



South Wales and South West
**Congenital Heart
Disease Network**

South Wales and South West Congenital Heart Disease Operational Delivery Network

Annual Report 2023/2024



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Foreword

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



Welcome to our Network Annual Report for 2022/23. There is a lot to digest in this year's report and a lot to be inspired by. Although the British Congenital Cardiac Association (BCCA) conference was only halfway through the financial year, it seems a very long time ago and much has been achieved since then. We have had to say goodbye to colleagues in the Network team and around the region who moved on and welcomed new colleagues.

With the NHS being so financially challenged in recent years, we continue to ensure that we provide high quality and safe healthcare across all our 21 services in 14 NHS Trusts and Health Boards. Key to this is evolving care models, such as cardiac physiology and nurse-led clinics for simple lesions. Whilst there is an initial outlay for these models, they enable low risk patients to be seen more quickly and effectively, as well as saving consultant time and therefore costs. Setting up these clinics and pathways involves a significant personal commitment and investment of time, and I commend Dan Meiring and Owen Burgess for pioneering this work in our region.

Improving image sharing across the Network was one of our key projects in 2023/24 and, despite the significant IT challenges in the NHS, links were made with Wales and Bath, and Exeter's imaging system was made safe. Being able to store images robustly and access and transfer images rapidly across Trusts and Health Boards is not only crucial for patient care but essential for good governance.

The integration of psychology into healthcare has been gradual and very welcome. Our patients, more than most, face many hurdles throughout their lifetimes, and I am very pleased to see our psychology teams growing and able to support more patients and their families across the Network. We have one of the strongest patient representative relationships, which is vital to our work.

On the operational side, we were gratified that NHS Wales formally adopted the NHSE CHD Standards after their self-assessment reviews and even more gratified that they found the process helpful and engaged so much with it. We have also made great progress with the delayed transfers project, allowing us to examine in detail the reasons for delays from our children's cardiac centre and protecting our commissioned bed base in Cardiff to ensure maximum efficiency in the use of our precious children's cardiac beds.

Our education programme, run by our Lead Nurses, is one of our Network's strengths. The numbers attending and the feedback from these study days always astounds me. Congenital cardiology is endlessly fascinating and challenging, and as many more staff become trained, I am confident that our patients will receive excellent care by dedicated staff for many years to come!

About Us

Background

The South Wales and South West 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 Welsh Health Specialised Services Committee (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.



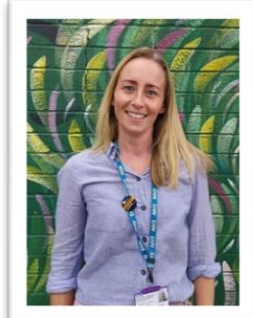
Meet the Core Network Team (2023/24)



Dirk Wilson
Network Board Chair
(until February 2024)



Louise Hudson
Network Manager
(until October 2023)



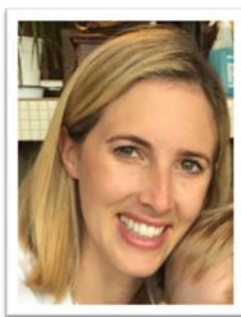
Michelle Jarvis
Network Manager
(from November 2023)



Steph Curtis
Clinical Director



Sheena Vernon
Lead Nurse



Jess Hughes
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 ensure it can demonstrate the value of the Network and its activities



To support the delivery of equitable, timely access for patients



To support improvements in patient and family experience



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



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



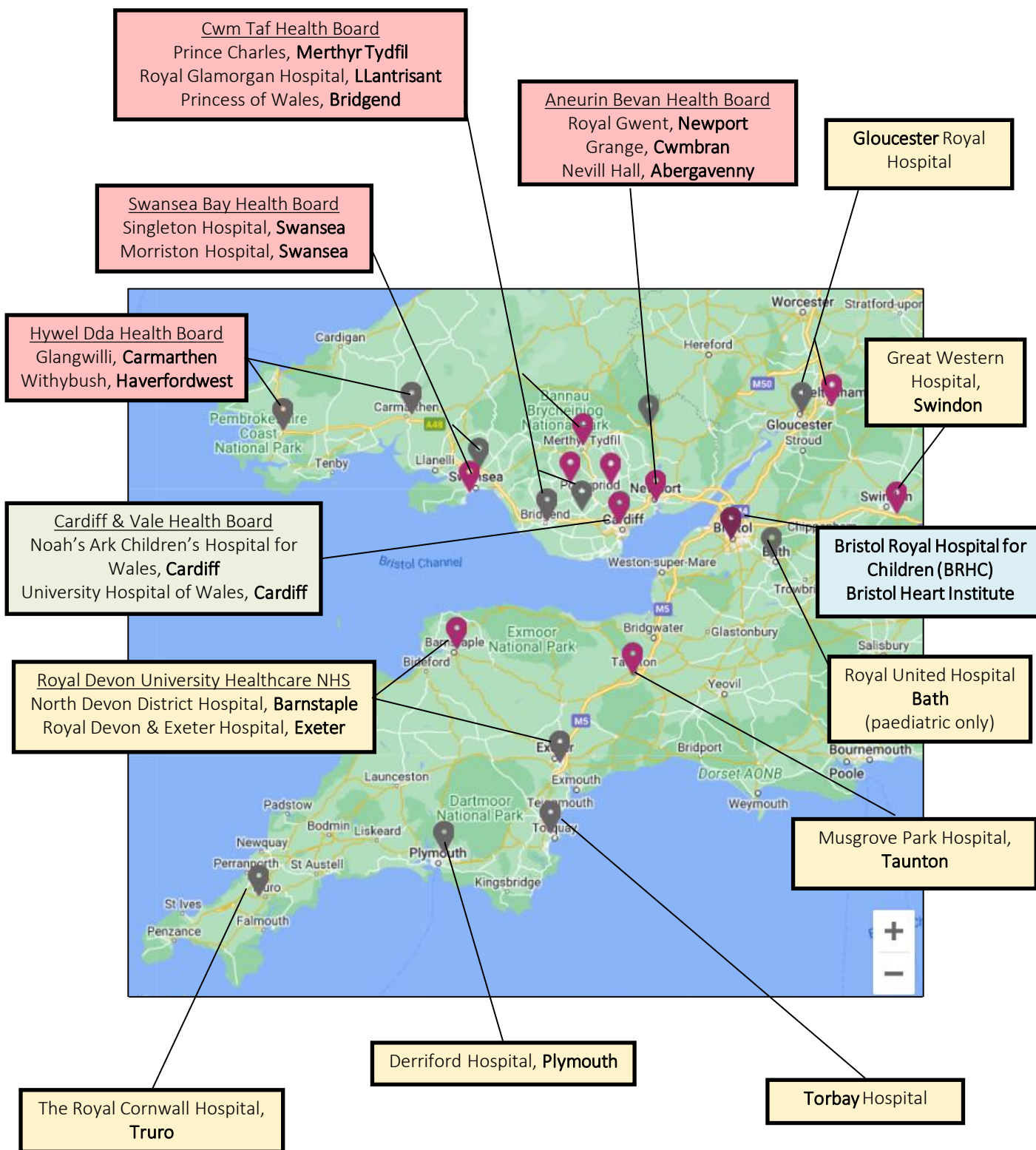
To provide strategic direction for CHD care across South Wales and the South West



To monitor and drive improvements in quality of care



Our Network Centres



Our Network in Numbers 2023/24

CLINICAL CARE



429

Heart operations



729

Cardiac catheters



c. 17,450

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

33 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

68 Cardiac nurses (some in
unfunded positions)



**Allied Health
Professionals staff:
c. 100**

COMMUNICATION AND ENGAGEMENT



32

Webinars



9

Study Days



177

Future Platform
staff members

Visit us: www.swswhdco.uk

Follow Us: [@CHDNetworkSWSW](https://twitter.com/CHDNetworkSWSW)



Key developments and highlights 2023/24

1. CHD self-assessment process in Wales

Self-assessment reviews were held with Health Boards in May-July 2023 in collaboration with the Wales Cardiac Network. This directly resulted in the decision for adoption of the NHS England standards across Wales. The eight services (4 adult and 4 paediatrics) were asked to highlight where their RAG rating against the CHD standards had changed since the original 2021-22 self-assessment review and to identify improvement opportunities to further develop centres.

There was a high Level of engagement from all providers with self-assessments completed thoroughly leading to constructive conversations about services. The reviews showed that compliance of individual health boards with the CHD standards had mostly improved. The common themes of challenge across both adults and paediatric CHD services included: time in consultant job plans; variation in nursing support for CHD services; image transfer and storage; variation in physiology support; and dental services. A summary report highlighting the key issues, progress, and good practice was presented to the Network Board. The stronger and more widespread engagement reflects the maturity of the Network.

Towards the end of the financial year, planning commenced for the next phase of self-assessments across the South West of England to commence in May/June 2024.

2. National CHD Network Annual Meeting & BCCA hosted in Bristol

The British Congenital Cardiac Association (BCCA) Annual Conference was successfully hosted in Bristol, in November 2023, with thanks to the many across our region who were involved in the planning and delivery.

This two-day face-to-face conference brought together over 400 delegates from across the country, as well as some international attendees, to share learning and agree area of focus to improve outcomes for CHD patients.

Following this, the Network were delighted to host the National Network of CHD Networks, in Bristol on the following day. 67 attendees were welcomed from around the country, including patient representatives, charity partners, CHD Network Leads and NHS England Leads and Commissioners. Attendees participated in discussions and considered solutions to contribute to better patient outcomes.



3. Delay in flow audit project – Bristol & Cardiff

This NHS Wales Joint Commissioning Committee (previously known as the Welsh Health Specialist Services Committee) commissioned audit project was launched with the aim of auditing delayed transfers and supporting centres to investigate the barriers to seamless delivery of care and identify mitigating actions to reduce delayed transfers. The pilot focused on monitoring delays in transfer between Bristol and Cardiff paediatric services to better understand issues with patient flow. Regular review meetings between the teams were held and this audit mainly highlighted issues with flow from Bristol to Cardiff due to challenges with beds. The project team have established a clear escalation process for both sites to use when flow issues arise, and an investigation into the use of the Cardiff children's commissioned beds.



4. Transition and transfer between paediatric and adult services

The Level 3 transition pilot project continued to support participating Level 3 paediatric centres (Taunton, Torbay and Gloucester) to enhance the delivery of transition consultations to young people aged 12 to 16 years, sharing good practice and learning via meetings and events. The Network facilitated regional transition programme days were held with good representation across staff groups.

5. Image sharing

Following a highlighted issue from the Welsh self-assessment reviews, this project implemented processes to allow the smooth sharing of patient images across the Network, particularly from Wales to England. A mapping exercise and much effort led to a major breakthrough with a new portal to Swansea and links to be established with the other South Wales Health Boards.

In Exeter, there has been an ongoing paediatric storage issue and through support offered to the local team, this has been resolved with images being permanently stored on PACs with worklists being created for clinics. The new echo platform in Bath was due to go live in May 2024 allowing all images to be transferred seamlessly to the Level 1 centre.



6. Recruitment in the core Network team

New Network Team Manager, Michelle Jarvis, commenced in post in November 2023. Special thanks to Louise Hudson, outgoing Network Manager and to Jessica Hughes, outgoing Network Lead Nurse. Succession planning is key to a stable workforce and to ensure the smooth running of the Network.



Reflections from Network Board Chair, Dr Dirk Wilson

As my time as Network Chair comes to an end, I can reflect on how the Network is evolving and maturing. In November 2023, we hosted the annual meeting of all the CHD Networks across the UK. It was clear from our interactions in this meeting that we remain an exemplar of how a Network team can serve all of the stakeholders across the region.

The annual report demonstrates the scope of work being undertaken across the South Wales and South West CHD Network. With a relatively new team in place (Clinical Director Steph Curtis; Network Manager Michelle Jarvis; Network Chair (from April 2024) Radwa Bedair) I am confident that the work will continue apace.

When I started as Network Chair one of my goals was to try to ensure that the “patient voice” is heard. I think we have achieved this as a Network team. There are some great examples of this in the annual report. I commend it to you!



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.

0% DNA rate in some centres with nurse micro-management of lists

5th ACHD Consultant post created in Bristol

Clinic backlogs across the region for both ACHD and paediatric CHD

Cardiac physiology-led clinics for simple lesions established in Cardiff

Weekend lists for paediatric cardiac surgery

Variable DNA rates due to lack of admin support

New ACHD Fellow post & Consultant post in Cardiff

New EP Consultant and imaging Consultant in Bristol

Long ACHD interventional waiting list

Transition/engagement with paediatric cardiology

Long surgical waiting list for paediatrics

Level 2 psychology wellbeing group established

Long waits for JCC discussion in both ACHD and paediatric CHD

JCC tracker set up in Wales



Absence of ACHD co-ordinator (Bristol) for long periods of time

Additional ACHD clinic in Swansea

Balancing ACHD CPD of local cardiologist with other local general cardiology commitments

Swansea ward refurbishment

Junior doctor and radiology industrial action

Taunton Young Persons clinic up and running twice a year

Insufficient Level 1 Paediatric Cardiology time in Level 3 centres

Confirmed funding for Taunton ACHD nurse specialist post 0.4 WTE B7 & new nurse specialist in Gloucester ACHD service

Retirement of ACHD Consultant in Exeter

Lack of maternity cover for ACHD consultant in Truro



Clinical advances across the Network

New Clinical Guidelines 2023/24: Specific discharge guidance at transfer for minor lesions



By Dr Stephanie Curtis, Network Clinical Director

Our Transfer of Care Task and Finish Group has been busy this year with trying to improve the safety, efficiency and patient/family experience at the time of transfer from paediatric to adult cardiac services. This work has been challenging with many centres introducing new and varied electronic systems.

One of the challenges we face is the inappropriate transfer of patients who do not need long term follow up. This can result in unnecessary anxiety for the patients and their families as they are under the impression that they have a serious lifelong condition. It can also result in a loss of trust in their previous and new healthcare teams if the information they are receiving is not consistent.

Five members of our Network, Dr Katy Huxstep (Consultant Paediatrician with Expertise in Cardiology, in Truro), Dr Radwa Bedair (ACHD Cardiologist, Bristol), Dr Eva Kapravelou (Paediatric Cardiologist, Bristol), Dr Idoia Grange (Paediatric Cardiologist, Bristol), and Dr Stephanie Curtis (ACHD Cardiologist, Bristol) wrote a guideline entitled, 'Specific Discharge Guidance at Transfer for Minor Lesions', to enable Paediatric Cardiologists and Paediatricians to know which patients can be safely discharged from ongoing cardiological care.

Clinical Guideline Specific Discharge Guidance at Transfer for Minor Lesions	
SETTING	South West England and South Wales
GUIDELINE FOR	Congenital cardiology teams in South Wales and South West England Hospitals
PATIENT GROUP	Patients with congenital heart disease in South Wales and South West England

The was finalised in October 2023 and is available on our Network website under https://uhbw.mystaffapp.org/14286/document_view.pdf (MyStaff guideline number 14286)



Another issue faced by teams transferring patients, is knowing to whom patients should be referred. There is a tendency for Paediatric Cardiologists and Paediatricians with Expertise in Cardiology (PECs) to refer all children to the ACHD team, who may not have the appropriate expertise to care for that patient. Whereas all children with heart disease are cared for by Paediatric Cardiologists (and PECs), there are so many adults with heart disease that Cardiologists are typically more specialised and may be experts in a variety of fields, such as heart failure, valve disease, arrhythmias, pacing, and coronary intervention.

We drafted a document detailing the names and subspecialties of all of the Cardiologists in our Network to which patients can be referred with valve disease, cardiomyopathies, arrhythmias and inherited cardiac conditions, as well as ACHD, so that they can be referred to the correct team. This will result in less inappropriate referrals, better patient and family experience, and most efficient use of services. This can also be found on our website: [ACHD Consultants and their speciality for referral from BRHC v3 October 2024.pdf](#)



Education and Training 2023/24

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:



Annual Adult CHD Study Day with over 80 delegates



Two Clinical Nurse Specialist Away Days (Cardiff, July '23 and Bristol, Feb '24)



Monthly bitesize "Lesion of the month" for nurses



Annual Paediatric Cardiology Education Forum



Webinar series led by Cardiac Clinical Nurse Specialists



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



Fetal cardiology study day (October '23)



Psychology Study Day (June '23)



Bi-monthly link nurse sessions



Transition regional training programme (May '23 and October '23)



ACHD advanced training programme (April '23)



Cardiac physiology virtual forum

I just love learning more about these complex patients. This event has given me a better understanding which will be helpful. (ACHD study day, October '23)

I'm better informed to support our patients' transition. I will also make use of the Learning Disability team! (Transition event, May '23)

I have developed a better understanding of the role of psychology within cardiac services. This has further developed my interest in clinical health psychology for the remainder of my training. (Psychology event, June '23)

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, October '23)

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

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



Nursing updates

Clinical

- Ongoing transition pilot project to support Level 3 clinics
- Work on dental pathway across the Network with dental team
- Work with the learning disability and autism services to produce a directory of teams across the Network. Easy read cardiac information resources available.



PECSIG Programme

**Preparing for Transition:
what you (and your patient) need to know**

Sheena Vernon
Lead nurse
University Hospitals Bristol and Weston

Tuesday 14th November 2023

Education

- Presenting in BCCA and the PECSIG stream at BCCA on transition
- Transition study events twice a year for all network clinical staff
- 21st Annual ACHD day for all staff

Network

- Bristol hosting and presenting at the national Network of Networks day after BCCA November 2023
- Level 1 and 2 adult and paediatric clinical nurse specialist away days. The focus in February was advanced care, learning disability and autism
- Level 3 nurses' bi-monthly virtual meetings which provide support in local service delivery, challenging clinical cases, 1-1 support for Level 3 nurses for service development and mentorship

South Wales and South West
Congenital Heart
Disease Network

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Follow us on: @CHDnsws23

Save the date

**Level 2 and Level 1
Children's and Adult Nurses**

Tuesday 11th July 2023
09:00 – 16:30

Cardiff University Education Suite at
University Hospital Wales, Seminar Room A

For further information, please email:
Sheena.Vernon@uhw.ac.uk Jessica.Mather@uhw.ac.uk
Rachel.Davies@uhw.ac.uk

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**Transition
Study Morning**

Learning to 'talk the talk' when it comes to young people and the transition process, focusing on congenital heart disease.

Virtual via Microsoft Teams (no cost)

Thursday 5th October 2023, 08:45 – 12:30

Aimed at professionals working with young people aged 12-25 with congenital heart disease



A Year in the Life of our Healthcare Scientists

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

Our congenital echo training programme has been working with the South West of England’s Level 3 centres since November 2021. The team are very grateful for the continued financial support from NHS England, which allows us to deliver this. There has been strong progress towards the project’s aims of achieving a physiologist with congenital echo accreditation and establishing physiologist congenital echo clinics in each Level 3 centre across the South West.

Owen is proud to report that 6 of the 9 centres in the South West have active cardiac physiology echo clinics, led by the local workforce. This is soon to be 7, as training in Exeter is due to imminently commence and hopefully reestablish the work started by a previous staff member. This work is being almost entirely performed by staff who hold or are working towards congenital echo accreditation. The physiologists without full congenital echo accreditation are performing scans under direct supervision from Owen Burgess in their local paediatric physiologist led clinics. The project is working to develop strong governance processes to ensure patient safety is maintained. We aim to present audit data on these clinics in due course.

Centre	Clinic structure
Truro	Has a European Association of Cardiovascular Imaging (EACVI) accredited physiologist who performs independent echo lists mainly for simple lesions that have been triaged by the consultant paediatrician with expertise in cardiology (PEC). The physiologist reports back to the PEC to follow up as appropriate. She also scans alongside the visiting consultant clinic each month and performs echo alongside the PEC clinic each week. She also works with the PEC and paediatric nurse specialist at the bicuspid aortic valve screening clinic.
Barnstaple	As the physiology service did not have capacity for a physiologist to complete the full accreditation process, we have undertaken a local competency assessment (consisting of practical assessments and sitting our Mock British Society of Echo exam). The local physiologist performs echo lists when the PEC is on leave and discusses these with the PEC on his return with follow up as required.
Torbay	Now has a British Society of Echo (BSE) congenital accredited physiologist, who performs independent echo lists after the PEC clinic. The PEC is normally available, and remote support is available from the BRHC physiologists. The plan is to commence some lists/scanning support alongside the joint (visiting cardiologist) clinic.
Plymouth	Also now has a BSE congenital accredited physiologist who performs independent echo lists. The PEC completes the follow up with a letter/telephone consultation. The plan is also to commence some lists/scanning support alongside the joint (visiting cardiologist) clinic.
Taunton	Independent echo lists are being performed. The PEC completes the follow up with a letter/telephone consultation as needed. These physiologists are currently supervised by Owen Burgess.
Swindon	Echo lists are performed alongside the consultant/joint clinic lists. The physiology staff involved are currently supervised by Owen Burgess. This model is currently being piloted and there is a plan for some independent echo lists in due course.
Exeter	Up until a recent staff vacancy, the accredited physiologist supported with complex scans for consultant led clinics; performed independent echo lists on low-risk new patients with normal or suspected simple pathologies and also followed up known “simple” lesions, reporting back to the PEC for follow up as appropriate. A new member of the team is due to commence soon and will hopefully re-establish this work.

For Adult CHD services – The Bristol Heart Institute have started a health care scientist led clinic for patients with simple ACHD lesions. Two of the team have also sat the EACVI CHD exam, supported by Owen and Dan. National and international colleagues often visit to gain insight from the service.



Fetal Cardiology Update

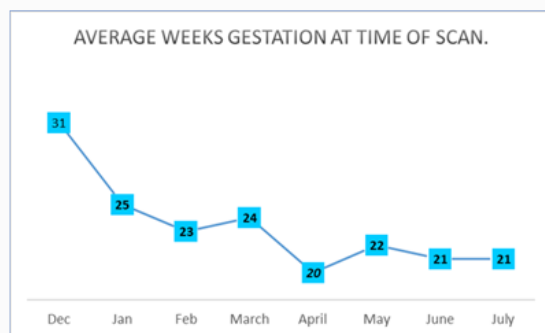
By Angie Smith, Lead Fetal Cardiac and Midwife Sonographer, University Hospitals Bristol and Weston

Development of a sonographer led screening clinic

Screening patients accounted for around a third of the Fetal Cardiologists' workload until the end of 2022, which resulted in a demand that surpassed provision. Screening patients were not being seen within the optimum screening window of 18 to 22 weeks and there were delays in urgent referrals.

In December 2022, a sonographer led screening clinic was launched. Developing the existing senior sonographer role enabled them to autonomously perform fetal echocardiograms for certain high-risk groups, such as those with a maternal history of congenital heart conditions.

- ✓ Since the implementation of the sonographer-led clinics, significant improvements have been made to patient waiting times. The graph (right) shows the reduction over 2023.
- ✓ This has reduced the burden on the specialist fetal consultant clinics, ensuring that women were seen within the recommended screening windows without compromising patient safety.



Teaching and supporting education

In July 2023, the team launched an online interactive monthly teaching session for sonographers in Cornwall. The objective was to increase training opportunities and confidence in scanning the fetal heart for sonographers performing the Fetal anomaly screening programme (FASP) anomaly scan.

The pilot project proved very successful and with the help of the South West Fetal Medicine Network this was rolled out across the South West of England in January 2024. Teaching sessions are held on the second Friday of the month.



In October 2023, Bristol Royal Hospital for Children successfully hosted its third Fetal Cardiology Study Day, led by Dr Patricia Caldas, Consultant Paediatric and Fetal Cardiologist. This was sponsored by Canon Medical Systems.

60 delegates made up of fetal medicine specialists, sonographers, trainees, and paediatricians attended both in person and virtually. Delegates came from all over the region, and we even had a group attending from Iceland!

The next Fetal Cardiology Study Day will be held on 20th September 2024.



A Year in the Life of our Allied Health Care Professionals

Psychology

Update from the South Wales team



By Dr Anna McCulloch, Consultant Clinical Psychologist and Lead Psychologist for Cardiac Services, Cardiff and Vale

The past 12 months have been challenging for the Welsh ACHD Psychology Service as our Band 7 post has been vacant since October 2023. This is likely due to the challenge of recruiting to a part-time post at this Level. Despite this challenge, we continue to deliver inpatient and outpatient psychological assessment and intervention and support patients when they are making decisions about their care. We have also developed online resources for patients to access whilst on the Psychology waiting list.

We are fortunate to work closely with the multi-disciplinary team and offer consultation and reflective supervision to the nursing team. Recent highlights include the successful pilot of both the "Book Club" a psychotherapy group for people living with CHD, and "Time for Tea, Talk and Tai Chi" in which patients attended peer support and tai chi sessions. We are also delighted to have co-written the successful British Heart Foundation bid with the nursing and medical leads.



Patient feedback: "I really felt more connected to the emotional aspects of having CHD. This session really made me understand that it's OK to feel sad/angry/anxious and gave me coping strategies to deal with it. It also made me realise that it's important to use these strategies when feeling joy and happy. It's always so valuable to share your experiences with people who understand and to listen and learn from them too. The laughter is also a huge bonus!"

Update from the Bristol team

By Dr Vanessa Garratt, Consultant Clinical Psychologist for Cardiac Services



Continuing to deliver in-patient and out-patient psychological interventions for young adults and adults living alongside ACHD. With an increase in referral rates, priority out-patient session slots are offered to those on the advanced care pathway (including transplant) and surgical pathways. As part of the SWSWCHD Network, video platforms and telephone session formats permit input to out-patients across the South West of England for those registered with a Bristol ACHD Consultant Cardiologist.

This year in Bristol, the Psychology Department and the Youth at Heart charity submitted a bid to the University Hospital Bristol and Weston Hospital charity and were successful in obtaining funds to refurbish a wall in the BHI out-patients area. Through a real BHI team approach (from nurse managers, the learning disability team to estates), the new wallpaper is up and aims to ease the transition from child to adult ACHD services. Working with the patients' voice, ideas of making this a conducive space for young adults and/or those with neurodiversity is welcomed and will be regularly reviewed. We hope this designated space will facilitate a sense of safety and

connection.



A Year in the Life of our Allied Health Care Professionals

Psychology

Update from the Bristol team - continued



The online patient support group, based on the book 'Healing Hearts and Mind' by Livecchi & Morton, was run as a pilot study and results pre- and post-attendance tentatively indicated that patients felt an increased sense of connection and safety after attending this programme. Qualitative feedback stated that being part of the group 'exceeded expectations'. Another group is planned for September 2024.

Future plans

The pilot intervention was accepted for poster presentation at the European ACHD conference in London (April 2024). ACHD Psychology was also very pleased to have accepted the invitation to verbally present the Psychologists' view of anxiety in ACHD at the British Cardiovascular Society (June 2024). Psychology is being integrated into the world of the expert ACHD patient and medical space. This may be seen as an important move towards holistic care, and aims to facilitate living alongside the forced life event of ACHD.

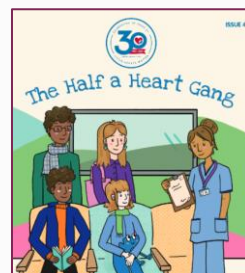
The paediatric psychology service in Bristol



The paediatric cardiology service continues to offer inpatient and outpatient support for young people and their families. Demand remained high throughout 2023/24. However, the service works hard to ensure interventions and support are focussed and time-limited so that waiting time standards are met. Priority support is provided to families who are soon to be admitted to hospital and those on the fetal pathway.

Our team presented at the BCCA conference on 'A psychological guide to supporting adolescents during transition to adult services', which was well received. We also supported at the Network psychology day presenting on topics including 'Compassion focussed therapy with parents in paediatric cardiology inpatient settings' and 'The role of psychology in the fetal cardiology pathway'.

Following the BCCA conference presentation we were asked by the charity Little Hearts Matter to write a comic article for children aged 7-11 with a single ventricle heart condition on how to support them with medical procedures involving needles. This was published in their 'Hospital tests and what they are for' comic. [Comic book 4 - Little Hearts Matter](#)



As part of the cardiac foundation course, our team continues to provide teaching to nurses on Dolphin Ward and those on PICU with an interest in cardiology on supporting children and young people with a cardiac condition.

Looking forward, our team hope to publish a 'Psychological guide to cardiac surgery for parents' to support parents in looking after themselves and supporting their child through the surgical pathway. We also plan to roll out a pilot of a 'Take a breath' group (Rayner et al., 2016) for parents of children with a cardiac condition.



Pharmacy

By Susie Gage, Lead Paediatric Cardiac Pharmacist, Bristol Royal Hospital for Children



2023-2024 has been another busy year, with involvement in several different projects. Locally, I have set up a mini governance monthly message group to highlight and share learning amongst nursing, medical and pharmacy staff in BRHC.

Regionally, I have been involved with Network projects such as; helping to develop an ADHD pathway for CHD children and development of a new anticoagulation guideline for children with Fontan circulation.

Nationally, I continue to be a clinical member of the Clinical Reference Group for CHD in NHS England, looking at non-nursing/non-medical workforce to try and shine a light on more than 20 professions involved in the CHD pathway. I have become chair of a national, newly set up paediatric cardiac pharmacists' group, where we hope to develop national learning tools and share expertise. I also led a workshop at the BCCA conference on anticoagulation in CHD children.

Research update



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

The [national transforming collaborative research strategy](#) was published in July 2023, by The University of Birmingham. This is a national strategy to address the 2022 James Lind Alliance (JLA) clinical priorities identified for children and adults with CHD. It aims to provide a structure through which the priorities can be translated into funded collaborative research studies, to improve clinical care and the lives of those affected by CHD.

The SWSW CHD Network has been showcased nationally as one of the only CHD Networks to currently have a Research Lead. We are grateful to Dr Giovanni Biglino for taking on this voluntary role. It has been exciting to continually enhance and share research and academic activity across our region, nationally and internationally.

Research is thriving in the SWSW CHD Network. Network members have published a wide range of scientific papers in high quality peer reviewed journals. One of our main contributors is Massimo Caputo, Professor of Congenital Heart Surgery and Consultant in Cardiothoracic Surgery, who was re-awarded the Chair of the British Heart Foundation (until 2027). Millions of pounds have been raised in research funds in the region and there are active research groups working in areas such as exercise physiology, pregnancy, cardiac surgery and interventions.

Research activities are run in a collaborative way and updates are shared at the bi-annual regional Network Clinical Governance Group. This is a great opportunity for healthcare professionals across the region to hear more about research in the Network. The Network plans to launch a refreshed research portal for members to log and capture research studies they have published.

Following a survey to gather Network interest, we are excited that plans are underway to launch a pilot, online, research forum. The forum will be open to all Network members with an interest in research, regardless of experience, and be an opportunity to discuss and feedback on project ideas. Journal clubs also are held across the Network for clinical teams.



Quality Improvement & Audit Programme

Dr Helen Wallis, ACHD Consultant Cardiologist

As the Network Quality Improvement Lead, I would like to extend a 'big thank you' to all those who have undertaken audits and quality improvement projects over the past year. We were fortunate to hear three of these projects presented at the Governance meeting held virtually in October 2023 (due to the workforce strikes, this meeting was held once this year). These projects reflected both paediatric cardiology and ACHD practice in both England and Wales and across Level 1, 2 and 3 centres.



Audit of medication use in Marfan Syndrome

Dr Steph Curtis, Consultant Cardiologist, Dr Paul Brennan, ACHD Fellow, Dr Uma Thirumoolasangu, CT2, and Hayden Simmons, medical student.

A characteristic of patients with Marfan syndrome is aortic dilation (guidelines recommend treatment to try to delay this with either a beta blocker or an angiotensin receptor blocker (ARB) in maximally tolerated doses (unless contraindicated). This audit looked at 165 adult patients seen in the Level 1 centre. The audit standard was that all patients with Marfan syndrome should be either on a beta blocker (audit showed 51% of patient cohort) or an ARB (audit showed 71%). The reasons for not achieving the audit standard of 100% were outlined. The audit showed 98.4% of patients were offered either an ARB or beta blocker. There is now published data (Lancet, August 2022) showing that patients do better on both drugs – when more data supports this, guidelines may adjust.

Heart block requiring pacemakers following cardiac surgery

Presented by Marium Aljareh, F1 doctor in Cardiology, with the support of Dr Dirk Wilson, Consultant Cardiologist, Cardiff.

This audit project looked at the incidence of bradyarrhythmia (predominantly heart block) requiring permanent pacemaker insertion following paediatric cardiac surgery, over a 10-year period (2012-2021), in patients with a Welsh postcode. The results showed that overall there was a 4% incidence of post-operative heart block requiring pacemaker insertion. This is a higher rate than would be expected, and it was suggested that the reasons for this are explored. However, similar to other studies, it was found that the highest rates were post mitral and tricuspid valve interventions, VSD closure and tetralogy of fallot repairs. The main limitation of the audit was the relatively small cohort size, limiting the general applicability of the results. A similar exercise looking at Bristol patients is planned.

National CHD Audit Report (NCHDA) 2020-21 data analysis

The NCHDA report published in 2022, seeks to measure the performance of CHD services. The report benchmarks Bristol against centres nationwide and provides an analysis of outcomes for further discussion within the forum.

We are constantly on the lookout for ongoing audits and quality improvement projects, so please contact either Dr Helen Wallis or Rachel Burrows in readiness for the next audit/quality improvement session.



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. Here are a few highlights:

Feedback on the Network Newsletter “Its brilliant and very professional. With so many ongoing work challenges with waiting lists, staffing etc, it’s really uplifting to read a newsletter full of positive news! Really like the patient story. Reminds me of why I come to work.”

Further enhanced the Network NHS Future Platform with education resources, and the Network website for the benefit of all our members.

Training & Education Events

2021	2022	2023	2024	2025
<p>January</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>February</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28</p>	<p>March</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>April</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30</p>	<p>May</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>
<p>June</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30</p>	<p>July</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>August</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>September</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30</p>	<p>October</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>
<p>November</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30</p>	<p>December</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>January</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>	<p>February</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28</p>	<p>March</p> <p>Sa Su Mo Tu We Th Fr Sa</p> <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</p>



Recruited some new patient representatives to join the team and continued engagement with a virtual pre-meet and debrief around Network Board meetings. Positively received and led to more active engagement.

Supported the Listening Event for Gloucester families with BRHC. Also supported the South Wales ACHD patient information day in Bridgend, organised by the Cardiff ACHD CNS team.



Attended the National Patient Involvement Meeting (March '23) with CHD Networks across the UK and fed back at the Network Board .

Staff photographic competition as a wellbeing initiative and to signpost to the Network website (September '23 and March '24).

Feedback on the Network newsletter “I love reading about what is going on across the Network - it helps keep me up to date with things and to feel part of a wider Network. I like the picture competitions; it reinforces a holistic approach to healthcare.”

Produced our biannual CHD Network newsletter



Photo credit: Amanda Doyle, Cardiff



Communication and Engagement

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

As a Network, we invite our patient and family representatives to participate in our Board meetings, task and finish groups and to comment on documents and pathways. Their balanced consideration, experience and contribution to our work enables us to keep the patient at the heart of everything we do.

We asked some of our current patient and family representatives for their reflections on what has gone well and what has been challenging for them over the past year.



Patient representative – Rebecca

Rebecca had the opportunity to share her patient story both at a Network Board meeting and as part of the Network newsletter and reflected on this: “It really emphasised the importance of the patient voice and reflecting on my journey was very welcomed when I looked at it through a positive lens of what I’ve been through and what I have achieved against the odds.”

Rebecca has been pleased to have had the opportunity to co-produce and shape the cardiac psychology service and her input into this work has been really appreciated by the team.

Patient representative - Frankie

Frankie enjoyed speaking at the ACHD day in Wales (January 2024), which offered a great opportunity to meet new people and pool resources. Frankie values the opportunity to connect with other patient/parent reps saying, “it is always good to know that you are not alone and have the support of other people who have gone through similar experiences.”

Patient representatives were invited to an external conference signposted to by the Network earlier in the year, which was unfortunately a negative experience. Frankie described the information as being “irrelevant,” the patient reps felt as though they were there to meet a tick list and mortality rates were discussed without considering the patient attendees. Hearing this feedback reminds us all of the importance of being clear on the remit of representatives, being considerate to the material we are sharing with them, whilst ensuring we can incorporate the patient and parent voice into our work.

In regard to working with the Network, Frankie describes great communication with the Network team and SWSW CHD Board, with the group being kept up to date with the contents of each meeting and the option to step out of a meeting if the need arises. Frankie finds the debrief after each Board meeting really helpful.

The Network encourages patients and family representatives to only be involved as much as they feel they can and understands that this may fluctuate depending on work, health and family life pressures. Frankie values that the patient and parent representative work is not ‘demanded,’ but is a choice, depending on capacity. Frankie is positive about the patient and parent representative involvement in the Network:

“I can see the changes happening. Points and comments that patient/parent reps are bringing up are being actioned on. We are being heard, valued and appreciated. Brilliant!”



Communication and engagement



Patient representative - Gareth

Gareth has been pleased to be part of the Network patient and family representative group, describing this as having given him peace and purpose. He describes being proud to be able to share his experiences with others and is grateful that this can help others.

This year, Gareth enjoyed attending the South Wales patient engagement day and has been particularly valuing the patient group led by Cardiff psychology lead Dr Anna McCulloch, which is going from strength to strength.

Gareth reflects on the group, “Despite many of us being in the treatment queue, the support and backing we've been able to give each other has made things easier and we're now organising days out among ourselves where nature and movement fit alongside conversation and discussions. Also, support we've been able to give to other members when they've been inpatients.”

We are very grateful to Gareth, Frankie, Rebecca and all of our patient and family representatives for everything they do for the Network. Having them involved directly influences the work towards improvements in pathways and services for all patients with congenital heart disease.

Work with local and national charity partners

The SWSW CHD Network collaborates with our local and national charities to provide as much support as possible to our patients in the Network.

Local support for children, young people and their families is provided by Heart Heroes. Support for young people aged 13 years to 25 years is provided by Youth@Heart and the Bristol Heart Institute Youth worker, Xander. Xander provides support for young people along their cardiac pathway, with lifestyle decisions, career and welfare support.



www.heartheroes.co.uk



www.youthatheart.co.uk

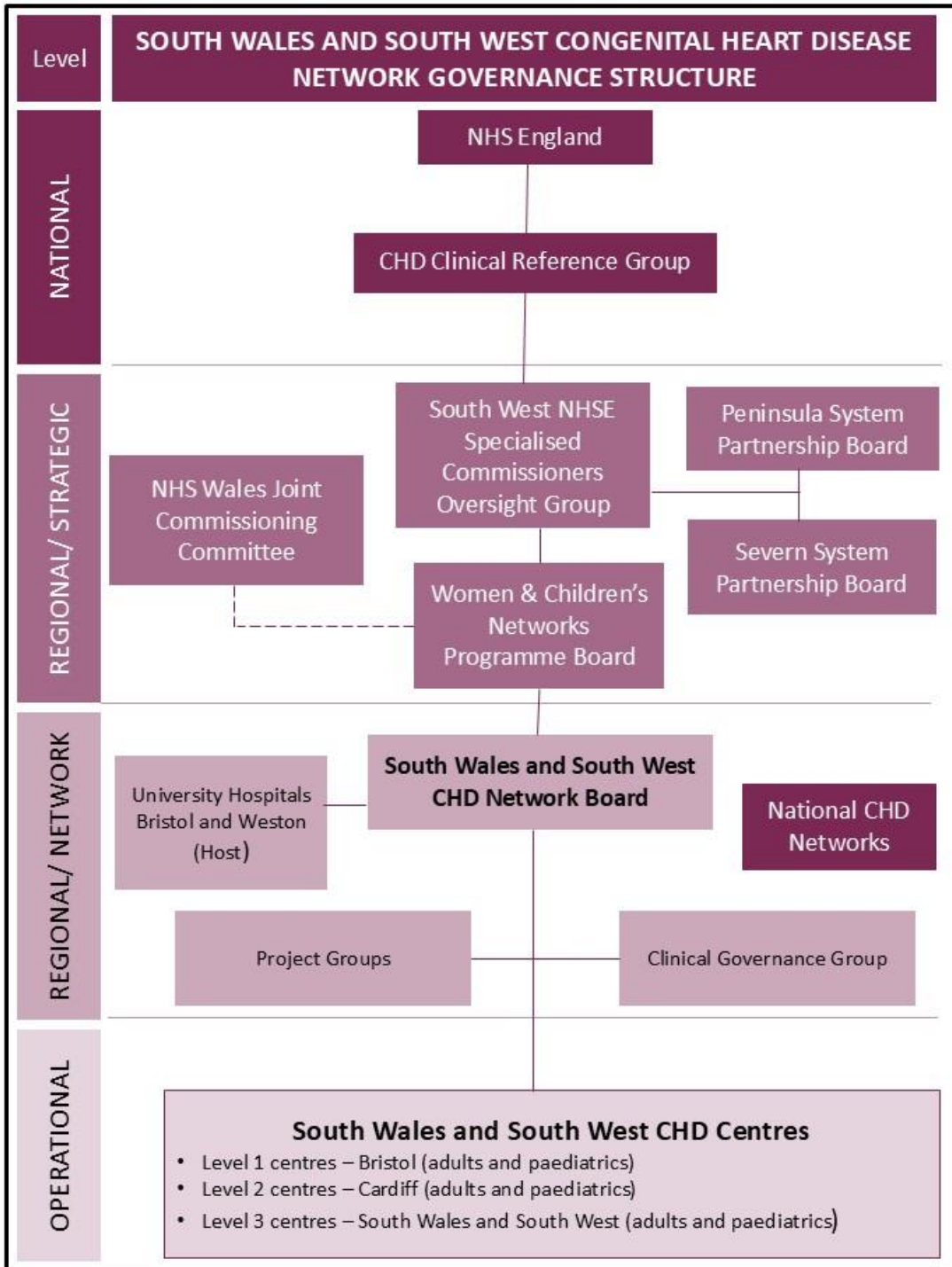


The Network promotes the national cardiac charities which support children and adults with congenital heart disease by promoting events and resources for patients and families.



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 maintains an issue log for any high priority challenges 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 Network issue log held 16 items at the close of 2023/24. Two issues of high priority are described in the table below:

Issues / Challenge	Mitigating action
Concerns around flow between paediatric CHD centres (Level 1 Bristol ↔ Level 2 Cardiff)	<ul style="list-style-type: none"> • Network Delay in Flow project workstream instigated with representatives across both sites and including Welsh Specialist Commissioners. • Audit held to understand where challenges were occurring • Escalation process developed to support swift resolution of flow challenges • Work with Level 2 site team to support bed availability for cardiac patients transferring from Level 1 • Investigation into commissioning arrangements regarding the number of Level 2 funded cardiology beds
Concerns raised across the Network about waiting times for case discussion at the CHD Joint Cardiac Conference and patient risk as a result	<ul style="list-style-type: none"> • Concerns discussed at Network communications group • Network improvement workstream to support improvement in ACHD JCC developed • Scoping Survey regarding adult CHD JCC launched to MDT (March 24) • Findings, Recommendations & Implementation work planned for 2024/25

Financial Report

The SWSW CHD Network is funded by NHS England and was allocated an annual budget of £207,106 in 2023/24, 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. Variance was due to staffing gaps and some ring-fenced money being released following success in securing last minute sponsorship for the hosting of the national Network of Networks conference. Some already committed costs have been carried over into the 2024/25 budget.

Network funding		2023/24		
		Budget	Expenditure	Variance
Pay	Total	£ 198,168	£ 196,295	£ 1,872
Non-Pay*	Total	£ 8,939	£ 4,519	£ 4,420
Total		£ 207,106	£ 200,814	£ 6,292

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



Our focus for 2024/25

In addition to our core 'business as usual' activities, such as education and communication, our workplan priorities for 2024/25 are:

Self-assessments against NHS England CHD Standards (South West England)

The Network CHD centres are asked to self-assess against the 2016 NHS England CHD standards every 3-5 years. Within 2024/25 our South West England adult & paediatric centres will complete their assessments. Review meetings will then be held with each centre and the core network team to allow the following:

- To understand the Level of compliance with NHSE standards for each centre
- Understand key achievements & areas of innovation allowing shared learning across centres
- Escalate any risks & concerns
- Agree actions to close gaps in compliance
- Consider where support is required from the network

The findings of the self assessments help to inform the Network workplan and areas of focus moving forward.

Joint Cardiac Conference (JCC) Improvement Project

Work will take place to identify and implement learning opportunities to improve throughput and management of the Adult JCC following the launch of the Network-led scoping survey at the end of 2023/24.

If this project is successful, consideration will be given as to how this can be used to improve the paediatric JCC in 2024/25.

Supporting Clinical Care

- Guidelines
- Communications
- Patient Experience

- Work will continue / start on producing the following guidelines within 2024/25:
 - Clarifying and updating dental pathways for CHD patients, including for those patients requiring pre-surgical or intervention assessment, antibiotic prophylactics or urgent assessment
 - Pregnancy and contraception advice
- The Network-led project group set up to improve patient related communications from Level 1 to Level 2 and Level 3 centres will continue with the aim to improve patient safety and care through efficient communication pathways.
- Engagement opportunities will continue for our patient and family representatives to support with enhancing patient and carer experiences of CHD services across the Network.
- Work to create a contact list and link up professionals working within Learning Disability (LD) services across the Network. Quarterly LD link forum to be established.



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
CNS	Clinical Nurse Specialist
JCC (MDT)	Joint Cardiac Conference (Multi-Disciplinary Team)
Level 1	Specialist Congenital Heart Surgical Centre – University Hospitals Bristol and Weston NHS Foundation Trust (BHI & BRHC)
Level 2	Specialist Congenital Heart Centre - University Hospital of Wales / Noah's Ark Children's Hospital, Cardiff
Level 3	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
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:

- ♥ Become a Board member
- ♥ Attend a training event
- ♥ Take part in our M&M meetings

Patients and families can:

- ♥ 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

Follow us on X (twitter): @CHDNetworkSWSW

Email: CHDNetworkSWSW@uhbw.nhs.uk



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.

