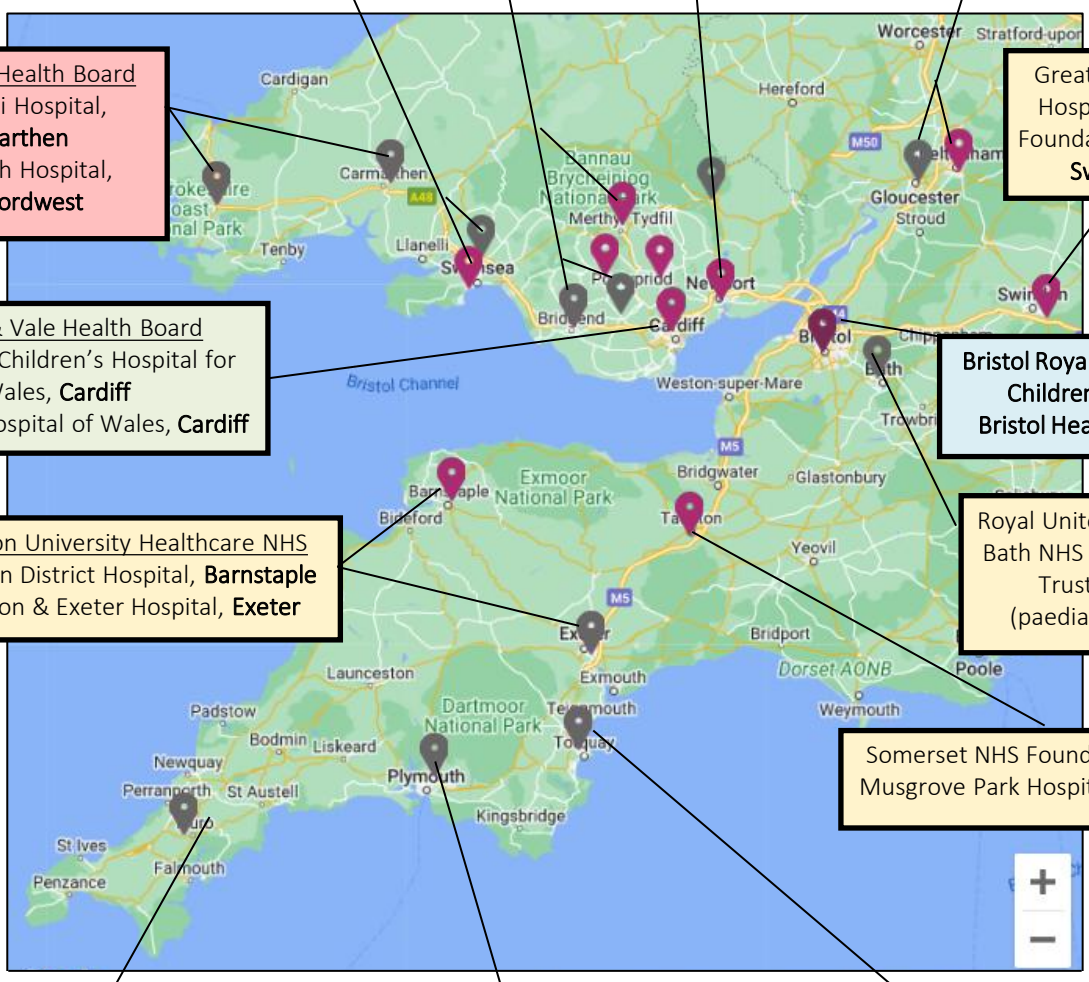
Background

The South Wales and South West England Congenital Heart Disease (SWSW CHD) Operational Delivery Network was officially formed in April 2016, following the publication of the NHSE CHD standards, There was already a long established informal clinical Network in the region, and a formal partnership with South Wales, agreed in 2001.

The Network is funded by, and accountable to, NHS England (NHSE) and hosted by Bristol NHS Foundation Trust (formerly University Hospitals Bristol and Weston NHS Foundation Trust). We work closely with the NHS Wales Joint Commissioning Committee (formerly WHSSC).

Our Network covers a broad geographical area with a population of approximately 6 million (1 in 100 children are born with CHD). It brings together clinicians, managers, patients, carers, and commissioners working together to support children with heart disease and adults with CHD and their families. Our collective ambition is to improve the quality and equity of care for patients.

Our Network Centres



Cwm Taf Health Board
Prince Charles Hospital, **Merthyr Tydfil**
Royal Glamorgan Hospital, **LLantrisant**
Princess of Wales Hospital, **Bridgend**

Aneurin Bevan Health Board
Royal Gwent Hospital, **Newport**
Grange Hospital, **Cwmbran**
Nevill Hall Hospital, **Abergavenny**

Gloucestershire Hospitals NHS Foundation Trust, **Gloucester**

Swansea Bay Health Board
Singleton Hospital, **Swansea**
Morriston Hospital, **Swansea**

Hywel Dda Health Board
Glangwilli Hospital, **Carmarthen**
Withybush Hospital, **Haverfordwest**

Great Western Hospitals NHS Foundation Trust, **Swindon**

Cardiff & Vale Health Board
Noah's Ark Children's Hospital for Wales, **Cardiff**
University Hospital of Wales, **Cardiff**

Bristol Royal Hospital for Children (BRHC)
Bristol Heart Institute

Royal Devon University Healthcare NHS
North Devon District Hospital, **Barnstaple**
Royal Devon & Exeter Hospital, **Exeter**

Royal United Hospitals Bath NHS Foundation Trust, **Bath**
(paediatric only)

Somerset NHS Foundation Trust
Musgrove Park Hospital, **Taunton**

Royal Cornwall Hospitals NHS Trust, **Truro**

University Hospitals Plymouth NHS Trust
Derriford Hospital, **Plymouth**

Torbay and South Devon NHS Foundation Trust, **Torquay**

Our Network in Numbers 2025/26

CLINICAL CARE

426
Heart operations

709
Cardiac catheters

c. 19,248
Clinic attendances (Level 1 and 2 only)

OUR NETWORK

18 Adult and 19 Paediatric centres

Covering Level 1 (specialist surgical), Level 2 (specialist medical), and Level 3 (local centre) services

Consultants including:

4 Cardiac surgeons

19 Paediatric cardiologists (including fetal cardiologists)

11 Consultants in adult congenital heart disease

36 Paediatricians with expertise in cardiology (PECs)/neonatal consultants

16 Adult cardiologists with specialist congenital interest

Nursing staff including:

22 WTE Clinical nurse specialists (level 1 & 2)

3 WTE (11) Local nurse specialists

Allied Health Professionals staff: c. 100

COMMUNICATION AND ENGAGEMENT

60
Webinars

9
Study Days

226
Future Platform staff members

Visit us: www.swswchd.co.uk

Paediatric Successes and Challenges Around the Region

Each quarter we ask our members to highlight successes (green) and challenges (red) at the Network Board using the 'exception reporting' process. This enables us to problem-solve and share good practice. Some examples are shown below.

Business case for substantive investment into paediatric cardiology Level 1 approved

Long outpatient waits in Bristol; large cohort of ICC patients

Gloucester outreach clinics now covered by Level 1 paediatric cardiology consultant in a permanent post, providing stability after several years of locums

Lack of formal transition clinics across region due to lack of nurses in Level 3 centres

Echo storage problem in Exeter resolved - images are now stored permanently

Funding agreed for specialist children's cardiac nurse in Plymouth

Merger between Taunton and Yeovil (also part of Southampton Network), resulting in confusion around referral pathways; need for Taunton PEC to cross-cover; effects of CQC closure of maternity services for six-months

Successfully recruited paediatric cardiology local nurse in Swansea Bay

Locum paediatric cardiology post in Bristol approved to become substantive

Lack of continuity of visiting consultant in Truro due to rotation of locums through Bristol paediatric cardiology consultant work force

Significantly improved waiting times for JCC discussion; new JCC Lead now appointed

Still insufficient numbers of specialist nurses in Level 3 centres

Excellent surgical and interventional outcomes in Level 1 centre

Increase in cardiac physiology led clinics, increasing outpatient department capacity

Demand > capacity for out-patient appointments in many level 3 centres

Adult Successes and Challenges Around the Region

Each quarter we ask our members to highlight successes (green) and challenges (red) at the Network Board using the 'exception reporting' process. This enables us to problem-solve and share good practice. Some examples are shown below.

All self-expanding valve platforms now in use in Bristol; significant reduction in waiting times

Two new ACHD consultant cardiologists in Cardiff (one new post)

BHF Moving Hearts Group in Cardiff continues with positive psychological and physical outcomes.

Lack of formal transition clinics across region due to lack of nurses in Level 3 centres

Continued improvement in level 1 (Bristol) JCC processes; patients discussed with minimal delay

Long outpatient waits in Bristol; large cohort of ICC patients

Joint transfer clinics now established in Taunton

New ACHD Clinical Fellow appointed in Truro

Merger between Taunton and Yeovil (also part of Southampton Network), resulting in confusion about referral pathways for adult patients

New CP-led ACHD clinic in Truro

Monthly ACHD Nurse clinic to support transition in Gloucester.

New ACHD MRI post in Cardiff with cross-network imaging protocols group established

Growing ACHD cohort continues to challenge outpatient capacity and most centres

New ACHD consultant post advertised in Plymouth

Different IT systems across Network continues to challenge smooth communication

New South Wales transition process resulting in significant reduction in loss to follow-up

Key Developments and Highlights 2025/26

The Network set out several priority areas for delivery during 2025/26, focused on improving patient experience, reducing variation in care, strengthening governance, and supporting the workforce. Over the past year, the Network has made good progress across these areas, with a combination of delivered actions and work that is now embedded or ongoing. The table below summarises progress against each of these agreed priorities, demonstrating how the Network has continued to move forward against the commitments set out last year.

Achieved

Area	Priority / Focus	Progress
Health Inequalities / Patient Experience	Use patient experience feedback to improve services	Patient experience survey established in Gloucester with good engagement - plans to extend across other Network centres
	Increase patient representation, including lived experience and learning disability	Additional representatives recruited - now embedded and ongoing
	Develop PPV representative roles to support service improvement	Independent patient representative group established and actively contributing
Model of Care	Transition – evaluation, education and implementation	Transition education ongoing. Young person clinic plans agreed through Transfer of Care Group. Network wide transition guidance shared and under review to align with new NHSE guidance
	ACHD cardiac rehabilitation	Website updated with clearer signposting to Level 1 ACHD cardiac rehab resources.
Transformation / Quality Improvement	Improve effectiveness of Paediatric JCC	Named lead in place; improvements underway with ongoing monitoring and re-surveying
	Track JCC outcomes across Level 3 centres	Network MDT tracker and SOP developed; to be rolled out early 2026/27
	Improve antenatal detection via fetal medicine collaboration	Cardiac Champions work ongoing led by fetal medicine network, champions identified in all regional South West England hospitals
Governance & Guidelines	Update Network clinical guidelines	Full Network guideline update during 2025/26
	Service reviews against National CHD Standards	Self-assessment reviews completed for Level 1 and Level 2 adult and paediatric services
	Strengthen governance and risk management	Governance arrangements updated and to be published early 2026/27. Next phase focused on issue log and learning processes

Key Developments and Highlights 2025/26

Achieved

Area	Priority / Focus	Progress
Nursing & Medical Workforce	Identify and escalate CHD nursing workforce gaps	Risks escalated to provider executives; some recruitment progress achieved, with ongoing challenges
	Support development of CHD nursing roles	Role resources developed, including competencies, role outlines, case studies and risk register entry for centres with no / inadequate local nurse resource
	Provide mentoring and support for CHD nurses	Mentoring and support framework established and ongoing, including regular group meetings (face to face and online) and 1:1 supervision and support for specialist nurses across the Network
Training & Education	Develop long-term Network strategy	Beyond Compliance Strategy (2025–2035) developed and agreed
	Complete Network training needs analysis	Training needs analysis completed
	Deliver ACHD medical study day	ACHD medical study day delivered (April 2025)

Partly achieved / in progress

Area	Priority / Focus	Progress
Model of care	Transfer of care between paediatric and adult services	Transfer of Care group reinstated. Gold/Silver/Bronze transition service gradings agreed. Electronic transfer process introduced in Level 1 centre – needs support
	Palliative care and bereavement	Included within various 2025/26 education events; further development planned.
Nursing & medical workforce	Improve Level 3 CHD resource in job plans	Limited progress to date; issue escalated via executive letters and remains a priority. Some centres have secured job planned time to attend JCC.
Training & education	Deliver Network education and training plan	Education and training plan published; ongoing work to strengthen AHP support

Not yet

Area	Priority / Focus	Progress
Governance & guidelines	Develop cross-Network research opportunities	Area identified; further work required to align with James Lind Alliance (JLA) priorities

Key Developments and Highlights 2025/26

1. CHD Standards Self-Assessment Review Programme for Level 1 (Bristol) & Level 2 (Cardiff)

During 2025/26, the Network completed a comprehensive programme of self assessment reviews across adult and paediatric CHD Level 1 and Level 2 services. This marked the final stage of a wider review cycle delivered across the Network. This work represents a significant achievement for all centres across the Network reflecting their engagement, openness and continued passion to improve services and outcomes for patients.

Across the full cycle, which began in May 2024, 23 centres have now completed self assessments against the national NHSE CHD standards, reflecting a strong commitment within services to review and continually strengthen the care they provide in line with national expectations. All reviews were undertaken with a high level of engagement, with centres completing detailed and transparent assessments. This provided a clear understanding of compliance with the National CHD standards, alongside insight into local challenges and any opportunities for improvement.

Key Outcomes

- Robust assessment of services against national CHD standards, identifying areas of good practice and opportunities for development
- Clear, locally owned action plans, with early progress already seen in strengthening compliance and addressing areas of risk
- Common themes identified across centres, providing a strong evidence base to inform the Network's multi-year workplan and priority areas
- Centre specific outcome reports produced, supporting local service development and escalation of key risks to organisational leadership teams
- Strengthened governance and oversight with monitoring through regular progress reporting at Network Board

Measurable Improvements

The programme of work has already led to positive changes within services, with teams implementing improvements to better align with the National CHD standards and improve patient care.

- Investment and recruitment into key workforce roles, particularly local CHD nursing provision and additional cardiology posts
- Increased job planned time for consultants, supporting attendance at JCC meetings and wider Network activity
- Improved participation in MDT processes, with more clinicians able to attend JCC and contribute to decision making
- Investment in essential equipment including replacement of outdated echocardiography machines to support safe and effective service delivery

While these improvements are significant, progress is not consistent across all centres. Most services continue to operate within challenging financial constraints at an organisational level, which can limit the pace and extent to which changes can be implemented, despite the clear commitment and efforts of local teams.

2. Level 1 (Bristol) and Level 2 (Cardiff) Strategy Event

Event overview

A collaborative strategy event between the Bristol and Cardiff adult and paediatric CHD services was held in September 2025 to strengthen partnership working and shape the future direction of CHD services across the region. The event was attended by 39 delegates (37 in person and 2 online), with strong representation across centres and professional groups, enabling broad engagement and active participation.

Strategic vision and future planning

All four services presented their 5–10 year vision, providing delegates with a clearer understanding of the future direction of CHD services, including plans for clinical service development, workforce expansion through recruitment, and education and training opportunities for clinical teams. NHS England Regional Medical Director, Dr Emma Redfern, opened the event with an overview of the NHS England landscape and the important role of clinical networks in supporting future service delivery.

Collaborative workshops

Workshop sessions focused on identifying opportunities to improve joint pathways, strengthen communication between services, and address inequalities in access and outcomes. Analysis of the workshop outputs led to the development of a draft action plan and informed priorities for the 2026/27 Network workplan.

Key outcomes delivered including:

- Broader understanding across services of strategic priorities and future development plans.
- Greater sharing of clinical guidelines, protocols and pathways, supporting more consistent approaches to care.
- Stronger collaborative working across the CHD Network to support the delivery of high-quality and equitable care.
- Identification of shared challenges and opportunities, with agreed actions to support ongoing service development.
- Updates to the Network workplan to ensure that agreed priorities and actions are progressed.

An action plan was produced, with immediate priorities included in the Network workplans; many of which have been achieved. Momentum from the event was translated into tangible improvements across the CHD Network.

Feedback from attendees

Feedback from attendees was extremely positive, with an overall satisfaction score of 4.83/5. Participants particularly valued dedicated time for networking, strategic thinking and learning from colleagues across centres, specialties and professional groups. Many comments highlighted the benefits of face-to-face engagement, cross-centre collaboration and the sharing of good practice.

Continued… Level 1 (Bristol) and Level 2 (Cardiff) Strategy Event

Feedback from attendees

"Networking opportunities… immensely valuable and worked well... as the group was about the right size. In our current environment we are constantly busy and often meet people for 1 or 2 minutes in the corridor. Being face to face and away from the hospital was the perfect opportunity to be able to network."

"Really informative and good things were learnt from the Welsh team to implement in Bristol."

"Most useful…cross pollination between centres, between adult and paediatric services and allied health professionals. All talks were excellent and small group discussions very useful."

4. Developed refreshed Network strategy 'Beyond Compliance 2025 – 2035'

The Level 1 and Level 2 Strategy Day which took place in September 2025 saw the launch of our refreshed Network Strategy, *Beyond Compliance: Vision 2025–2035*, setting out an updated strategic direction for the next decade.

Since our Network was established in 2016, our strategy has evolved with both the maturity of the Network and the development of changes in the NHS and medical care. We felt that we should change our formal strategy in line with this.

We felt that the Network had achieved its goals of providing "a strong and collective voice for Network stakeholders", "a strong culture of collaboration and action to continuing improve services", "the provision of high-quality information for parents, families, staff, and commissioners", and a clear demonstration of "the value of the Network and its activities".

We wanted to retain the concept of striving for high-quality care that was seamless between "locations, services, and where there are co-morbidities", but also make it clear that we are striving for care led by the latest clinical developments.

We wanted to clarify that not only would patients have "equitable access to services regardless of geography", but also equitable outcomes.

A strong and sustainable CHD workforce is crucial to providing specialist care for our patients and so we have specified the importance of this in our strategy, and we have also made a point of the importance of the patient and public partnership with diverse representation.

Finally, a new strategy would not be complete without the acknowledgement of the effect of AI and innovation on healthcare. As a Network, we want to use these developments wherever we can to improve care for our patients.

5. Joint cross-sectional imaging protocols task and finish group

Over recent years, members of our Network have reported variation in the use of cross-sectional imaging (CT and MRI) for patients with congenital heart disease. This inconsistency has on occasion resulted in patients undergoing duplicate imaging, exposing them to unnecessary radiation, creating inefficiencies in care delivery, and generating avoidable costs for Trusts and Health Boards. In addition, inaccurate or inconsistent imaging can lead to false-positive findings, inappropriate treatment decisions, and diagnoses maybe missed.

To address this issue, we established a task and finish group consisting of imaging cardiologists and radiologists from our Level 1 and Level 2 centres in the Network. The group scoped and reviewed national and international guidance,and developed a draft protocol to standardise imaging practice. This document is currently undergoing review by members of the group.

Once finalised, the protocol will be disseminated across the Network and shared with cardiology and radiology departments to support consistent imaging practices. This will help ensure that all our patients receive high-quality, standardised care regardless of where they are treated, and are benefitting from the same protocols.

The impact of the project will be evaluated through an audit comparing the number of inappropriate or suboptimal scans brought to the awareness of the multidisciplinary team before and after implementation of the protocol.

6. Investment in the Network's Level 1 Paediatric Cardiology & Cardiac Surgery Specialist Centre

Bristol Royal Hospital For Children

The Bristol paediatric service successfully secured approval in February 2026 for a significant investment in paediatric cardiac services following a comprehensive business case developed by the clinical and operational leadership team. Recruitment to a number of the new posts commenced shortly after approval. The investment responds to increasing demand, workforce pressures and growing waiting lists across the service and represents a major achievement for the Bristol paediatric service.

Through a phased investment programme delivered over the next three years, the service will:

- Increase outpatient diagnostic and elective procedure capacity across the specialist cardiology pathway
- Reduce waiting times and decrease overdue follow-up appointments
- Improve clinical outcomes and patient & family experience through timelier access to assessment, diagnosis and treatment
- Strengthen transition and transfer services for young people
- Increase access to care closer to home by expanding local paediatric cardiology services in Weston
- Creating a sustainable and resilient clinical workforce by introducing advanced clinical practice roles across the CHD MDT
- Improve workforce retention by reducing reliance on short term funded posts, creating a more resilient service able to meet future demand

7. Patient and Public Voice (PPV) Group Relaunch

Establishing an Independent PPV Group

In early 2026, after much preparation, the SWSW CHD Network PPV Group was successfully relaunched. While a previous PPV group had existed within the Network, and many of its members continued into the new group, the relaunched group was established as an independently managed member-led forum with PPV representatives taking ownership of its direction and activities, supported by the CHD Network team.

This marked an important step forward in strengthening patient and public involvement within the Network. The relaunch was informed by the model in the North West, North Wales and Isle of Man CHD Network, showing the value of creating a self-governing, member-led group with a strong sense of ownership and accountability.

This relaunch reinforces the Network's commitment to ensuring the lived experience of patients and families meaningfully informs service development, priorities, and improvement across the Network.

Launch and Early Development

The relaunched PPV Group supports the Network's commitment to working in partnership with patients, families and carers to ensure lived experience helps inform service development, communications and Network priorities. As members of the Network Board, PPV representatives play a role in Network governance and provide valuable insights that inform Network decision making. The group have agreed to coordinate their Board attendance on a rotational basis, ensuring consistent PPV representation while sharing the commitment across their group.

The group have a designated chair and currently meet on a monthly basis. One of the first tasks of the group was to develop a PPV representative role description, a Chair role description and the PPV group Terms of Reference, providing a clear framework for participation, governance and accountability. These documents were then presented and approved by the Network Board. The group are currently developing educational resources for patients, families and carers.

Outcomes and Future Development

As the group continues to develop, there will be focus on widening participation, supporting inclusivity and ensuring the membership reflects the diversity of the populations served, including people from different ethnic, socioeconomical, geographical and ages as well as those with a range of lived experiences of CHD. .

As the group becomes established, the Network will continue to demonstrate how PPV feedback has influenced decision-making and service improvement.

Delivering Clinical Care across the Network

Transfer of Care from Paediatric to Adult CHD Services Task and Finish Group

This group was re-launched following a hiatus due to the completion of the paediatric and adult self-assessments in the South-West of England. The aim of this group is to implement a robust and consistent transfer of care process between paediatric and adult CHD services across the Network. This will help reduce the risk of patients being lost to follow-up and improve continuity of care.

The long-term objectives are to achieve an auditable electronic transfer of care process for all patients and to ensure that every young person in the region has access to a specialist multidisciplinary team transfer clinic, or an equivalent service, in line with the National CHD Standards.

Our South Wales hospitals have established a successful consultant-led transfer model. This has shown a significant reduction in the number of patients lost to follow up. As a result, the current focus of the project is on supporting the implementation across the South West England hospitals in the Network.

At present, three levels of transfer/young person clinic provision exist in the South-West. Over the last 12 months, Gloucester and Truro have progressed from bronze to silver status. Work is also underway in Swindon and Exeter to group patients, enabling the provision of remote support from specialist nurses and youth worker.

GOLD STANDARD
Young people are seen in a dedicated clinic with a specialist nurse and youth worker.
Taunton

SILVER STANDARD
Young people are seen in a dedicated young person clinic with *virtual* nurse and youth worker support
Truro
OR Young people seen and supported by a specialist nurse but not grouped together or seen by a youth worker
Gloucester

BRONZE STANDARD
Young people not grouped together and no specialist nurse or youth worker support
Exeter, Barnstaple, Bath, Swindon, Torbay

The following steps are designed to support all level three centres in achieving the gold standard for transfer stroke young person clinics:

Grouping patients in a nominated Young Person clinic – any available Network nurse or Level 1 nurse can do virtual clinic and support. Youth worker could attend.

Increasing specialist nurse input into clinic either virtually or in person from Level 1 or Network (this is difficult due to staffing).

Delivering Clinical Care across the Network

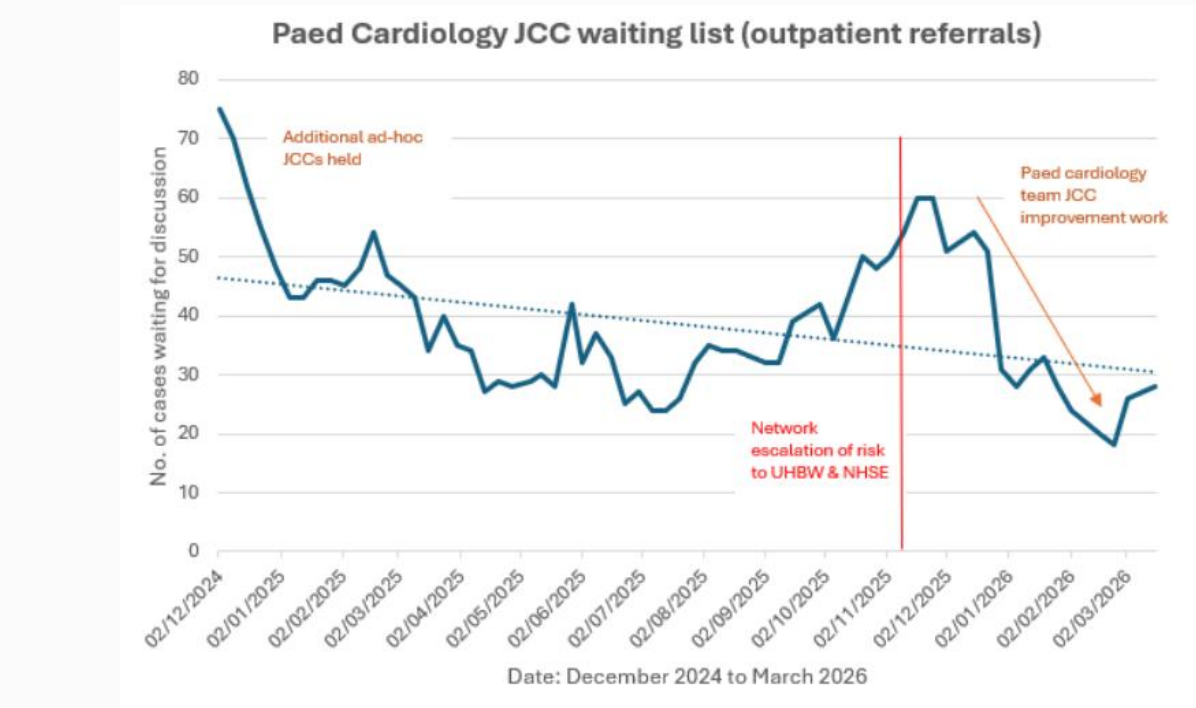
Paediatric CHD JCC Improvement Project – Completed Scoping Work

During 2024–25, the Network undertook a transformation project aimed at improving the throughput and management of the Adult Joint Cardiac Conference (JCC). A stakeholder survey was conducted, and the findings and recommendations were presented to the Bristol and Cardiff teams, as well as to the Network Board and Clinical Governance meetings. Terms of Reference were subsequently developed and implemented.

These changes resulted in a substantial improvement in performance. The waiting time for discussion of patients within the Adult Congenital Heart Disease (ACHD) JCC reduced from approximately four months to effectively real-time review. A follow-up stakeholder survey demonstrated a significant increase in satisfaction among participating teams.

Following the success of this project, consideration was given in 2025-26 to how the same principles could be applied to the Paediatric JCC. Drawing on the ACHD JCC Terms of Reference, the paediatric team has already reduced its waiting list while developing a more formalised approach to JCC management and leadership through job planning arrangements. Strong leadership from Mr Shafi Mussa has increased discussion throughput and supported service improvement.

In March 2026, Dr Silvia Caroli was formally appointed as Paediatric Cardiology JCC Lead and has already introduced significant operational improvements, including an online referral system for case discussion requests, triaging of cases prior to listing, and strengthened chairing of meetings. These changes are expected to further enhance efficiency, governance, and timely decision-making within the Paediatric JCC.



Delivering Clinical Care across the Network

First Specialist ACHD Clinics at the Royal United Hospital, Bath

Another key achievement during 2025/26 was the successful establishment of the first Adult Congenital Heart Disease (ACHD) clinics at the Royal United Hospitals Bath (RUH), improving access to specialist care for patients across Bath and North East Somerset.

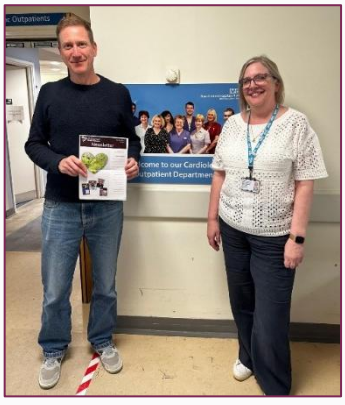
Previously, patients with CHD could receive paediatric cardiology care locally at RUH but, following transfer to adult services, were required to travel to Bristol for ongoing specialist follow-up. RUH was the only Trust in the South West without local ACHD provision aligned with its paediatric cardiology service.

The introduction of local ACHD clinics has begun to address this gap, enabling patients to access specialist review closer to home and reducing the burden of travel for routine outpatient care. Feedback from patients attending the first clinics has been overwhelmingly positive, with many expressing their appreciation for the opportunity to receive specialist care locally.

The clinics are delivered by Dr Stephanie Curtis, ACHD Consultant Cardiologist at the Bristol Heart Institute and Clinical Director for the Network, with specialist nursing support provided by Becky Lambert, Network Lead Nurse for the first few clinics. Local medical support is supplied by senior doctors in training. It is hoped that one of the local cardiology consultants will take on specialist interest in ACHD. The successful establishment of the service reflects strong collaboration between the Network and the RUH team, together with the commitment of local clinical leaders, including Dr Raveen Kandan and Bradley Isaac (service manager), who were instrumental in securing support and funding for the service.

Beyond the immediate benefits for patients, the establishment of ACHD clinics in Bath represents an important step towards greater equity of access to specialist CHD care across the South West. Work is now underway to explore the development of sustainable local specialist nursing support to enable the continued growth of the service.

This achievement demonstrates the Network's commitment to delivering high-quality specialist care closer to patients' homes, improving patient experience and strengthening local service provision.



Delivering Clinical Care across the Network

Network Communications Task and Finish Project Group

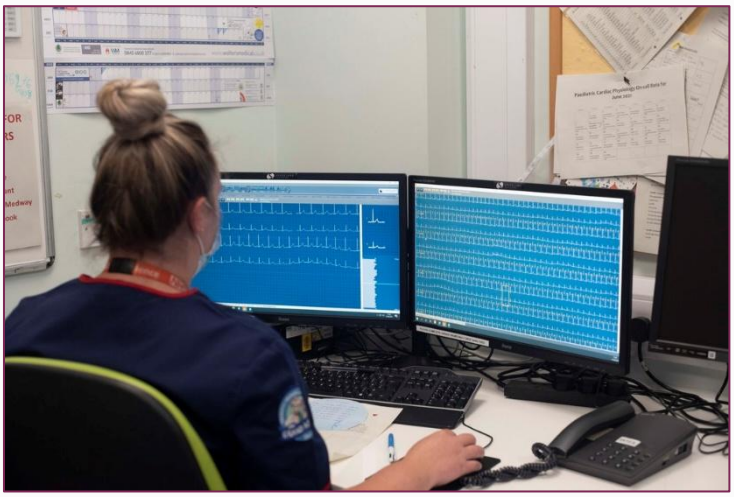
Communication between hospitals across the Network continues to present challenges. Even with the best email, postal services, and telephone communication, the gold standard is for all our hospital IT system to seamlessly interact with one other, enabling the secure sharing of patient information in real time.

The adoption of the EPIC Electronic Patient Record system across Devon has significantly transformed communication and information sharing between centres. Somerset NHS Foundation Trust (Taunton) is also scheduled to implement EPIC within the next two years, which will further strengthen connectivity within the region. However, several of our other hospitals across the Network continue to use a variety of other IT systems, limiting interoperability.

NHS Wales is not part of this project and uses entirely separate systems. To address this challenge, the Network procured six laptops for use by paediatric and adult congenital cardiology teams in our Level 2 centre (Cardiff). Consultants have been granted honorary contracts and provided with IT accounts, enabling secure, live access to Bristol's clinical systems. This initiative has transformed patient care by allowing clinicians to view all patient records, imaging, and real-time inpatient data directly, regardless of location.

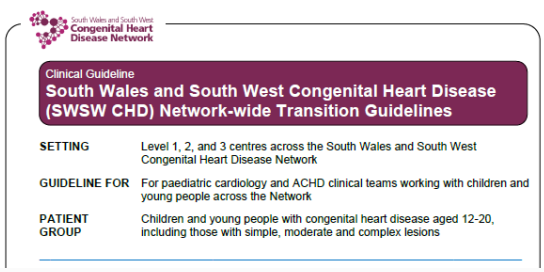
Bespoke training has been delivered to Level 2 paediatric cardiology consultants, and the efficiency of the project is currently being assessed.

In the meantime, the Network team will continue to support and advocate for the adoption of universal IT systems across the Network. Improving digital connectivity will enhance communication and efficiency, while most importantly strengthening patient safety and the quality of care delivered across the region.



Delivering Clinical Care across the Network

Network-Wide Transition Guidelines


South Wales and South West Congenital Heart Disease Network

Clinical Guideline

South Wales and South West Congenital Heart Disease (SWSW CHD) Network-wide Transition Guidelines

SETTING	Level 1, 2, and 3 centres across the South Wales and South West Congenital Heart Disease Network
GUIDELINE FOR	For paediatric cardiology and ACHD clinical teams working with children and young people across the Network
PATIENT GROUP	Children and young people with congenital heart disease aged 12-20, including those with simple, moderate and complex lesions

The Network-wide Transition Guidelines (2026) were created to provide a broad framework to support centres across the Network, recognising that organisations are at different stages in developing and delivering transition services. The guidelines complement local policies, procedures and standard operating procedures (SOPs), and can be adapted to reflect local context, resources and service needs.

A key priority for the Network is to support all centres to provide an appropriate level of transition care, including where limited staffing and resources mean that a dedicated transition clinic is not currently possible. This principle underpinned a revamped online Transition Study Morning attended by a wide range of clinicians from across the Network.

New Clinical Guidelines released/refreshed in 2025/26:

Continued the refresh of Network protocol documents, working with designated guideline owners to review, update and align content.

New Paediatric CHD Clinical Guidelines

- Access to second opinion and referrals to other centres/services
- Collaborative arrangements to facilitate joint operating, and mentorship in operating for children
- Red flag system to determine risk for children with CHD undergoing any procedure under general anaesthesia

Updated Network Adult CHD Clinical Guidelines

This ACHD guidelines were updated in 2025/26 and are available on our Network website and on the MyStaff document management system for Network healthcare professionals:

- Atrial septal defect (ASD)
- Bicuspid aortic valve disease and associated aortopathy
- Chronic thoracic aortic disease
- Coarctation of the aorta
- Congenitally corrected transposition
- Cyanosis in CHD and Eisenmenger's syndrome
- Ebstein's Anomaly
- Fontan circulation (total cavopulmonary circulation)
- Right ventricular outflow tract obstruction
- Specific discharge guidance at transfer for minor lesions
- Subaortic stenosis
- Supravalvar aortic stenosis
- Tetralogy of Fallot repaired
- TGA (previous Rastelli procedure)
- TGA (previous Mustard or Senning procedure)
- TGA (previous arterial switch)
- Ventricular septal defect
- Transfer and repatriation arrangements
- Regional referral guidance adult patient with CHD in South West England

Delivering Clinical Care across the Network

The Patient and Public Voice – At The Heart Of What We Do

Patient stories presented at the Network Board – learning and purpose

Patient stories are shared at our Network Board meetings to ensure that the patient voice remains central to decision-making. They provide real-life insight into how services are experienced, highlighting what works well, where improvements are needed, and the impact that care has on individuals and their families and carers.

In 2025/26, we piloted a new approach using pre-recorded interviews, with the PPV representatives being invited to the Network Board for Q&A. This format has enhanced the way patient experiences are shared with the Board, enabling more engaging accounts of care and supporting meaningful discussion to inform service development and improvement.

3 year old Francisco 	Tetralogy of Fallot	• Described the family experience of a post natal diagnosis of TGA • The emergency transfer to Bristol from Truro with cardiac surgery and ECMO support in PICU • Followed by excellent recovery
13 year old George 	Double inlet ventricle	• Described the experience of a family from Truro dealing with repeated admissions to Bristol for surgery • The impact on the family with a single Mum and another brother • The impact of this now in the early teenage years
21 year old Jack 	Born with transposition of the great arteries and additional needs	• Described the impact of having additional needs as well as CHD requiring surgery • The vital role of the ACHD CNS support in this journey
59 year old Debbie 	Transposition of the great arteries	• Described the childhood experience of a Welsh patient with childhood care in London • The gradual clinical deterioration and transplant assessment in Newcastle • The vital role of psychology for patients with complex CHD

Education and Training Programme 2025/26

A core objective of the Network is to support and promote training and education opportunities for our healthcare professionals across the region. These are designed to bring together professionals from centres across the Network to strengthen knowledge, skills and professional practice, and create opportunities for evidence-based learning, collaboration and knowledge exchange.

Key impact highlights 2025/26

FutureNHS

9 training and education events delivered

346 participants engaged representing all centres

226 Network Members accessing Network training on our Futures platform

36 new webinars on our education resource platform

In summary, participants reported:

✓ Increased competence and confidence

✓ Improved understanding of key concepts

✓ Stronger professional networks and collaboration

✓ Increased sharing of learning between centres

✓ Greater ability to apply learning to enhance patient care

Education resources are available on the Network website (www.swswchd.co.uk) and Future Platform

Learning outcomes across events

Event	Attendees	Primary learning outcomes reported by attendees
ACHD Medical Study Programme	59	Improved knowledge, confidence and clinical decision making when caring for adults with CHD
Psychology Network Day	40	Improved understanding of neurodiversity, appropriate use of AI in healthcare, and the value of lived experience in person-centred care
Transition event (part 1)	18	Increased confidence in supporting young people through transition and applying structured transition tools and assessments
Paediatric Cardiology (PEC) forum (1)	19	Enhanced knowledge of PDA management, ECG holter interpretation and clinical decision-making in paediatric cardiology
CNS away day (1)	22	Strengthened collaboration, reflection and communication across the Level 1 & Level 2 CNS workforce
ACHD study day (aimed at nurses, AHPs & junior staff)	116	Improved understanding of Fontan physiology and confidence in recognising deterioration and managing complex ACHD patients
CNS away day (2)	23	Strengthened reflective practice, coaching skills and professional development to support high-quality patient care
Transition event (part 2)	20	Increased knowledge and confidence in supporting discussions around contraception, sexual health and medication adherence during transition
Paediatric Cardiology (PEC) forum (2)	29	Improved recognition, assessment and management of complex and less common cardiac conditions

Health Care Scientists

Developing a National Pilot for Congenital Echocardiography Training

Addressing a Workforce Challenge

During 2025/26, significant progress was made in developing a new national training programme in congenital echocardiography, supported by NHS England funding and led by colleagues within the South Wales and South West CHD Network.

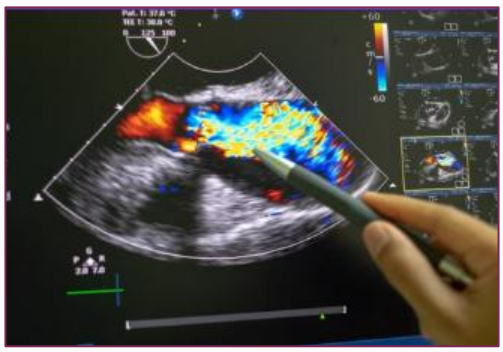
The Postgraduate Certificate in Echocardiography in Congenital Heart Disease (CHD), developed in partnership with the University of the West of England (UWE), was created to address a recognised workforce challenge by increasing access to specialist congenital echocardiography training and supporting the development of expertise within cardiac physiology teams

Led by Owen Burgess, Deputy Head Cardiac Physiologist and Joint Echocardiography Lead at Bristol Royal Hospital for Children (pictured right), the programme was developed in line with the British Society of Echocardiography congenital syllabus and designed to support progression towards professional accreditation.

Preparing for Launch

Throughout 2025/26, work focused on curriculum development, governance arrangements, recruitment of learners and establishment of a network of practice educators to provide supervision and support across participating centres. By the end of the year, all preparations were complete for the programme launch in April 2026. The first cohort included five cardiac physiologists from across the SWSW CHD network alongside additional learners from other congenital heart disease networks across England, reflecting the programmes' national reach and the Networks leadership in workforce development.

The six-month programme combines specialist online teaching delivered by CHD experts with workplace-based learning, supervised echocardiography practice, assessments and case-based discussions.



Looking Ahead

As the first pilot programme of its kind in the UK, it represents an important opportunity to evaluate a new approach to developing specialist congenital echocardiography expertise. The programme is expected to support workforce development, strengthen service resilience and increase specialist echocardiography capacity across the CHD Network, helping to meet future workforce demands and support the delivery of high quality CHD care.

Fetal Cardiology Update

Cardiac Champions Programme Continues to Strengthen Regional Collaboration in Fetal Cardiac Screening

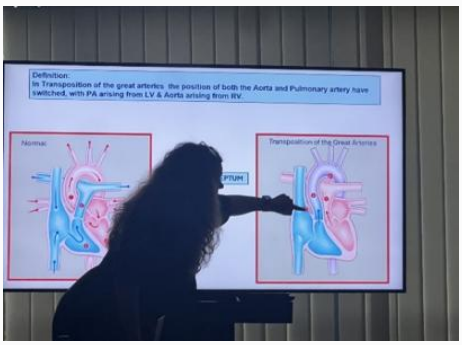
The South West Cardiac Champions Programme continued throughout 2025/26 as an ongoing regional Network designed to support sonographers with a special interest in fetal cardiac screening and strengthen links between local maternity units and the Bristol Fetal Cardiology Team. Each participating maternity unit has a nominated Cardiac Champion who acts as a local resource, promoting best practice, facilitating discussion of challenging cases and outcomes, and supporting peer learning and quality improvement within their department.

The Network continues to provide a valuable mechanism for communication, knowledge sharing and access to specialist expertise. However, engagement has been variable across the region. Many departments continue to experience significant workforce and operational pressures, making it difficult to release staff for educational and development activities. Feedback from some Champions has identified limited protected time and varying levels of organisational support for the role, which has affected participation and the pace of programme development.

Despite these challenges, the Network has established important relationships between local units and the tertiary fetal cardiology service and provides a foundation for future collaborative working. Participants continue to value the opportunities for shared learning, discussion of challenging cases and access to specialist support.

An example of the programme's wider impact can be seen in Cornwall, where Cardiac Champion Hollie Williams, Midwife Sonographer at Royal Cornwall Hospitals NHS Trust, is undertaking a Negotiated Specialist Practice Module in Fetal Echocardiography at the University of the West of England as part of her MSc in Medical Ultrasound. Supported by the Bristol Fetal Cardiology Team and her Fetal Medicine Consultant, Dr Robert Kerr, this training will help build local expertise and support fetal cardiac screening in a region where antenatal detection rates for congenital heart disease remain below the national average. This achievement reflects a significant personal commitment from Hollie, who has pursued specialist training alongside the demands of a busy clinical service despite the practical challenges many Champions face in accessing protected time for professional development.

While this level of specialist training extends beyond the original aims of the Cardiac Champions Programme, it demonstrates the opportunities that can arise through strong collaboration between local units and the regional specialist team.



During 2026/27, the focus will be on maintaining and developing the network, improving engagement where possible, and expanding opportunities for shared learning. Plans include reintroducing fetal cardiac case review sessions and holding the next South West Cardiac Champions Study Day on 16 October 2026. Although progress has been influenced by ongoing pressures within maternity ultrasound services, the programme has established a valuable foundation for future education, support and quality improvement across the South West.

Allied Health Professionals

Pharmacy

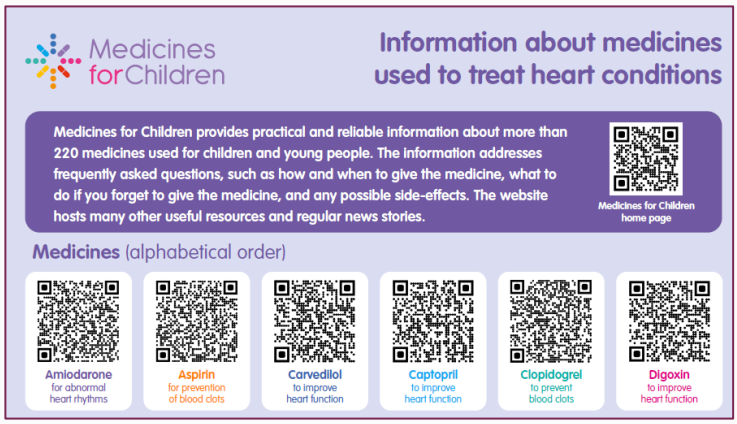
Susie Gage, Team Pharmacy Lead for PICU, Paediatric Cardiac & Paediatric Surgery,
Bristol Royal Hospital for Children and SWSW CHD Network Board Member

Susie has continued to chair a paediatric cardiac pharmacist group nationally and has led several national initiatives. During the year, Susie has completed a project to develop a poster incorporating QR codes linking to national Medicines for Children information leaflets, providing paediatric cardiac families with improved access to trusted medicines information.

Susie presented a poster on the development of the Network guideline for ADHD medication in children with cardiac conditions at the British Congenital Cardiac Association (BCCA) conference in London. Susie is also due to deliver an oral presentation at the Association for European Paediatric and Congenital Cardiology (AEPC) meeting in Padua, Italy (May 2026) on Extracorporeal membrane oxygenation (ECMO) pharmacy provision nationally across U.K. and Ireland.

Susie was invited, as a clinical member of the CHD Clinical Reference Group (CRG), to attend the national Network day in Liverpool (March 2026) to discuss the current cardiac standards. As the sole pharmacist in attendance, Susie continued to champion the role of the wider multidisciplinary workforce involved in CHD care. Moving forward, Susie has been appointed to officially represent AHP and other less well represented workforce groups at Network Board, helping to ensure these vital professions have a voice within the Network while incorporating her national work through the CHD CRG.

In recognition of her extensive clinical, leadership, educational and national contributions, Susie has submitted evidence for Consultant Pharmacist credentialing through the Royal Pharmaceutical Society. The outcome is expected in early 2026/27 and if successful would represent a national first for paediatric cardiology and paediatric intensive care pharmacy practice. The Network is proud to have Susie as part of the team and recognises the considerable impact of her leadership and expertise across both regional and national services.



To access the Medicines for Children information about medicines used to treat heart conditions posters, visit:

https://www.medicinesforchildren.org.uk/qr-code-posters/

Psychology Update: Spotlight on the Bristol ACHD Service

Delivering Specialist Psychological Care

During 2025/26, the Bristol ACHD Psychology Service continued to provide specialist psychological support to adults living with CHD across the South West of England. This service also remained committed to train psychologists of the future, whilst promoting the need for psychology within this highly specialist area.

The ACHD Psychology service received 72 referrals during 2025/26, providing assessment, formulation and intervention for ACHD related concerns including anxiety, depression, acceptance and adjustment to their condition, medical trauma, preparation for surgery, and the impact of CHD on daily life.

Understanding Patient Need

Screening data from 38 patients demonstrated high levels of psychological distress, with 37% meeting the criteria for probable post-traumatic stress disorder (PTSD), alongside significant anxiety and depression. Given these findings and in-keeping with wider Trust initiatives, the service will continue to promote and facilitate the delivery of trauma informed care, contribute to ongoing improvement of psychological safety and offer post-surgical psychological intervention.

Through use of additional screening tools for cognitive functioning and neurodiversity, the ACHD Psychology service in collaboration with the patient (and where appropriate, the specialist Trust learning disability and neurodiversity service) aims to offer an equitable service to all, through developing and disseminating care plans responsive to individual need.

Measuring Impact

Routine pre- and post-intervention screening questionnaires were introduced this year, strengthening evaluation of clinical impact. Feedback from patients and multidisciplinary colleagues has been positive, demonstrating the value of psychological support and intervention, in improving coping, adjustment, wellbeing, and patient experience.

Quality Improvement

Throughout the year, the service contributed to quality improvement initiatives. This included an evaluation of the ACHD Psychology transplant pathway funded by the Transplant Association, during NHS England's ongoing review of specialist heart and lung transplantation. Early findings highlight the importance of understanding patients within their home, work, health and social context. Lived experienced reported by patients emphasised the need for services to think in a more systemic way. This resulted in the ACHD Psychology service broadening their exploration of ways to enhance psychological support, communication, and care coordination for patients and their families. Findings, which align with the NHS Neighbourhood Health Framework, will be shared later this year

Looking Ahead

The ACHD Psychology service priorities include continued collaboration with Cardiff and Vale Trust in developing clearer aligned pathways; improving equitable access across the South West of England; enhancing links with community services; and exploring opportunities to expand inpatient psychological support in response to growing demand.

Research Update

The Network continues to maintain a strong and active research portfolio with a focus on patient-centred outcomes. Activity during the 2025/26 reporting period reflects sustained multidisciplinary collaboration.

Our Network Research Lead is Dr Giovanni Biglino (photo right), who is an Associate Professor in Bioengineering by background, supported by Dr Jack Gibb (photo far right), paediatric cardiology trainee undertaking his PhD, Both contribute to the strategic development, academic coordination, and research engagement across the Network.

Ongoing Research Programmes

1. Caputo Group

The Caputo Group continues to lead a broad programme of research focused on CHD and surgical innovation. Key areas include:

- Tissue engineering and bioprinting of valved right ventricular outflow tract (RVOT) conduits, shunts, and live patches for CHD
- Immune profiling of failed RVOT conduits
- Experimental animal models investigating the impact of fetal hypoxia on cardiopulmonary bypass outcomes
- Multicentre biobanking initiatives, including OMACp and PEARL
    - Multi-omic and immuno-metabolic profiling in single ventricle CHD
    - Maternal metabolomic profiling for prediction of fetal CHD risk
    - Cytokine profiling around cardiac surgery

2. Bioprinting and Shape Modelling Programme

This workstream continues to advance computational and engineering approaches to CHD. This includes development of patient-specific anatomical modelling to support surgical planning and regenerative approaches to cardiac repair.

3. Exeter Group – Functional Assessment and Exercise Physiology

The Exeter Group continues to lead clinical and physiological research focused on exercise capacity and cardiovascular adaptation in CHD:

- Exercise echocardiography for assessment of cardiac functional reserve and pulmonary vascular response
- National surveys examining patient with CHD attitudes towards exercise training
- Development and evaluation of strength training interventions in CHD populations
- Planning of British Heart Foundation (BHF) fellowships and PhD programmes in cardiometabolic disease in CHD
- Establishment of normative MRI datasets in young athletes and stress echocardiography in young people

Continued… Research Update

4. Outcome Development and Patient and Public Involvement (PPI)

A significant focus continues to be the development of meaningful clinical outcomes and patient-centred measures in CHD research:

- National Institute Health and Care Research (NIHR) programme development grant awarded - led by Mr Serban Stoica (Consultant Cardiologist in Bristol), focusing on improving perioperative care for children undergoing surgery in CHD.
- National Engagement Collaboration (NEC) Patient and Public Involvement (PPI) and outcomes funded project, led by Nigel Drury – collaborating with teams in Bristol and Southampton on strengthening PPI in research design and prioritisation.

5. Clinical Studies Portfolio

The Network continues to support recruitment and delivery across several multicentre clinical studies:

- ICONIK – multicentre observational study of genetic cardiomyopathy
- Fiore – multicentre randomised controlled trial evaluating finerenone in paediatric heart failure (Local Principal Investigator: Catherine Armstrong)
- SPIKA-401 – multicentre randomised controlled trial evaluating elamipretide in Barth syndrome
- Apollo – multicentre observational study evaluating cognitive, motor, psychosocial, and quality-of-life outcomes following congenital cardiac surgery

6. Network Research Forum

A Network Research Forum was established in June 2024 and has continued throughout 2025/26. The forum is a key opportunity to learn, exchange research ideas, and for researchers to receive feedback from the Network. The forum has been well attended by healthcare professionals, academic researchers, students, and patient representatives from across the region.

Key themes in 2025/26 included:

- National CHD research strategy and priority setting
  Presentation on James Lind Alliance (JLA) priorities and the Congenital Heart Research Network (CHRN), delivered by Nigel Drury
- Research engagement and methodology
  “What is research and how do we all play a part” – delivered by Dr Jack Gibb
- Research culture and psychological safety
  “The art of failing well” – exploring psychological safety and learning culture in research, delivered by Dr Giovanni Biglino

7. Summary

2025/26 reflects continued growth and diversification of the Network’s research portfolio, with sustained activity across translational science, clinical trials, and outcomes research. The integration of engineering approaches, clinical investigation, and patient involvement remains a defining feature of the Network’s research strategy.

Quality Improvement & Audit Programme

Dr Helen Wallis, Network Audit and Quality Improvement Lead, and ACHD Consultant Cardiologist

Throughout 2025/26 numerous QIPs and audits have been undertaken across the Network, a selection of which are highlighted below. Work presented at Network forums has focussed on service delivery, clinical pathways, workforce innovation and patient experience, helping to identify opportunities for improvement and to share best practice across centres.

2025/26 Highlights

- CHD / pacing audit - presented by Dr Georgia Spentzou, Consultant Paediatric Cardiologist and Interventionist, Bristol.
  Reviewed permanent pacemaker implantation following CHD surgery to improve risk stratification, family counselling and clinical practice.
- Transfer of care from paediatric to adult services - presented by Dr Helen Wallis, Consultant Cardiologist, Cardiff.
  Identified successful transfer rates and opportunities to reduce the number of young people lost to follow up during transfer
- Evaluation of a sonographer-led model in outpatient paediatric echocardiography (retrospective service audit) - presented by Dr Isa Ghaidan, Foundation Year 3 Doctor, Torbay Hospital.
  Demonstrated that a sonographer-led model can increase service capacity and efficiency while safely managing a substantial proportion of routine paediatric echocardiography referrals
- ACHD Psychology Service Audit - presented by Dr Pauline Aiston, Clinical Psychologist, Bristol.
  Reviewed service accessibility, referral patterns and opportunities to improve equity of access to psychological support

Planning for 2026/27 – Network wide audit development

In collaboration with stakeholders at the Network Clinical Governance meeting, strategic discussions have generated ideas and led to the development of a coordinated cross-Network audit programme for 2026/27. A key priority is a prospective, 12-month audit of infective endocarditis cases across paediatric and adult CHD services.

The infective endocarditis audit aims to:

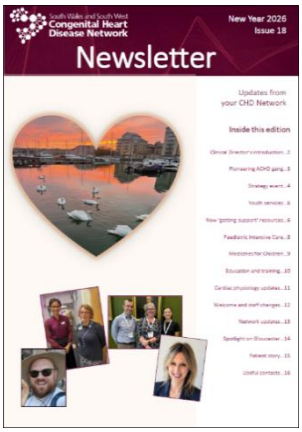
- Establish a comprehensive Network-wide database of infective endocarditis cases
- Assess whether dental intervention and/or inadequate antibiotic prophylaxis may contribute to disease occurrence
- Evaluate the potential adoption of the Cardiff ACHD antibiotic prophylaxis guidance, developed through a QI project led by Dr Stephanie Connaire (May 2025, UHW Cardiff)
- Improve clinical management, communication pathways, and adherence to prophylaxis guidance across the Network
- Ensure all confirmed cases of infective endocarditis continue to be discussed with the Level 1 (Bristol) or Level 2 (Cardiff) paediatric/adult CHD teams in line with established clinical pathways.

Conclusion

The 2025/26 audit and quality improvement programme demonstrated strong engagement across the Network, supporting service improvement, shared learning and collaboration across CHD services.

Communication and Engagement

The Network acts as a central point of communication and information sharing across all stakeholders. Through well established channels, including the popular Network newsletter (published twice yearly), the Network website, stakeholder meetings and forums, we are able to support members and ensure consistent engagement across the Network.



Network Website

During 2025/26, the psychology 'getting support' pages were refreshed in collaboration with PPV representatives to enhance clarity, relevance, and user engagement. In addition, the homepage imagery was updated to more fully represent the Network's identity and strengthening visual consistency. One of our PPV representatives described the layout as *"simple, easy to navigate, and user-friendly, which is especially important for users experiencing anxiety or stress who are looking for support and helpful resources."*

Liverpool Event launches national CHD standards Review

The Network contributed to the national CHD standards review programme by attending the Liverpool workshop at Alder Hey Children's Hospital, alongside clinicians, managers, commissioners and patient representatives from across all Networks.

The event initiated the refresh of the national CHD standards and specifications, in place for almost 10 years, and covering adult and paediatric services across Level 1,2 and 3 centres. Discussions confirmed the scale of the work required and the ongoing focus on high-quality equitable care.

A key outcome is the decision to adopt a lifetime pathway approach to the standards. This represents a significant shift towards more integrated care across the patient journey and will require a coordinated national programme of work.

The Network will continue to play an active role in this programme, ensuring regional priorities and patient perspectives are represented as the review progresses.

Integrated Care Board (ICB) Engagement Event – Showcasing Network Value

The Network Clinical Director & Network Manager presented at the Operational Delivery Networks ICB / NHSE engagement event in January 2026, using the opportunity to share the Networks achievements, workplan and strategic priorities with commissioning colleagues. The Network presentation demonstrated how the Network translates national CHD standards into practical delivery, supports cross-system coordination and provides whole pathway oversight to inform commissioning decisions. Engagement at this event ensured visibility of the Network's role and impact, helping to evidence the value of Networks in supporting safe, equitable and sustainable CHD services, and strengthening relationships with ICB partners.

Communication and Engagement

Network Maturity Matrix

During 2025/26, the Network completed a Network Maturity Matrix assessment using the NHS England framework to understand how effectively the Network is functioning and to identify priorities for future development. The assessment was undertaken as a self-assessment by Network Board members and reviewed performance across eight core areas, including leadership, governance, learning, impact and sustainability.

Overall, the findings demonstrated a strong and well-established level of maturity across the Network, particularly in leadership, strategic direction, communication and member commitment. Feedback highlighted effective leadership and facilitation, clear and efficient arrangements for project delivery, high-quality education events, and valued communication channels, including Network resources and newsletters. This provided assurance that the Network is operating at a high level of maturity and effectiveness.

The assessment also identified targeted areas for further improvement, including refreshing governance arrangements and terms of reference, enhancing the diversity and reach of patient and parent representation, broadening engagement across professional groups, and continuing to develop approaches to training, education and member engagement. These findings directly informed priority actions during 2025/26, with some work already completed and other projects ongoing, including refreshing the Network vision, progressing the education and training strategy, enhancing patient representation, and clarifying member engagement and induction processes.

"Education events are really valuable"

"A positive structure – embracing success but striving to improve"

"Very organised and strategic with project groups. Excellent communication"

"Huge impact on program development"

"Membership is not as transparent as could be to the members"

"Excellent leadership & facilitation"

"Do we all have a clear shared vision?"

"More Cardiac Physiologists / therapies needed"

"Positive engagement and commitment across Network"

"More formal recognition of other professionals required"

"Excellent resources & love the newsletters!"

Network Governance

Refreshed Network Governance Protocol

The Network Morbidity, Patient Safety Event, Learning and Risk Reporting protocol (2026) was developed and circulated for Network-wide consultation, supporting the transition to a strengthened PSIRF-aligned governance framework focused on shared learning, collaborative working and clearer oversight across the Network.

The Patient Safety Incident Response Framework (PSIRF), introduced by NHS England in 2022 to replace the Serious Incident Framework, represents a significant change in the approach to responding to patient safety incidents, with greater emphasis on proportionate responses, system-based learning and improvement rather than focusing primarily on the severity of an incident.

In line with the NHS England Congenital Heart Disease Standards (2016) and PSIRF, the Network provides system-level oversight by identifying cross-provider themes, pathway risks and opportunities for improvement across partner organisations.

Provider organisations remain responsible for reporting and responding to patient safety events through their local governance processes and PSIRF arrangements. The Network's role is to coordinate discussion of cross-provider and system-wide issues, facilitate shared learning and support improvements across the CHD pathway.

As part of this work, a new Patient Safety Event, Risk and Learning Reporting Form has been developed, together with accompanying guidance to help organisations identify which events, risks and concerns should be reported to the Network.

Learning and emerging themes are reviewed through the Network Clinical Governance Group and Network Board, supporting collaborative action and the delivery of safer, more effective care for children, young people and adults with congenital heart disease.

To find out more and to access the new reporting form, please visit: Network Governance

Network Board Membership

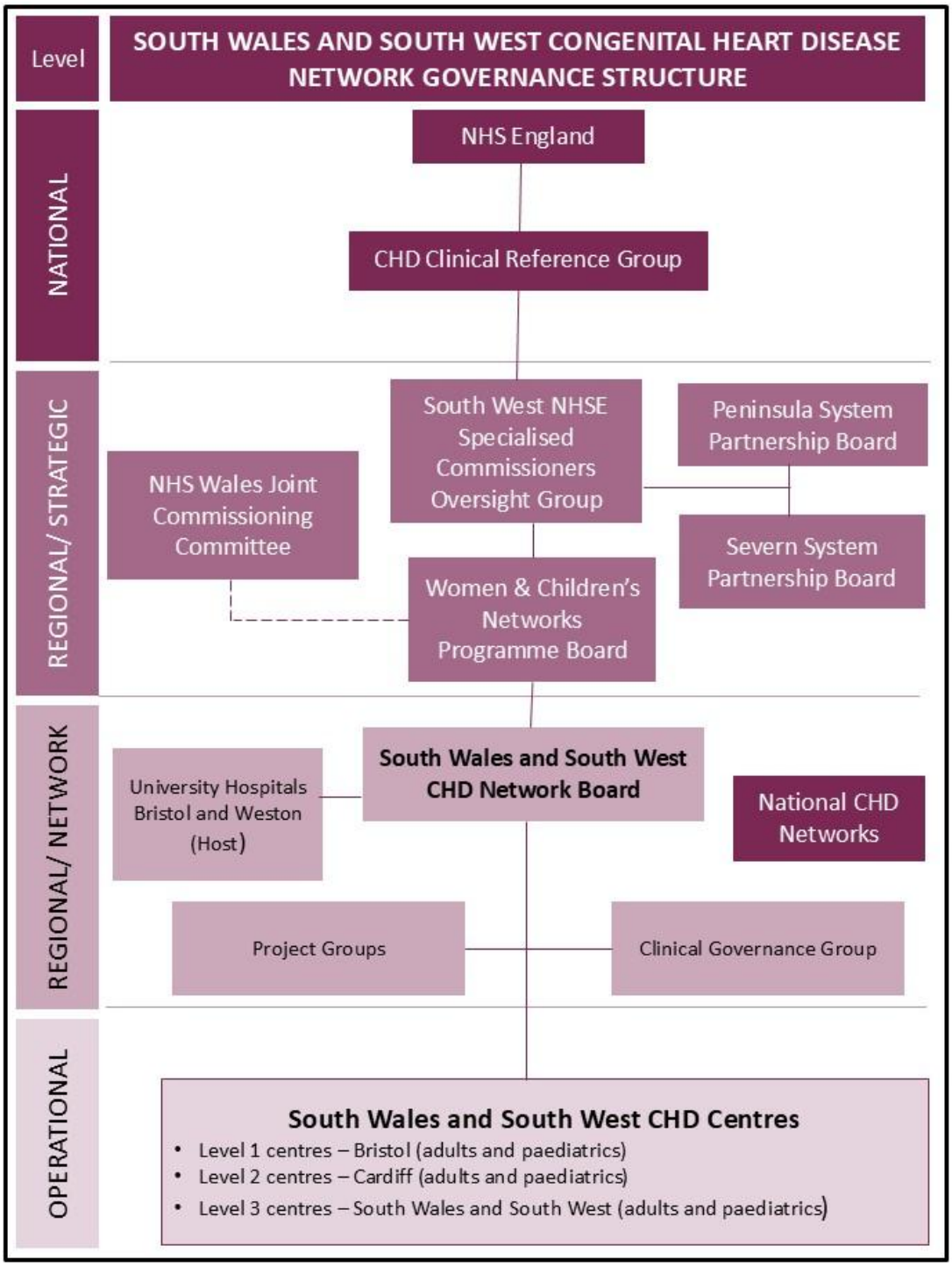
During 2025/26, the Network progressed a planned refresh of its Board membership and governance arrangements, with this due to be finalised by mid 2026/27. While this work had already been identified as a priority, feedback from the Network maturity matrix exercise further highlighted the importance of clarifying roles and responsibilities, strengthening governance arrangements and ensuring representation reflects the scale of services, professions and geographies across the Network.

As part of this work, the Network team has reviewed and updated the Terms of Reference, reviewed Board membership arrangements, and developed a proposed model for future representation. Expressions of interest will be sought from a range of professional and stakeholder groups to strengthen multidisciplinary representation and ensure the Board continues to reflect the diverse expertise within the Network. The refreshed arrangements aim to support effective governance, collaborative decision making and a strong collective voice for congenital heart disease services across South Wales and South West England.

All professionals and stakeholders working across the Network's regions are considered part of the wider Network. Individuals who are not designated Board members will remain welcome to attend and contribute to Network Board meetings.

Network Governance

The oversight of the SWSW CHD Network is through the SWSW CHD Network Board, with an established Clinical Governance Group and ad hoc project groups feeding into the priorities and planning. The operational and governance structure is illustrated through the diagram below:



Patient Safety, Learning and System Improvement

As an Operational Delivery Network, the SWSW CHD Network is no longer formally required to maintain a Network risk register, as operational risks are managed by individual provider organisations. However, the Network has an important role in identifying and overseeing pathway risks that span organisations, supporting system-wide improvement, and providing assurance to NHS England and NHS Wales.

Partner organisations are encouraged to notify the Network of events, risks or concerns that may have:

- Cross-provider impact
- Workforce capacity or service sustainability implications
- Quality, audit, regulatory or reputational implications
- Opportunities for wider learning across the CHD Network

These are reviewed through the Network Clinical Governance Group to identify themes, support shared learning and coordinate system-wide improvement.

During the 2025/26 reporting period, two patient safety events brought renewed attention to a longstanding pathway risk associated with patients receiving care across network boundaries. In some areas, this can increase the risk of patients being lost to follow-up and may result in individuals with complex co-morbidities receiving care across more than one specialist centre.

In response, the Network has initiated collaborative work with neighbouring CHD Networks and commissioners to review patient pathways, clarify responsibilities and agree the safest arrangements for patient flow and ongoing care. This work is continuing.

Financial Report

The SWSW CHD Network is funded by NHS England and was allocated an annual budget of £227,485 in 2025/26, after overhead contributions were made to University Hospitals Bristol and Weston NHS Trust as the host organisation. The end of year position is shown below. The variance (overspend) reflects that the Network's pay budget is funded at the midpoint of the Agenda for Change pay scale, in line with standard practice. A number of core team members sit above this midpoint due to their NHS experience and length of service. This results in a small notional overspend which will be addressed by NHSE. Due to lower than anticipated travel and event costs in 2025/26, the network utilised underspend within the non-pay budget to support a development opportunity. This enabled funding for a South Wales Cardiac Physiology colleague to undertake the Postgraduate Certificate in Echocardiography in Congenital Heart Disease.

Network funding			**2025/26**	
		Budget	**Expenditure**	**Variance**
Pay	Total	£ 217,601	£218,723	-£1,122
Non-Pay*	Total	£9,884	£9,825	£59
Total		£227,485	£228,548	-£1,063

*Non-pay includes website and IT costs, travel, print and training expenditure.

Looking Ahead: Our Focus for 2026/27

The Network team produces an annual workplan to capture the projects and workstreams that are prioritised for the year ahead. For 2026/27, the workplan includes the continuation of existing projects together with new priorities from the Beyond Compliance 2025-2035 strategy, while responding to the challenges, opportunities and areas of variation identified through our self-assessment review programme and feedback from Network stakeholders

The workplan focuses on improving patient and family experience, supporting equitable and timely access to care, strengthening the workforce, reducing unwarranted variation and promoting innovation and collaboration across the Network. This work will be delivered alongside our core business as usual activities, including education, training, governance, quality improvement, communication and engagement.

The table below summarises the Network's key priorities for 2026/27 outlining the areas of focus and the impact we aim to achieve for patients, families and services across South Wales and South West England.

Project	Focus for 2026/27	What we aim to achieve
Beyond Compliance 2025 - 2035 Strategy Delivery	Progress the Year 1-3 priorities of the strategy focusing on equity, lifelong pathways, workforce sustainability, patient partnership, innovation and reducing variation	Measurable progress towards the Network's 2035 vision and strategic objectives
Level 3 Stakeholder Events	Deliver face to face events across South Wales and South West England to bring together teams from across Level 3 services to share learning, discuss common challenges, showcase innovation and strengthen Network connections	Improved collaboration and stronger relationships across the Network Sharing of best practice Greater consistency in the delivery of CHD services
Young Person Clinics	Expand the provision of dedicated young person clinics (for first adult appointments) across the Network and support centres to progress towards the Network's gold standard model	Improved patient experience Better preparation for adult services Reduced loss to follow up
Transition	Embed the principles of the Network transition guidance across all centres, with each service identifying practical improvements that can be delivered within their local workforce and service model	More consistent transition provision across the Network Improved support for young people and their families

Our Focus for 2026/27

Project	Focus for 2026/27	What we aim to achieve
Transfer of Care	Implement and standardise transfer of care processes between paediatric and adult services, building on existing electronic solutions	Safer transfer arrangements Improved continuity of care Fewer patients lost to follow up
Paediatric Joint Cardiac Conference (JCC)	Deliver the next phase of the JCC improvement project, embedding new processes, monitoring performance and strengthening communication with referring centres	Reduced waiting times More timely clinical decision making Improved efficiency
Cross Network Imaging Protocols	Development and implementation of network wide CT and MRI protocols for common congenital lesions, ensuring consistent imaging standards across centres	Improved consistency and quality of imaging Reduction in repeat scans and unnecessary radiation exposure More efficient use of resources & faster clinical decision making
Patient & Public Voice (PPV)	Further support the development of the independent PPV group, ensuring representation reflects the diversity of the population we serve and increasing opportunities for patients and families to shape service development and improvement	A stronger and more representative patient voice that informs decision making, service improvement and future Network priorities
Equity of Access and Outcomes	Deliver targeted work to better understand and address barriers faced by underserved patient groups, including patients who are neurodiverse, digitally excluded or living in areas of deprivation	Reduced health inequalities Improved engagement with services and more equitable access and outcomes across the Network
CHD Workforce Development	Deliver workforce development work that strengthens specialist CHD nursing, medical, physiology and AHP / other CHD workforce capability across the Network	Improved workforce resilience Enhanced specialist skills More consistent delivery of CHD care across the Network

Glossary

ACHD	Adult Congenital Heart Disease
BCCA	British Congenital Cardiac Association
BHI	Bristol Heart Institute
BRHC	Bristol Royal Hospital for Children
CHD	Congenital Heart Disease
ICC	Inherited Cardiac Conditions
CNS	Clinical Nurse Specialist
F/UP	Follow up (outpatient appointment)
JCC (MDT)	Joint Cardiac Conference (Multi-Disciplinary Team)
Level 1 / L1	Specialist Congenital Heart Surgical Centre – University Hospitals Bristol and Weston NHS Foundation Trust (BHI & BRHC)
Level 2 / L2	Specialist Congenital Heart Centre - University Hospital of Wales / Noah's Ark Children's Hospital, Cardiff
Level 3 / L3	Peripheral NHS hospitals in South Wales and South West of England
MyStaff	Document management system hosted by University Hospital Bristol and Weston NHS Foundation Trust
NHSE	National Health Service England
PEC	Consultant Paediatrician with Expertise in Cardiology
PICU	Paediatric Intensive Care Unit
SWSW	South Wales and South West of England
W JCC	Welsh Joint Commissioning Committee

How to get involved

There are many ways to get involved with the Network:

Professionals can:	Patients and families can:
♥ Become a Board member ♥ Attend a training event ♥ Take part in our M&M meetings	♥ Visit our website (www.swswchd.co.uk) ♥ Sign-up to our newsletter mailing list ♥ Become a patient/parent representative ♥ Attend an engagement event

For more information, please:

Visit our website: www.swswchd.co.uk

Email: CHDNetworkSWSW@uhbw.nhs.uk

South Wales and South West Congenital Heart Disease Network

Our patients are at the heart of our services. We would like to thank all the patients and families who have shared their experiences with us.