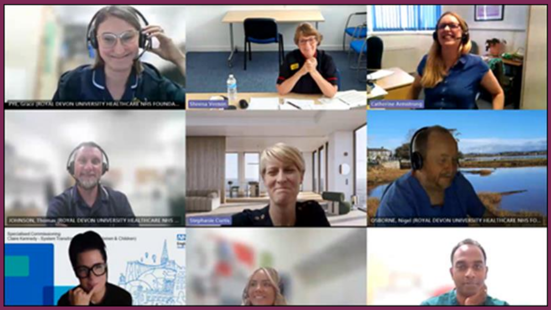
South Wales and South West
Congenital Heart
Disease Network

South Wales and South West Congenital Heart Disease Operational Delivery Network

Annual Report
2024/2025



GIG CYMRU
NHS WALES

NHS
England

Contents

Foreword

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

Welcome to our Network Annual Report for 2024/25. As another year goes by, I am very pleased to report that the members of our Network continue to be busy providing high-quality care for patients with congenital heart disease throughout South Wales and the South West of England.

Our program of education, audit, and research, as well as clinical governance, board, and morbidity and mortality meetings continues to provide a framework for interaction of Network members, a safe governance framework for our work, and a collective voice for our stakeholders.

One of our aims is to ensure equitable care for all patients across the Network. With this in mind, in 2024/25, we carried out Self-Assessments in our South West of England Level 3 Centres (pages 11-15) against the published NHS standards of care, mirroring those done the previous year in Wales. These were felt to be valuable by all involved and highlighted gaps in services and areas of inequity. Not only did we find engagement from senior members of staff in the Trusts we assessed very encouraging, but actions were quickly taken after the meetings such that we have seen improvements in staffing, patient flows and multiple other areas of services since the visits. We would like to thank our colleagues for their excellent engagement and for their work in achieving as much as they can within the current financial constraints of the NHS.

Whilst we appreciate that these financial constraints make service development difficult and continue to try to provide more efficient pathways and cost-effective practices, some investment is required in certain areas to ensure safe care. It is our job to point out these gaps to care providers and advocate for our patients and families.

In the meantime, we continue to drive efficiency (see the project on Flow of Patients from Bristol to Cardiff on page 17) and transformation (see our adult JCC transformation project on page 16).

It is one of our core objectives to ensure that our patients have equitable care in a timely manner and we continue to strive for this.

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 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.

Meet the Core Network Team (2024/25)

Radwa Bedair
Network Board Chair

Michelle Jarvis
Network Manager

Steph Curtis
Clinical Director

Sheena Vernon
Lead Nurse

Becky Lambert
Lead Nurse

Rachel Burrows
Network Support Manager

Our Vision

#1	Patients have **equitable access** to services regardless of geography
#2	**Care is provided seamlessly** across the Network and its various stages of transition (between locations, services and where there are co-morbidities)
#3	**High quality care** is delivered, and participating centres meet national standards of CHD care
#4	The provision of **high-quality information** for patients, families, staff and commissioners is supported
#5	There is a strong and **collective voice** for Network stakeholders
#6	There is a strong culture of collaboration and action to **continually improve** services
#7	To ensure it can **demonstrate the value** of the Network and its activities

Network Objectives

To support the education, training and development of the workforce within the Network

To support the delivery of equitable, timely access for patients

To support improvements in patient and family experience

To be a central point of information and communication for Network stakeholders

To provide strategic direction for CHD care across South Wales and the South West

To ensure it can demonstrate the value of the Network and its activities

To monitor and drive improvements in quality of care

Our Network Centres

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

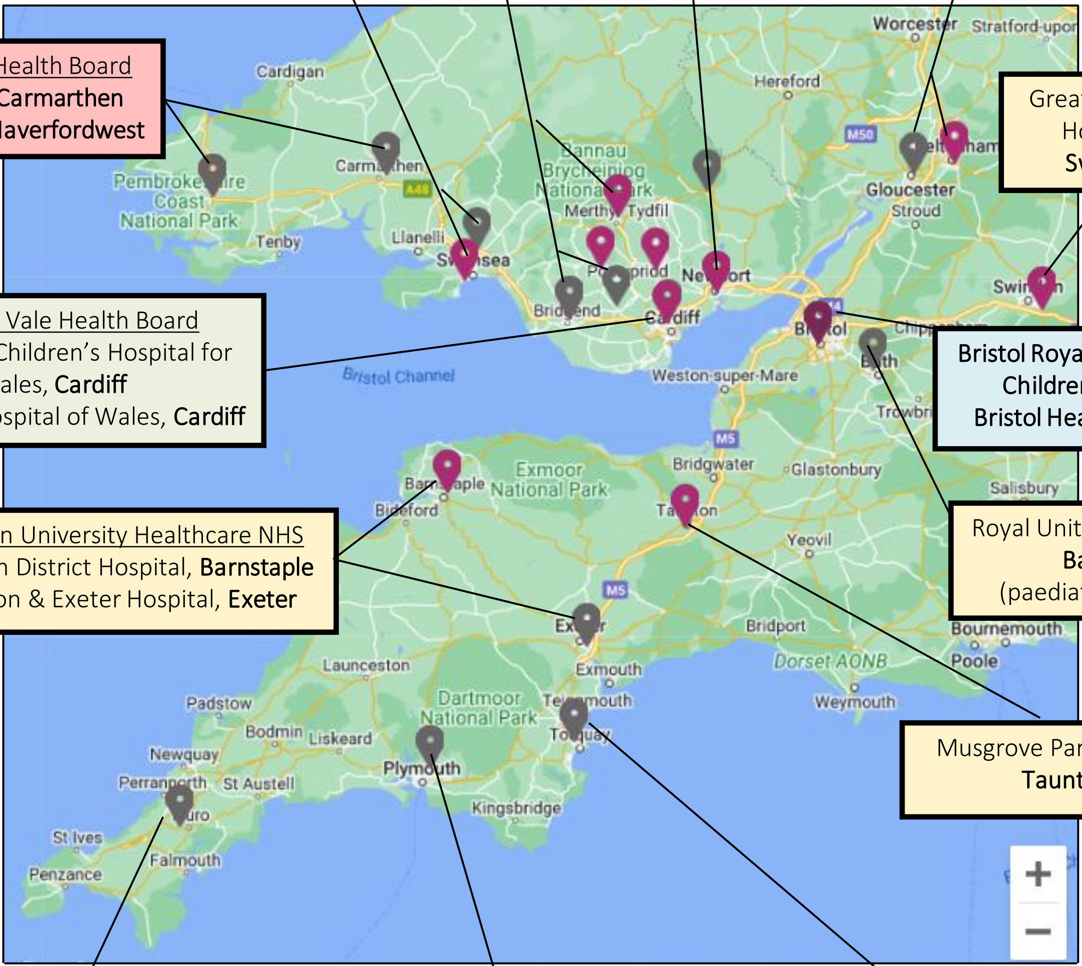
Aneurin Bevan Health Board
Royal Gwent, **Newport**
Grange, **Cwmbran**
Nevill Hall, **Abergavenny**

Gloucester Royal Hospital

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

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

Great Western Hospital, **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 Hospital
Bath
(paediatric only)

Musgrove Park Hospital, **Taunton**

Derriford Hospital, **Plymouth**

Torbay Hospital

The Royal Cornwall Hospital, **Truro**

Our Network in Numbers 2024/25

CLINICAL CARE

425
Heart operations

779
Cardiac catheters

c. 17,743
Clinic attendances
(Level 1 and 2 only)

OUR NETWORK

Consultants including:

4 Cardiac surgeons

19 Paediatric cardiologists (including fetal cardiologists)

9 Consultants in adult congenital heart disease

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

15 Adult cardiologists with specialist congenital interest

18 Adult and 19 Paediatric centres

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

Nursing staff including:

28 Clinical nurse specialists (level 1 & 2)

8 Local nurse specialists (5 paediatric, 3 adult)

Allied Health Professionals staff: c. 100

COMMUNICATION AND ENGAGEMENT

36
Webinars

8
Study Days

203
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 Network Board using the 'exception reporting' process. This enables us to problem-solve and share good practice. Some examples are shown below.

- Cardiac physiologists in Taunton, Plymouth and Swansea Bay achieving CHD accreditation
- Taunton - Backlog driven Cardiac Physiologist led clinics to reduce new referral waits, impressive discharge rate (23%), saving PEC time
- Surgical activity increasing, largely due to increased nursing allowing optimal use of PICU beds
- Clarity on commissioning of Cardiff paediatric cardiology activity achieved
- Torbay – JCC tracker and monthly check in process established
- New paediatric cardiac echocardiographer clinics in Torbay and Bristol
- Bath – exceeding pre-pandemic activity levels
- Reductions in Taunton f/up backlogs and waiting times
- Plymouth – appointment of a 3rd PEC
- Barnstaple – excellent dental access pathway in place for paediatric cardiac patients

- Single-handed electrophysiologist in Bristol with long waiting list
- Insufficient outreach clinics in Hywel Dda
- Fetal target of 3 days not being met due to new staff shortages
- Rapid increase in ICC referrals
- Perpetually changing visiting cardiologist in Gloucester
- Unclear transition strategy Level 1
- Insufficient CNS provision throughout region
- Excessively long paediatric JCC waiting times with risk of disease progression or adverse outcomes while awaiting discussion
- Difficulties in differentiating CHD patients from general paediatrics and cardiology in hospital IT systems
- Lack of integration of IT systems across region, affecting tracking patients through pathways

Adult Successes and challenges around the region

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

Transformation of adult JCC: waiting time reduced from 12 weeks to no wait.

No local consultant in Aneurin Bevan UHB

Consistently improved ACHD surgical and interventional waits through 2024/25

New ACHD medical staff in Cardiff – clinical fellow and 3rd consultant appointed

Lack of ACHD identified and funded local CHD nurse across region

New dedicated ACHD MRI sessions in Cardiff, reducing long waiting times in region

ACHD clinic backlogs across South Wales and South West (improvements in Bristol with appointment of more middle grade staff)

New ACHD 'hot clinics' in Cardiff

Risk to local services due to standalone workforce

Permanent ACHD consultant appointed in Taunton

Inconsistent delivery of patient transition and transfer to adult services

New ring-fenced post - ACHD JCC clinic slots in Bristol to avoid delays to intervention

No cardiac rehabilitation provision specific to ACHD patients

New cardiologist appointed in Exeter to cover ACHD and ICC

New Singleton clinic with Dr Wallis and new Imaging/Heart Failure consultant.

Inadequate time in consultant job plans to attend the Joint Cardiac Conference (JCC) MDT meeting to the degree required by the CHD standards

Cardiff - Health Innovation Project 'Moving Hearts’ awarded prestigious BHF-funding

The ability to deliver joint clinics with a specialist ACHD cardiologist (Swindon)

Cardiac physiologists across region awarded CHD echo accreditation (2 BSE in Taunton funded by Health Education England)

Inadequate access in some centres to CHD trained cardiac physiologists

Resolved challenges from around the region 2023/24

Here are some of the challenges flagged to the Network Board via the ‘exception reporting’ process in 2023/24, and what has been done to problem-solve

Challenges 2023/24	Status / What has been done to problem-solve
Clinic backlogs across the region for both ACHD and paediatric CHD	Staffing challenges throughout the country due to current financial constraints facing NHS.
Variable DNA rates due to lack of admin support	Dependent on admin support to ensure clinics attended. To be scoped in Network workplan.
ACHD interventional waiting list	Much improved due to increased lab time with new lab timetable in the BHI.
Surgical waiting list for paediatrics are long	Much improved with increased PICU nursing, also supported by Saturday lists and continued enhanced recovery programme.
Long JCC waits in both paediatrics and adult CHD	ACHD transformation project has cleared ACHD waiting list and cases now discussed in real time with no wait. Paediatric JCC project is ongoing.
Absence of ACHD coordinator (Bristol)	Problems solved with coordinator now attending JCC meetings.
Balancing ACHD CPD of local cardiologist with other general cardiology commitments	Ongoing issue, highlighted to hospital management teams in 2024 Level 3 self-assessments. Two Level 3 cardiologists now regularly attend the JCC.
Industrial action for junior doctors and radiology	Now resolved with new pay deals from government.
Insufficient Level 1 paediatric cardiology time in Level 3 centres	Being addressed currently in Level 1 cardiologists’ job plans.
Retirement of ACHD consultant in Exeter	New consultant appointed.
Lack of maternity leave cover for ACHD consultant in Truro	Local consultant cardiologist has returned from maternity leave.

Key developments and highlights 2024/25

1. CHD self-assessment process in South West England

Self-assessment reviews were held with the adult and paediatric CHD services across South West England in May-November 2024. The nine adult and eight paediatric centres were asked to score their compliance against the NHS England CHD standards and to identify improvement opportunities to further develop their services.

There was a high Level of engagement from all providers, with self-assessments completed thoroughly and honestly, leading to constructive conversations about services. The common themes of challenge across both adults and paediatric CHD services included:

- Unfunded or inadequate local CHD nursing resource
- Inadequate consultant job planned time to attend specialist MDT meetings and engage with the Network
- Risks associated with standalone workforce
- No Network wide database
- Inconsistent delivery of transition care
- Limited / varying advice around pregnancy & contraception
- No cardiac rehab provision specific to ACHD patients
- Dental access challenges for paediatrics

Individual outcome summaries were produced for each centre noting their level of compliance against the standards with actions and next steps described to address any gaps. A full benchmarking report was produced for adult and paediatric services across the South West England region to understand areas of mutual challenge and to support shared learning of good practice and innovation. The findings of the self assessments are to be used to inform the upcoming Network workplan for the next year to support in addressing areas of non-compliance across centres. Summary letters were shared with the wider Trust organisations to commend areas of excellence whilst highlighting risk within services and offer recommendations to mitigate these.

In response to the findings of the review there has already been notable progress to address workforce risks within many of the South West England centres as captured on the following pages of this report.

Towards the end of the financial year, the Level 1 paediatric (BRHC) review was held, and planning commenced for the next phase of self-assessments across the other Level 1 adult and Level 2 centres.

> *"This self-assessment shows how vital it is to have the Network's support and input, to discuss and share the learning and celebrations within the Network."*
>
> Taunton Paediatric Cardiology Team Consultant (November 2024)

Key developments and highlights 2024/25

Key Findings, Actions and Progress Updates from Self Assessment Reviews:

Key Finding	Network Support	Centres' Progress Updates
1. Unfunded or Inadequate Local CHD Nursing Resource	• Letters to executive leads highlighting risks associated with inadequate nursing provision and advocating for investment prioritisation • Business case template support • Risk register template support • Network mentoring and peer support structure for local nurses	**Plymouth** • Funding confirmed for 1wte paediatric local CHD nurse, aim to recruit by June 2025 • Role of ACHD specialist nurses to be reviewed to ensure appropriate support **Gloucester** • Extension of local ACHD nurse post for an additional 12 months with view to make permanent • Strong support from adult cardiology matron re ACHD service and the transition and transfer of patients from adults to paediatrics **Exeter & Barnstaple** • Business case being developed across both Royal Devon University Healthcare ACHD centres (Exeter & Barnstaple) – to include local ACHD nursing, wider workforce needs also being considered
2. Inadequate time in consultant job plans	• Letters to executive leads highlighting risks associated with inadequate job plan time on service delivery, ability to attend JCC, wider Network engagement	**Plymouth** • All PECs now job planned to attend recommended no. of JCC meetings annually • All PECs now allocated minimum 20% of total job plan for cardiology
3. Standalone workforce	• Letters to executive leads highlighting risks associated with standalone workforce impacting staff and service delivery	**Plymouth** • Acknowledged risk of standalone post in adult service – planning to appoint second cardiologist with interest in ACHD in Quarter 3/4 of 2025/2026 **Taunton** • ACHD service are actively reviewing succession planning for local CHD nurse

Key Findings, Actions and Progress Updates from Self Assessment Reviews:

Key Finding	Network Support	Centres' Progress Updates
4. No Network wide CHD database	• Limited by funding requirements, though closely following the progress in North Wales, North West England CHD Network who, following some regional commissioning funding, are due to launch an auto-populated Network wide database within 2025/26 • Supporting centres who have the capacity to set up a local CHD database with a standardised template	**Taunton adult service** • Maintaining local CHD database to support local service and provide lesion specific patient numbers and information
5. Limited JCC tracking of patients	• JCC improvement projects – supported reduction of the JCC waiting list and increased throughput of cases discussed reducing the need to track long waiting cases • Network wide JCC tracker template to be developed - based on a good working model between the Torbay paediatric service and Bristol Level 1 paediatric service	**All paediatric centres** • Individual patient outcome summaries of JCC discussion shared with level 3 centres
6. Inconsistent delivery of patient transition	• As inadequate nursing resource is a key factor in the inability to deliver quality, consistent transition care - letters to exec leads highlighting risks associated with inadequate nursing provision and advocating for investment prioritisation • Continuation of bi-annual Network led transition study days to support all Network teams in delivery of good transition care • Local CHD nurses to be supported by Network Lead Nurses to have transition conversations where formal clinic not in place • Advertising / signposting to external national and international CHD events focusing on transition	**Bristol Level 1 Services** • Plans to define & develop transition model with support from hospital wide transition nurse lead within paediatric service • Level 1 paediatrics CNS team considering a model for virtual transition clinics when CNS staffing levels allow • Network lead nurses to refresh Network transition protocol • Transfer of care service order process launched in March 2025 to avoid lost to follow up

Key developments and highlights 2024/25

Key Findings, Actions and Progress Updates from Self Assessment Reviews:

Key Finding	Network Support	Centres' Progress Updates
7. Limited / varying advice for pregnancy & contraception	• Network wide guideline drafted, approved, published & circulated • Network training sessions delivered / further available on pregnancy & contraception risk / advice	**Bristol paediatric service** • Considering a prompt on PAS to remind clinicians of the importance of delivering this advice (as appropriate)
8. Dental Access Challenges	• National access challenges limit support options however, Network Lead Nurse has worked with regional and specialist dental colleagues to develop a document clarifying the appropriate pathways for ACHD patients for both urgent assessment and for pre-surgery fitness checks. Pathway to be shared at Network Board & circulated • South West 'Managed clinical advisory group' for specialist care dentistry have a workplan item for 2025/26 for cardiac patients – Network team will provide updates on progress	**Truro & Somerset paediatric services** • Big Brush education project being delivered in both Truro and Taunton paediatric centre CHD clinics https://bigbrushclub.co.uk/
9. No cardiac rehab provision specific to ACHD patients	• Develop and ACHD cardiac rehab guide to support clinicians and services around rehab support for patients in the absence of commissioned rehab for CHD patients.	**Available for all Centres** • Bristol adults service launched a cardiac rehab webpage with generic content that is suitable for ACHD patients, includes exercise videos with safety instructions and monitoring guidance. Additional psychology information is currently being developed – links to webpages to be circulated and signposted from Network website.

Key developments and highlights 2024/25

Key Findings, Actions and Progress Updates from Self Assessment Reviews:

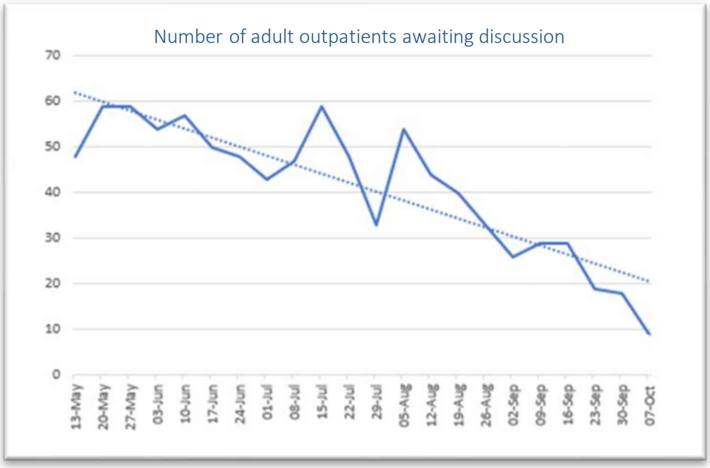
Key Finding	Network Support	Centres' Progress Updates
10a. Audit & Patient Feedback	• Network workplan item within 2025/26 to provide centres with a standard set of questions for collecting and analysing localised service feedback • Plan within 2025/26 for joined up audits across the Network	
10b. Training & Education	• Refreshed Network wide annual training plan circulated to all centres • Network training needs assessment to be produced within 2025/26 to ensure existing annual events and resource for delivery is best utilised to Network need	
10c. Palliative Care & Bereavement	• Ensure inclusion of palliative care education within Network owned training events • Network team to seek out and share education opportunities for Network stakeholders including training from paediatric and adult hospices • Network team to share template letters with regional clinicians for supporting families during bereavement	
10d. Ageing / Obsolete Echo Machines	• Letter to executive team at Royal Cornwall to flag the risk associated with the ageing echo machine within the paediatric service on service delivery	**Torbay Paediatric Service** • Secured funding for a new echo machine through a capital prioritisation process bid – machine now in use within the service

2. Joint Cardiac Conference Improvement Projects – for both adult and paediatric CHD services

Work took place to identify and implement learning opportunities to improve throughput and management of the Adult Joint Cardiac Conference (JCC) following the launch of the Network-led scoping survey at the end of 2023/24.

A 'Findings and Recommendations' report was produced in relation to improvement opportunities for the Adult JCC meeting following the scoping survey which was shared with JCC members across the region. The Network team and the Bristol Heart Institute ACHD Leads met to discuss the findings, and many recommendations have now been implemented.

A revised terms of reference for the ACHD JCC has been published. Significant improvement to performance has already been identified since changes were made in both the numbers of cases being reviewed and the reduction of the Adult JCC waiting list (reduced by 87% in 4 months!). The average number of patients discussed per week increased from 9 to 13. Patients are now discussed mostly in real time though occasionally there is a one-to-two-week delay for the relevant clinicians to be present.

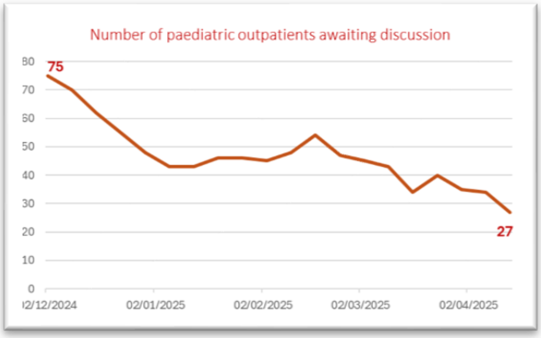


"Everyone seems to be at a better mood as they feel that things are working well"

"The team is more focused as the pace of the meeting is faster"

There has been excellent engagement and much positive feedback. The post project survey showed that 100% of stakeholders felt that the meeting had improved. They noticed that the meeting was "safer", "more streamlined", "more organised", and "more efficient"; also, that both the cases and imaging were presented more quickly. Dr Radwa Bedair now conducts a mini-MDT when needed for simple interventional cases and the JCC coordinator is present in the meeting. As well as being more efficient, members noted that it is easier to remember the cases as they are discussed so quickly after listing and they have fewer patient queries, which are inevitably generated when there is a backlog.

Following the success of this project, consideration was given as to how this can be used to improve the paediatric JCC. Using the ACHD JCC terms of reference, the paediatric JCC members have already reduced their waiting list whilst planning formal management and leadership of the JCC through job planning.



3. Transfer of care and lost to follow-up between paediatric and adult services

Ensuring safe transfer of care of patients from paediatric to adult cardiac services has been one of the Network team's priorities. Clinicians have presented lost to follow-up audits in both the South West of England and South Wales showing that between 7 and 15% of all patients are lost to follow-up during transfer.

Transferring care in South West England typically involves the paediatric cardiologist (or PEC) writing a letter to a cardiologist in adult services at the time of the last paediatric appointment. In Wales, a similar pathway is followed, although joint clinics with adult and paediatric cardiologists are carried out for the patient's last paediatric appointment to reinforce the process for both the adult clinician and patient and their family. Lost to follow-up levels are significantly lower in Wales.

Most Network members feel that an electronic system of transfer is the safest and most suitable for auditing and governance. Bristol adult and paediatric network members (Dr Victoria North, Dr Sri Narayan and Dr Catherine Armstrong) worked with our IT services to produce an electronic transfer pathway for Level 1 in Bristol. This is now active. Plans for a similar system in Wales and our Level 3 centres are under discussion but will most likely involve single point of referral. The project will continue into 2025/26 as IT systems become more streamlined throughout South West England. The aim will be to define a safe electronic transfer method for all regions in the Network, with standard operating procedures (SOPs) detailing how the pathway works.

4. Delayed transfers of care between paediatric centres – Bristol & Cardiff

This Network led project was launched in 2023/2024 in response to concerns raised by the NHS Wales joint commissioning committee regarding flow between Cardiff and Bristol. Where delays in transfer occur, patient flow within the centres is compromised directly impacting patient care.

The project aimed to support the centres to investigate the barriers to the seamless delivery of care with an initial task of setting up a process for auditing delayed patient transfers between the Level 1 (Bristol) and Level 2 (Cardiff) specialist centres. This data, which was captured as each delay occurred, allowed the project team to understand the scale of delays, barriers to transfer and consider mitigating actions to reduce delays in transferring patients. The project team met on a quarterly basis to review the ongoing audit data.

The data supported that most patient transfer delays (88%) were occurring from Dolphin ward (Bristol) to Pelican Ward (Cardiff). The typical delay was 3-4 days, minimising flow between PICU and Dolphin, impacting on the paediatric surgical programme at Bristol. The delays were mainly related to access to beds, with medical patients often occupying bed capacity on Pelican ward intended for cardiac patients. This led to an investigation into the commissioned bed numbers and use of these beds.

As the project developed, improved processes were established in Cardiff resulting in greater recognition within the Pelican ward and medical teams for prioritising cardiac patients and where possible to pro-actively identify capacity for patients once a date for transfer was planned. As a result of the project a clear escalation process was established involving the patient flow teams at both centres as key points of contact.

As of March 2025, a decision was made to stand down the project. Some delays between the centres continue to occur but the position has improved from the project infancy with an effective escalation process now in place to support teams in resolving any blockages quickly. The position will be re-visited with the project team across both centres in mid 25/26 to consider whether the improvements have been sustained, and the escalation process remains effective.

Delivering Clinical Care across the Network

New Clinical Guidelines released/refreshed in 2024/25:

New clinical guideline for pregnancy and contraception in patients with CHD for Paediatric Cardiologists and Paediatricians with Expertise in Cardiology

This new clinical guideline was created by Dr Stephanie Curtis, ACHD Consultant Cardiologist, and Dr Idoia Grange, Consultant Cardiologist at University Hospitals Bristol and Weston. This was in response to requests across the region, mainly from Consultant Paediatricians with Expertise in Cardiology, via the South West England Level 3 self-assessment reviews held during 2024, and very well-received talks on this topic by Dr Curtis at the South West Cardiology Education Forum (Exeter, September 2024) and the Network Transition Study Morning (2024). The new guideline was finalised and signed off at the Network Governance meeting in November 2024 and is available on our Network website and on the MyStaff document management system for healthcare professionals: https://uhbw.mystaffapp.org/28022/document_view.pdf

New clinical guideline for the management of chronic thoracic aortic disease in adults

This new clinical guideline was created by Dr Stephanie Curtis, Dr Sharareh Vahabi, Dr Mandie Towsend, Consultant Cardiologists and Mr Cha Rajakaruna, Consultant Cardiac Surgeon at University Hospitals Bristol and Weston (UHBW), in response to lack of clarity around the frequency of imaging surveillance for individuals with hereditary thoracic aortopathy (such as Marfan Syndrome and Loeys-Dietz syndrome). The best pathway of care required clarification with the rapid accessibility and streamlining of genetic testing within routine clinical care. Additionally, there have been multiple international guidelines over the last 5 years, which has led to some confusion. The guideline was created in conjunction with a new “remedy” guideline for general practitioners in the Bristol and North Somerset CCG to indicate when to refer to cardiology in patients with aortic disease. The guideline was finalised in November 2024 and signed off at the UHBW Clinical Governance meeting in January 2025. It is available on our Network website and on the MyStaff document management system for healthcare professionals: https://uhbw.mystaffapp.org/28079/document_view.pdf

Updated clinical guideline for subaortic stenosis (operated and unoperated)

This ACHD guideline was updated in February 2025 and is available on our Network website and on the MyStaff document management system for healthcare professionals: https://uhbw.mystaffapp.org/15931/document_view.pdf

New medication guideline for children with cardiac or suspected cardiac disease

Prescribing ADHD medication in children with cardiac or suspected cardiac disease guidelines is an area which can be unclear and time consuming for those needing to prescribe these drugs as they need to seek cardiology advice. Dr Gali Kolt presented new guidelines on prescribing these drugs for children under the care of cardiology to the CHD Network Clinical Governance Group in April 2024. They will be available on MyStaff.

ACHD dental pathways **review**

Work has progressed to refresh and clarify the Network dental pathways for ACHD patients, including patients requiring pre-operative surgical or intervention assessment or urgent assessment. This outlines the local support for Level 3 centres for both adult and paediatric patients. This is due to be approved at the Bristol Heart Institute clinical governance meeting in May 2025.

Delivering clinical care across the Network

Communications

Communications project group

This Network-led project group was set up to identify gaps in safely of patient information from Level 1 to Level 2 and Level 3 centres and to improve the communication of patient events between the centres. The adult CHD project is now complete with good feedback. This involved secretarial, JCC coordinator, and management training about the importance of communication between the centres and the fact that the Level 1 centre does not work in isolation. The clinical nurse specialists now liaise with Level 2 and Level 3 colleagues regarding in-patients stays. Enhanced attendance at JCC from Level 3 ACHD colleagues, along with improved deficiency of the JCC, has improved engagement with patients on the surgical and interventional pathways.

The paediatric CHD project is almost complete with some work still to be done on discharge summaries from the paediatric Level 1 centre.

Learning disabilities and autism team contacts

Some patients born with congenital heart disease will also have a learning disability which may be or may not be associated with a syndrome. Most of these patients will require lifelong follow up.

The patient’s clinical pathway will consist of regular outpatient visits, transfer to adult services at age 16 to 19 years, and may involve cardiac surgery or intervention. These patients will require individual support which may involve facilitating attendance and a mental capacity assessment.

As our CHD Network covers a large geographical area, it is key to have the involvement of the patients’ local learning disability or autism team as they may know the patient and family well. With the help of the Learning Disability and Autism team at University Hospitals Bristol and Weston (UHBW) a directory was produced with details of all local teams in South Wales and the South West of England, which will improve the communications between teams when caring for these patients.

The patient and family voice – at the heart of everything we do

Patient and family representative roles and engagement

In the CHD Network, we are well supported by an enthusiastic group of patients and family representatives, and there are various meetings and key projects which they are involved in. They are represented in our regular Board meetings and present an update on their recent activity. They are involved in small task and finish groups and are invited to comment on and contribute to website updates and policy documents prior to sign off.

There are currently ten representatives in the team, and we are seeking to recruit further representatives to broaden the range of experience within the group. The application process involves a telephone discussion.

Our job description and application form have recently been updated by the Lead Nurses and circulated to clinical teams to promote the role and encourage applications.

Education and Training 2024/25

A core objective of the Network is to support and promote training and education opportunities for our healthcare professionals across the region. Here are a few highlights:

ACHD ECHO Webinar series 2024/25

Transition regional training programme (June '24 and December '24)

Annual Adult CHD Study Day with over 90 delegates

Clinical Nurse Specialist Away Day (Cardiff, January '25)

Paediatric Cardiology Education Forums (June '24 & September '24)

Bi-monthly cardiac nurse sessions

Fetal cardiology study day (January '25)

Psychology Study Day (June '24) & 'Tea and Talk' webinar series 2024/25

Monthly bitesize "Lesion of the month" for nurses

Network wide annual mortality and morbidity session (over 30 attendees)

FutureNHS

Further expanded the Network healthcare professional education resource platform with 36 new webinars

203 Network Members accessing Network training on our Futures platform

"It will enhance the support I can give to my patients through greater understanding of their perspective and feeling supported."
(ACHD study day, 2024)

"An excellent event with well thought out programme and engaging speakers. Great to see the engagement from teams across the Network with lots of different roles represented. Clearly a valuable educational & training event for many."
(ACHD study day, 2024)

"This was a fantastic event. Thank you. I really benefitted from all the presentations and learned a lot that could be directly applied in my role. I also really enjoyed linking in with other psychologists working in cardiology."
(psychology study day, 2024)

"More confident in the reasons and rationale of referring these complex issues to tertiary centres."
(PEC forum, 2024)

What changes will you make to your practice following this study day?

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

Health Care Scientists

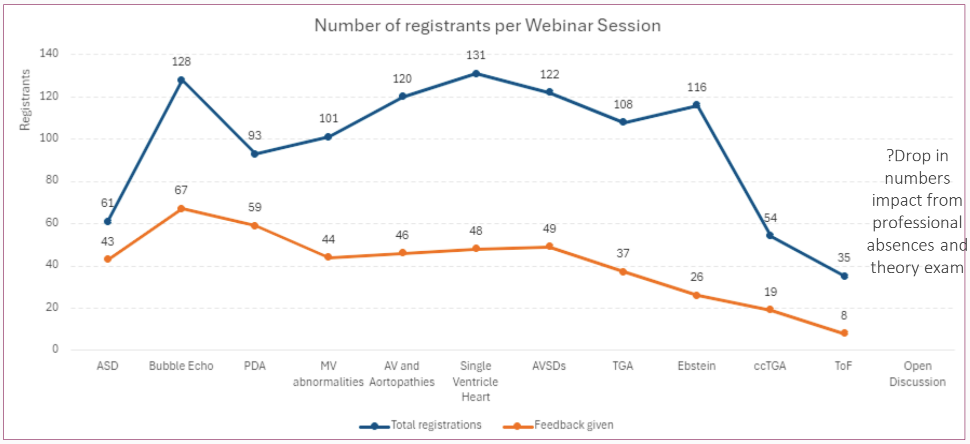
Gui Rego, Lead Healthcare Scientist in ACHD Echocardiography, Bristol Heart Institute

Over the past year, the department has made significant strides in professional development and training to enhance the skills and knowledge of the health care scientists. To better understand the team's needs, a departmental professional development survey was conducted, which directly contributed to the creation of targeted training programs. This approach allowed for professional development opportunities tailored to the unique needs of the team, ensuring continued growth and success.

A notable achievement was the development of the ACHD Training Plan, in collaboration with the Bristol Royal Hospital for Children, which was published on the British Society of Echocardiography (BSE) website. This structured training pathway was designed for professionals pursuing the CHD Echocardiography program at the Bristol Heart Institute but recently made available to all professionals with access to BSE data. The training plan outlines a progression from basic to specialized skills in CHD echocardiography, focusing on imaging techniques, reporting practices, and patient communication, particularly for those with learning disabilities or paediatric patients.

In addition to hands-on training, the team also engaged in theory-based learning, supported by the department’s CHD Echo Theory Guide. This year, one team member successfully passed the theory section of the EACVI CHD exam and is now completing the practical component, while two others are progressing through the theory section.

2024/25 saw the launch of the South Wales and South West ACHD Echo Webinars, offering monthly talks aligned with the accreditation syllabus. The webinars garnered 1,069 registrations with an average of 97 participants per session. Feedback was overwhelmingly positive, with the webinars receiving ratings of 4.89/5, and speakers earning a 4.9/5 rating. Based on this success, the plan is to continue the webinars and expand the program to offer practical and theoretical training opportunities to professionals from other centres in the region.



?Drop in numbers impact from professional absences and theory exam

> *“These sessions are exceptional. Thank you very much for your time setting everything up and presenting it to all of us”*
> Webinar delegate

Paediatric Congenital Cardiology Service – 2024/25 Update

Daniel Meiring, Head Cardiac Physiologist, & Owen Burgess, Deputy Head Cardiac Physiologist, Bristol Royal Hospital for Children

Our tertiary paediatric congenital cardiology service continues to provide specialist care across all cardiac physiology modalities for children and young people across the Southwest. This year saw the first UK implantation of an EV-ICD device in a paediatric patient—a significant advancement that offers safer, smoother implantation and broader therapeutic options compared to conventional leadless ICD technologies.

Furthermore, the size of the hardware that is being implanted is significantly smaller which is ideally suited to the paediatric population. This milestone reflects the team's strong engagement with emerging technologies and commitment to advancing care. Our pacemaker service also continues to move towards a paperless workflow, with digital systems starting to be integrated into much of our device follow-up and reporting.

The congenital catheter lab remains at the forefront of innovation, with several novel interventional procedures performed this year, tailored specifically for the paediatric population. However, sourcing appropriately sized consumables and equipment remains an ongoing challenge, requiring complex coordination and creative problem-solving by the team.

Workforce development is a major focus. Despite the absence of formal training pathways in paediatric cardiology for cardiac physiologists, we have successfully adapted adult educational frameworks to meet paediatric needs, creating local routes into specialist roles. In collaboration with our Level 1 adult cardiology centre, we are currently supporting an echocardiographer trainee, two PhD students, and a cohort of Level 2 and Level 3 apprentices. We have also celebrated the recent successes of an MSc candidate who successfully completed their training pathway and has successfully joined our substantive workforce.

Our regional congenital echocardiography training programme - designed to upskill regional sonographers in paediatric imaging - continues to grow, having recently received national recognition for its impact and innovation. This work has now been rolled out nationally and we are excited to see the impact that this can bring to the wider workforce.

This year we launched our **Cardiac Champions** programme, which aims to improve antenatal detection of congenital heart disease by training designated leads in all fetal sonography services across the South West of England. Early feedback has been overwhelmingly positive, and we expect this initiative to further strengthen early diagnosis and streamline referral pathways in the coming year. Find out more on page 23.

Looking ahead, we are focused on deepening regional collaboration, improving digital integration across services, and securing sustainable pathways for the next generation of paediatric cardiac physiologists.

Fetal Cardiology Update

Cardiac Champion Project

Angie Smith, Lead Fetal Cardiac and Midwife Sonographer, University Hospitals Bristol and Weston
Grace Warren, Network Lead Midwife and Manager, Fetal Medicine Network

Project Aim: Improve the antenatal detection rate of Congenital heart defect within the South West England region

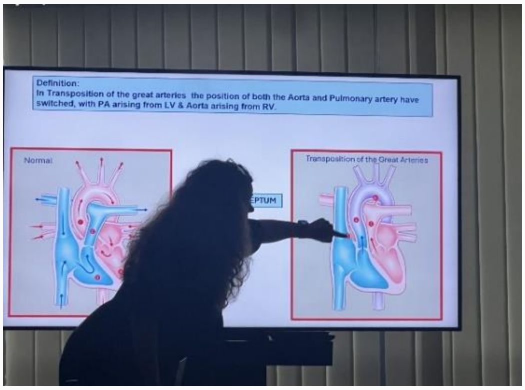
The role of the obstetric sonographer is a vital part of the antenatal patient pathway in terms of early detection of babies being diagnosed with congenital heart disease. The team in the specialist centre (Bristol) were keen to improve their support offer to obstetric sonographers across the South West. The Cardiac Champions pilot project was launched in February 2025 with the first face to face training date and will run for a year.

Each referring centre in SW England has nominated an experienced obstetric sonographer with a particular interest in scanning the fetal heart, These sonographers will become 'cardiac champions' within their local centres; a sonographer that is keen to actively encourage, support and motivate their peers and is dedicated to improving practice and antenatal detection rates of congenital heart defects.

Throughout the year the specialist fetal cardiology team will facilitate three theoretical group study sessions and two practical sessions for the Cardiac Champions which will run alongside the pre-existing monthly online case review sessions (running since July 2023) as well as ongoing support throughout the year.

The cardiac champions pilot offers an exciting opportunity for greater support and training for sonographers screening the fetal heart as part of the fetal anomaly screening programme (FASP) 18+0 - 20+6-week Physical examination within the South West England region. Benefits will include improved network links between centres, opportunities to share best practice and work together to tackle the regional variation of antenatal detection rates in order that overall detection rates of CHD improves.

So far, nine cardiac champions have now attended hands on training sessions! There has been excellent feedback, and the project team are incredibly passionate about the project knowing what a difference it will make to patients, staff and services moving forward.


Definition:
In Transposition of the great arteries the position of both the Aorta and Pulmonary artery have switched, with PA arising from LV & Aorta arising from RV.

Allied Health Professionals

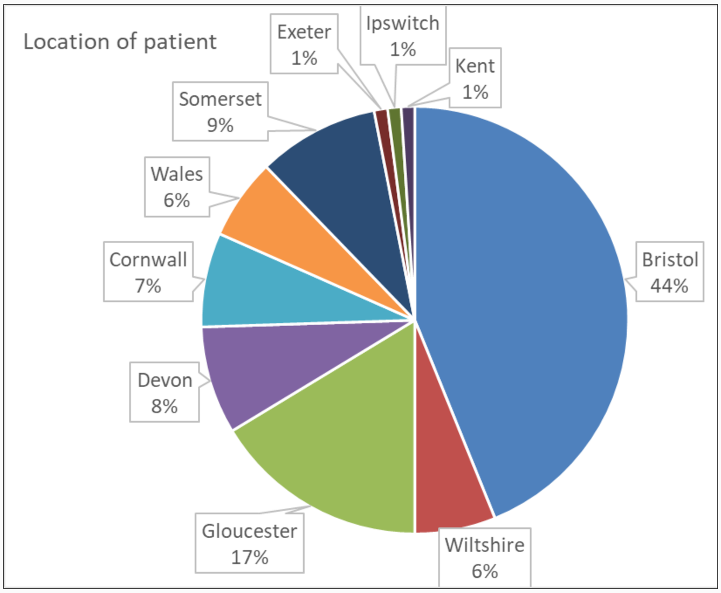
Psychology

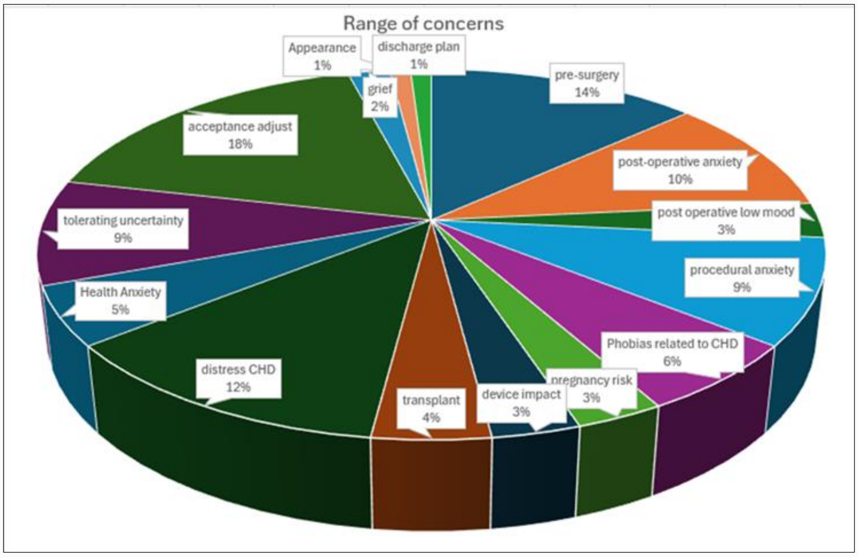
Pauline Aiston, Clinical Psychologist, University Hospitals Bristol and Weston

The ACHD Psychology service offers input to patients on an outpatient and in-patient basis. Over the past financial year, the service has seen 98 New referrals (79 outpatients and 19 inpatients were seen; females = 51, males = 47). The age of patients seen in the service, is most commonly when patients are in their 30's and 40's, with a clear need to continue engagement attempts for young adults. Data analysis suggests under representation from racially minoritised groups, neurodiverse individuals and people with learning disabilities. As patients are registered with Bristol but can live across the South West of England and South Wales, we have analysed the referrals by geographical location (which also show 3 out of area locations, which were inpatients).

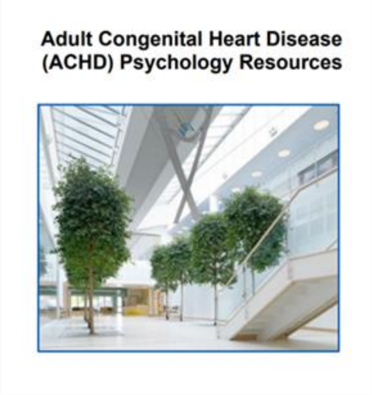
Analysis indicates that further on-going work may be needed to increase access to specialist ACHD Psychology services.

Due to the time sensitive nature of surgery, procedures, and high-risk pregnancy; these pathways are being trialled as having priority over and above acceptance and adjustment pathways. Due to the psychological impact of possible referral for transplant. Patients being considered for transplant are also prioritised.





The types of psychological concerns that patients hold regarding their ACHD are presented in the graph (left):


Adult Congenital Heart Disease (ACHD) Psychology Resources

Psychology (continued)

Book club for patients with ACHD

Over the past year, the service continued to deliver the ‘Healing Hearts and Mind’ (Livecchi & Morton, 2022) online group programme for ACHD patients wishing to connect and learn skills for living alongside their condition.

Transplant association

The ACHD Psychology service were also delighted to receive generous funding from the transplant association charity, which has meant for one-day a week, the service has an assistant psychologist, to look at the lived experience of those CHD patients who are being considered for transplant.

Ongoing engagement

In collaboration with the ACHD Youth Worker and the Arts and Culture team, we continue to work towards engaging our young people. We are also engaging with the Trusts learning disability and neurodiversity team.

Pharmacy

Susie Gage, Team Pharmacy Lead for PICU, Paediatric Cardiac & Paediatric Surgery, Bristol Royal Hospital for Children

Susie Gage is chair of a paediatric cardiac pharmacist group nationally and has recently led projects on co-ordinating and developing more national medicines for children leaflets such as digoxin, rivaroxaban for Fontan and propranolol for Tetralogy of Fallot.

She has co-ordinated an (extracorporal membrane oxygenation) ECMO Pharmacists national meeting and plans to develop training and competencies for Pharmacists nationally.

Susie is a clinical member of the national Clinical Reference Group for CHD in NHSE, looking at workforce and retention, making links with lead nurses and other lead AHP professions, to continue to try to be recognised in the CHD pathway and promote better patient care and quality improvement initiatives.

A pharmacy poster was presented at the British Congenital Cardiac Association (BCCA) conference in Dublin on the use of Rivaroxaban in paediatric Fontan patients, It highlighted how advances in patient pathways can be shared to improve patient experience.

Research Update

Our Network Research Lead is Dr Giovanni Biglino, who is an Associate Professor in Bioengineering by background.

The Network remains active in its research activities. A research forum was established (June 2024) and sessions covered a range of topics over the last year, from exercise and single ventricle physiology to patient's feedback on the Network's website. This forum is an opportunity to learn, exchange research ideas and for researchers to receive feedback from the Network. The forums have been attended by healthcare professionals, students, and patient representatives across the region.

#1 - June 2024 - Overview presentation on the national research strategy, presented by Dr Giovanni Biglino

#2 – August 2024 – Reviewing CHD Network website research pages, presented by Emily (Patient Representative)

#3 – September 2024 - New ideas around stenting aortic coarctation, presented by Yi Huang (PhD student at the Bristol Medical School)

#4 - November 2024 - Exploring research in single ventricle patients, presented by Jack Gibb (Trainee Cardiologist and PhD student)

#5 - January 2025 - Modelling the aorta in patients with hypoplastic left heart syndrome, presented by Yousef Aljassam (PhD student)

#6 – March 2025 - Understanding exercise physiology and health using cardiac ultrasound - presented by Dr Dan-Mihai Dorobantu, Senior Clinical Fellow in CHD at BHI and post-doctor research fellow, University of Exeter

Gareth Strange, patient representative: *"I'm loving the research calls (forums) that I've managed to get to. I'm really glad that patients are getting to be part of that. We may not have many questions, but we have been able to give feedback on presentations and I've been sharing the technologies mentioned with the wider (patient rep) group."*

The Network engages patient representative across different activities, e.g. a patient intern worked with the Network's Research Lead over summer 2024 and a patient will now join researchers from the University of Bristol as a co-applicant on a £1.2M grant (EPSRC) exploring novel 3D printing of stents for CHD patients.

The University of Bristol remains a centre for CHD research and a proposal for a national doctoral training centre exclusively centred around CHD is currently being planned across UCL, Bristol, Manchester and King's College London, applying for a new BHF-funded 4-year PhD programme. This would support tens of PhD students researching CHD topics, representing an invaluable opportunity to advance CHD research.

Researchers in the Network also remain involved in the implementation of the national strategy, emerged on the back of the James Lind Alliance CHD Priority Setting Partnership. Research is showcased and shared through public engagement activities, notably the first edition of the Bristol Heart Festival (March 2025), attended by hundreds of secondary school students and members of the public; the Festival included CPR training, heart dissections, presentation of 3D models, real-time scanning, public talks (including a patient panel) and the screening of a documentary realised by a CHD patient advocate ("Six Times Open") at the Watershed Cinema in Bristol.

Quality Improvement & Audit Programme

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

Dr Helen Wallis and the team have been impressed with the quality of the audits and quality improvement (QI) projects presented over the past twelve months (listed below) and continue to encourage Network professionals to share projects nearing completion.

The audit programme aims to improve patient outcomes and focus on high quality care by identifying and understanding varying practice across the Network, using audit to ensure safety and quality and implementing learning and action. The programme also encourages re-audits to measure effective change.

April 2024

- Audit of patient transfer from paediatric to adult CHD clinic (lost to follow up) – presented by Dr Efstathios Magkiosis, ACHD Fellow at Bristol Heart Institute.
- Re-audit of compliance with dental pathway for children referred for cardiac surgery in Bristol – presented by Zoe Jordan, Paediatric Clinical Nurse Specialist, Bristol Royal Hospital for Children.
- Sinus Venosus Atrial Septal Defect (SVASD) – presented by Dr Radwa Bedair, ACHD Consultant Cardiologist, Bristol Heart Institute

November 2024

- Physiologist-led murmur clinic to reduce the waiting time for heart murmur assessment – presented by Carys Newey (Williams), Paediatric Echocardiographer, Swansea Bay
- Audit of Cardiology Follow-up for Children with Duchenne Muscular Dystrophy (DMD) – presented by Dr Mohammed Elzoghby, St3 Paediatrics, Swansea with the support of supervisor Dr Ankita Jain, Paediatrics Consultant with cardiology interest

The plan for next year is for delivery of collaborative Network wide auditing. The aim is to launch two Network-Wide audit projects within 2025/26, one for paediatric cardiology and one for ACHD.

National Cardiac Programme Report 2023/24 (published March 2025) – Level 1 Activity

Olga White, Level 1 (Bristol) Clinical Data Manager, UHBW Congenital Cardiac Services

Please note the most recently published data covers the period 1st April 2023 – 31st March 2024. Overall, Bristol activity trends are similar to the national trends, though Bristol showed a slightly better recovery of surgical activity in 2023/24 and a more pronounced increase in catheter interventions compared to the national trends. There was a 4% increase in national activity in 2023/24 though a 15% increase in Bristol. Similar activity trends were observed within 2024/25 with additional growth in surgical activity in Bristol though national activity figures are yet to be finalised.

The CHD clinical data team working in the Bristol specialist centres achieved the highest data quality index result in the country at a 99.75% accuracy level whilst being one of a few centres nationally to meet the new data upload to NICOR target of two weeks post procedure.

Communication and Engagement

The Network acts as a central point of communication and information for stakeholders. With well-established communication channels, we have been able to support our members and wider teams. A popular publication is the Network newsletters, published twice a year with excellent feedback from patients and staff.

South Wales and South West Congenital Heart Disease Network

New Year 2025
Issue 16

Newsletter

Updates from your CHD Network

Inside this edition

Work with local and national charity partners

The CHD Network has continued to engage with local and national cardiac charities.

Local charities	Heart Heroes
	Youth@Heart @Somerville Foundation
National charities	Little Hearts Matter
	Children's Hearts UK
	Somerville Heart Foundation
	British Heart Foundation

Little Hearts Matter

The Network team and some of the adult congenital heart disease clinical nurse specialists (ACHD CNS) attended an engagement event for health care professionals, focusing on the care of single ventricle adults (SVA), in Birmingham, hosted by Little Hearts Matter. There were over 100 delegates from across the country who are all involved in the care of adult patients with single ventricle.

HEART HEROES

Heart Heroes, our local charity, continues to support children and families affected by heart conditions through a range of vital services. Our Family Support Worker, Nicola, provides weekly on-ward support to families on Dolphin Ward and PICU (at the Bristol Royal Hospital for Children).

Beyond the wards, the Heart Heroes charity have regional hubs across the region and beyond enabling families to connect with other heart families outside of the hospital environment. In Gloucester, Bristol and South Wales, the charity also run the 'I Can' programme which enables Heart children and their siblings to attend inclusive monthly activity sessions which sees children focus on what they can do rather than what they can't. Play therapy and mental health support are also key focus's to help our heart families.

CHILDREN'S HEARTS UK

The Children's Hearts UK (previously Children's Heart Federation) is currently working with us to provide Virtual Reality Headsets for children in Bristol Royal Hospital For Children to help children prepare for cardiac surgery and support their recovery.

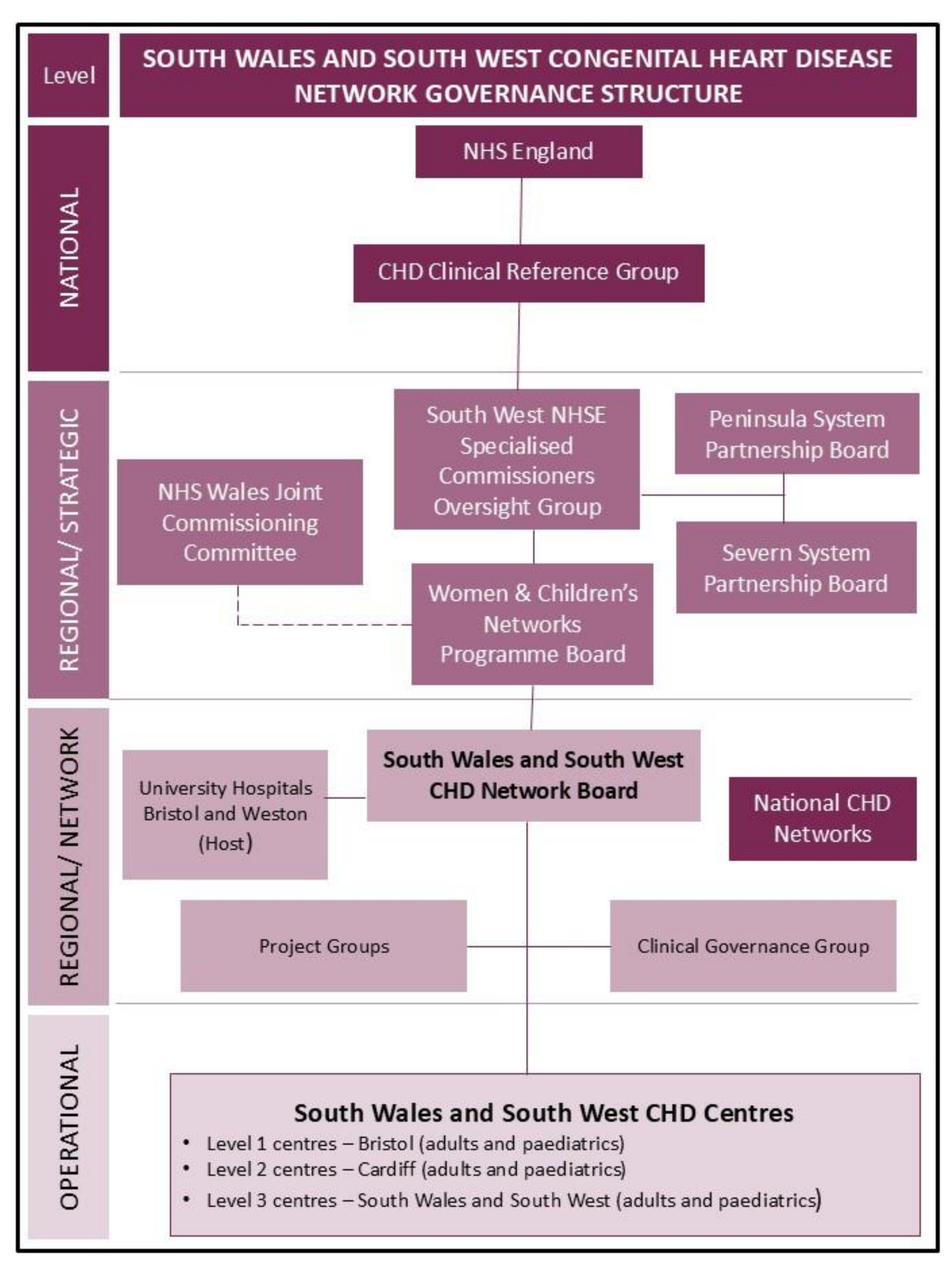
Somerville Heart Foundation with Youth at Heart

Our local charity Youth@Heart which supports young people, age 13years to 25years has merged with the national charity The Somerville Heart Foundation. The role of the youth worker in the Bristol Heart Institute and Bristol Royal Hospital for Children will continue to be based in the South West and South Wales in the immediate future and will gradually contribute to The Somerville Heart Foundations national youth work programme.

The annual Somerville Heart Conference was held in Bristol May 11th 2024. The Bristol ACHD team was involved in the organisation and presented several sessions. The conference was attended by approximately 75 delegates from across the country. The patient group enjoyed the opportunity to hear the presentations and meet other patients.

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:



Risks, issues and challenges

The Network team maintain an issue log for any high priority concerns we are made aware of, which may lead to a further risk for patients and / or workforce, issues that may lead to non-compliance of national CHD standards and / or cause a poorer outcome in patients. Assurance data is collected quarterly to support with the identification of issues impacting on performance. Incidents may be escalated to the Network for discussion at the six-monthly Clinical Governance meetings or quarterly Network Board. The Core Network team work collaboratively with centres to consider how any issues can be mitigated and resolved.

The highest priority issue within the Network at the start of 2024/25 was related to the timely delivery of paediatric cardiac surgery at the Level 1 specialist centre (Bristol). Progress has been made by the Bristol team / BRHC through the year in relation to the challenges causing delays to the paediatric cardiac surgery programme. As at Q4 2024/25, the waiting list for surgery was down to the lowest point in three years. Regular Network & Service Tri to Tri meetings continue to understand where L1 work is focused to mitigate concerns and how the Network can best support.

Issues / Challenge	**Mitigating action**
Paediatric patients across the network are experiencing delays in delivery of their planned cardiac surgery. This is adversely impacting patients clinically and psychologically.	1. Investment in nursing staffing meaning higher occupancy and fewer cancellations due to PICU beds 2. Few cancellations through better utilisation following the ‘automatic go’ process. 3. Fewer cancellations through improved theatre staffing and escalation processes

Moving into 2025/26, work is planned to update Network governance arrangements including the issue and incident management policy to best support management of risk whilst aligning with regional NHSE processes, PSIRF and ensure Network wide learning from patient safety incidents.

Financial Report

The SWSW CHD Network is funded by NHS England and was allocated an annual budget of £213,278 in 2024/25, after overhead contributions were made to University Hospitals Bristol and Weston NHS Trust as the host organisation. The end of year statement is shown below. The variance (underspend) was mainly due to lead nurse staffing gaps at the beginning of the year. As the SW England self assessment reviews with each of the centres were held virtually (online), travel costs within this financial year were minimal.

Network funding		**2024/25**		
		Budget	**Expenditure**	**Variance**
Pay	Total	£ 204,339	£ 199,862	£ 4,477
Non-Pay*	Total	£ 8, 939	£ 7,387	£ 1,552
Total		£ 213,278	£ 207,249	£ 6,029

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

Our focus for 2025/26

The Network team produce an annual workplan document to capture projects and workstreams that are prioritised for the year ahead. For 2025/26 the workplan includes a continuation of ongoing projects, recommendations and areas of focus from the 2024/25 self assessments plus other key priorities as identified by Network stakeholders. The Network's workplan priorities for 2025/26 are described in the table below. This work will be delivered alongside our core 'business as usual' activities, such as education, engagement and communication.

Health Inequalities, Patient/Carer Experience
• Work with Level 3 Centres to use patient experience feedback to improve their services • Recruit additional reps, with a focus on lived experience and learning disability, to improve the experience for this group of patients when accessing CHD services • Develop the role of patient/carer reps so they can advocate for the population they represent when improving or transforming CHD services
Model of Care
• Transition – Evaluation of transition pilot in Level 3 centres and progress to implementation of young persons clinics; Ensure focus is maintained on transition education & training for network clinicians • Transfer of Care - Identify patients lost to follow up between paediatric and adult care; investigate causes and ensure adequate transfer of care to improve safety and reduce unnecessary medical follow-up • Cardiac Rehab – Produce an ACHD cardiac rehab guide to support clinicians with rehabilitation support for patients, in the absence of a commissioned service • Palliative Care & Bereavement – Focus on palliative, end of life and bereavement care for education & training events in 2025/26 including the development of supporting information pack for L3 centres to use
Transformation, Quality Improvement, Unwarranted Variation
• Improve the effectiveness of the Paediatric Joint Cardiac Conference and reduce waiting time for discussion • Develop a network wide template for Level 3 Paediatric centres to track the outcome of agreed treatment plans for patients referred to the Joint Cardiac Conference • Work in partnership with the fetal medicine Network to improve antenatal detection rates across South West England through the development of cardiac champion roles in each local centre

Our focus for 2025/26… continued

Governance & Guidelines

- Guidelines - Identify risks related to an absence of guidelines in the care of adult and paediatric patients and develop guidelines to support mitigation of these risks and reduce variation in practice
- Service Review –Complete self assessment reviews against National CHD Standards for Level 1 (Bristol) Level 2 (Cardiff) Adult & Paediatric Services
- Update Network governance arrangements to best support management of risk and patient safety incidents while ensuring learning from CHD related patient safety events
- Research – Identify opportunities for cross Network research projects aligned to James Lind Alliance (JLA) national priorities

Nursing & Medical Workforce

- Identify gaps in CHD nursing across the region, where the service spec isn't being met, and inform Provider executives of the risks of not recruiting to these posts
- Develop resource materials to support centres to develop their CHD nurse role
- Provide a mentoring & support framework for CHD nursing
- Drive Level 3 centres to achieve the minimum standards of CHD resource within job plans with a focus on service delivery, CPD & Network engagement

Training and Education

- Develop a longer-term strategy for CHD Care across the Network. Initially with L1&2 stakeholders via a face-to-face event
- Complete a training needs analysis for the Network to support the delivery of an education & training plan
- Deliver an ACHD Medical Study Day (April 2025)
- Deliver a Network Education & Training Plan which includes a focus on AHP roles

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.