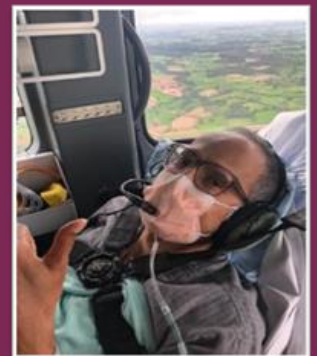




South Wales and South West  
**Congenital Heart  
Disease Network**

South Wales and South West  
Congenital Heart Disease  
Operational Delivery Network

Annual Report  
2022/2023



GIG  
CYMRU  
NHS  
WALES

**NHS**  
England



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# Foreword

By Dr Stephanie Curtis, Clinical Director, South Wales and South West Congenital Heart Disease (CHD) Operational Delivery Network (ODN)



2022-23 was a year of two halves. Our Lead Nurses, Sheena and Jess, and Support Manager, Rachel, ran the ship without a manager for many months and did an incredible job keeping our Network meetings on track, running a comprehensive education programme, supporting the specialist and link nurses in the region and maintaining patient engagement.

In the second half of the year, Louise and I joined the team and endeavoured to continue this good work and also move towards a new workplan, based around Task and Finish project groups with members from across the Network. The aim of these groups is to drive change on problematic issues, such as image sharing, safe transfer of patients from paediatric to adult services and collecting accurate data to support workforce planning. Our aim is high quality equitable care for all in South Wales and the South West of England.

This year Bristol has the honour of hosting the British Congenital Cardiac Association (BCCA) and National CHD Network of Networks Annual Conferences and we are looking forward to welcoming colleagues from all around the UK and beyond.

As always, it is privilege to work with such dedicated and skilled teams and I look forward to seeing what we can achieve in 2023/24!

## 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 (2022/23)



**Dirk Wilson**  
Network Board Chair



**Louise Hudson**  
Network Manager



**Steph Curtis**  
Clinical Director



**Sheena Vernon**  
Lead Nurse



**Jess Hughes**  
Lead Nurse



**Rachel Burrows**  
Network Support Manager

## Our Vision

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

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**  
 Morrision 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**

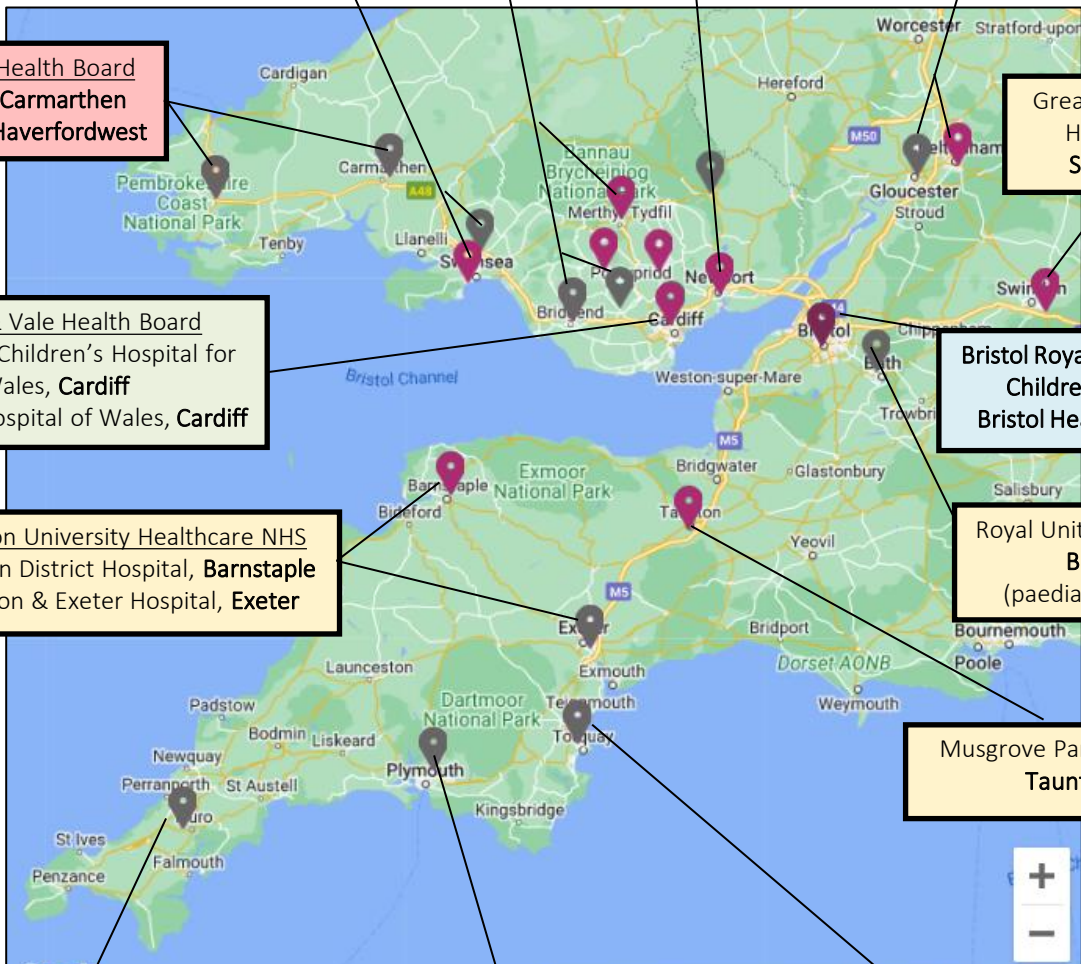
**Royal United Hospital Bath**  
 (paediatric only)

**Musgrove Park Hospital, Taunton**

**Derriford Hospital, Plymouth**

**The Royal Cornwall Hospital, Truro**

**Torbay Hospital**



# Our Network in Numbers 2022/23

## CLINICAL CARE



**341**

Heart operations



**612**

Cardiac catheters



**c. 18,331**

Clinic attendances  
(level 1 and 2 only)

## OUR NETWORK



### Consultants including:

**4** Cardiac surgeons

**19** Paediatric cardiologists  
(including fetal cardiologists)

**7** Consultants in adult  
congenital heart disease

**26** 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 Link nurses (in  
paid and unpaid positions)



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

## COMMUNICATION AND ENGAGEMENT



**40**

Webinars



**11**

Study Days



**539** (↑ 69)

Twitter followers

Visit us: [www.swswhdco.uk](http://www.swswhdco.uk)

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



# Key developments and highlights 2022/23

## 1. Adoption of the NHSE CHD Standards and the CHD self-assessment process in Wales

Following the completion of the CHD national standards self-assessment reviews in Wales, the Network team produced a recommendation report for WHSSC. This provided a summary of the findings to inform WHSCC and the Health Boards about services and the level of care received by patients in Wales.

Standard	Current	Target	Gap
A. The Network Approach	100%	65%	35%
B. Staffing and skills	100%	100%	0%
C. Practices	100%	100%	0%
D. Interdependencies	100%	60%	40%
E. Training and education	100%	100%	0%
F. Organisation, governance and audit	100%	77%	23%
G. Research	100%	50%	50%
H. Communication with patients	100%	67%	33%
I. Transition	100%	83%	17%
J. Emergency and contraception	100%	100%	0%
K. Fetal diagnosis	100%	100%	0%
L. Palliative care and bereavement	100%	87%	13%
M. Dental	100%	50%	50%

The report was presented at the WHSSC Management Board in December 2022, in partnership with the North West, North Wales & Isle of Man CHD Network, with a view to Wales adopting the standards and agreeing to implement recommendations. The decision was taken to adopt the standard, pending ratification by the Health Boards and to work with the Health Boards to drive forward improvement.

## 2. Collaboration with other Networks

The Network team strengthened links with other UK Networks throughout 2022/23. In November 2022 we joined CHD Networks at a National Conference in Birmingham and have met monthly to discuss shared issues such as elective recovery, workforce and data quality. We look forward to hosting the next meeting in Bristol in November 2023 after the British Congenital Cardiac Association (BCCA) annual conference.



We have also worked with the West Midlands CHD Network and the Welsh Cardiac Network to discuss patient flow and adoption of the NHSE CHD Standards in Powys. We have worked closely with the South West Paediatric Critical Care Network team on a regular basis to explore shared challenges including patient-flow and staffing and meet regularly with other regional ODNs.

## 3. Post-COVID – restoration and beyond

We continue to monitor CHD activity across the region, working with centres to improve equity of access and to support the restoration and recovery of CHD activity.

As a Network team we have maintained our online training and business meetings offer, which are cost-effective and popular. Some events resumed in person including the Welsh Paediatric Cardiovascular Network Study Day and the Level 1 and 2 Cardiac Nurse Specialists Days in June and November.

“Virtual events have been great at allowing me to attend some meetings that would otherwise not have been possible due to [geographical] distance”  
(CHD Consultant, Sept ‘22)

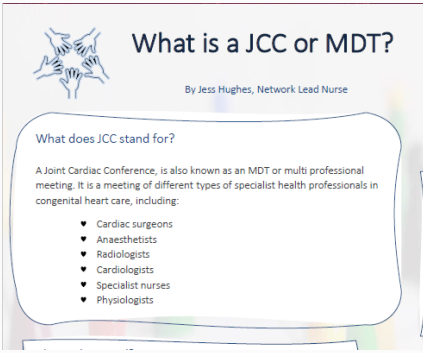




## 4. Patient experience

As a cornerstone of our services, a key ambition for 2022/23 was to strengthen the role of the patient representative and embed patient voice further into Network activity. In March 2023 we met with patients interested in the patient representative role. Working closely with existing representatives we supported participation in Board meetings, with pre- and post-Board meet-ups, reflecting together on how our meetings could be more inclusive of patient experience.

We worked with parents and the Bristol Royal Hospital for Children management team to improve communication around surgical cancellation, and wrote content for our website demystifying the Joint Cardiac Conference, where patients’ cases are discussed.



## 5. Transition between paediatric and adult services

Three centres – Gloucester, Torbay and Taunton – joined the Transition Peripheral Pilot project which supports the Level 1 taskforce implement clinics with Level 1 Cardiac Nurse Specialists.

We were delighted to support and champion the virtual transition clinic in BRHC and the ‘transition to adults’ pathway work in Truro. Twice-yearly Transition Study Days recorded attendance of over 35 professionals with feedback that they have been very helpful for those setting up local services across the Network. The Young People’s Open Evenings, introducing young people and families to adult services, were extremely well received.



## 6. Recruitment in the core Network team

After a vacancy gap of five months, ably covered by the Network Lead Nurses and Support Manager, autumn 2023 saw the new Network Team Manager, Louise Hudson and Dr Stephanie Curtis as Network Clinical Director commence in post. Special thanks to Dr Andy Tometzki, outgoing Clinical Director.



## Reflections from Network Board Chair, Dr Dirk Wilson



“I continue to enjoy my role as the Network Board Chair. I have valued the contributions made by a wide range of health care professionals and by parents/patients. The patient stories presented at meetings are emotive and there are always learning points. I hope we can continue to take steps to improve patient experience and outcomes across the Network”



# 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.

Successful recruitment into Level 1 Paediatric Cardiology consultant posts

Establishment of South Wales ACHD Psychology service and new psychologist starting at Noah's Ark Children's Hospital in Cardiff with another appointment planned

No time in job-plans for link nurses, PECS and cardiologists to attend training and meetings

Development of paediatric cardiology services in Swansea Bay including recruitment of a Consultant Paediatrician with Expertise in Cardiology (PEC) and two trainee paediatric physiologists

Slow surgical throughput and impact on patient flow across the region

New paediatric cardiology Clinical Nurse Specialist appointed in Truro



Slow recovery region-wide of some diagnostic and outpatient waits after COVID-19

Limited echo provision in South Wales ACHD and paediatric services

Physiologist-led clinics established in Taunton and Barnstaple

Widespread absence of link nurses to support paediatric and adult clinics across the Network

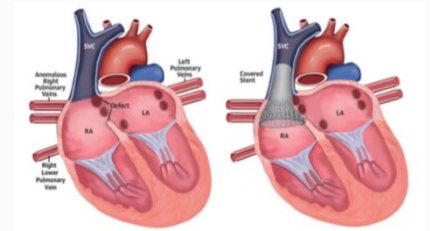


# Clinical advances across the Network

## Sinus venosus atrial septal defect

Sinus venosus atrial septal defect with anomalous pulmonary venous drainage has historically only been repairable by open heart surgery. Professor Eric Rosenthal from the Evelina Children's Hospital in London has pioneered a repair using a stent in the superior vena cava to redirect the pulmonary veins to the left atrium, simultaneously closing the defect.

Dr Radwa Bedair has introduced this novel technique to the Bristol Heart Institute. So far five patients have undergone the procedure with both Dr Bedair and Prof Rosenthal in London and a further four in Bristol with no adverse effects



Two thirds to three quarters of patients are suitable for this intervention, which has changed the patient experience immeasurably and is an exciting prospect for the future of interventional cardiology!

## Adult CHD Consultants

As the ACHD patient population expands, so must the workforce. Unfortunately, recruitment is always a little behind growth. However, the SWSW CHD Network has the greatest number of fully trained ACHD cardiologists working in L3 centres in the UK. Dr Georgina Ooues was appointed in 2020 and is based in Truro. She looks after patients in the South West peninsula and regularly attends the weekly Bristol JCC and fortnightly obstetric cardiology MDT.

Dr Mohamed Mehison was appointed in August 2022 as a locum cardiologist in Musgrove Park Hospital in Taunton. He is part of the Level 1 (Bristol) on call rota for ACHD and attends the weekly MDT as well as doing clinics for ACHD patients in Taunton.

In Wales, Swansea Bay Health Board is shortly to advertise two consultant posts in heart failure with an interest in ACHD. We hope that other Trusts and Health Boards will follow suit so that our patients have more access to trained health professionals close to their own homes.

## New and refreshed Clinical Guidelines

Standard Operating Procedure <b>FETAL CARDIOLOGY REFERRAL PROCESS BETWEEN LEVEL 2 AND LEVEL 1 CENTRES</b>	
<b>SETTING</b>	Fetal Cardiology and Fetal Medicine Departments in UH Bristol and UH Wales
<b>FOR STAFF</b>	All Fetal Cardiologists, Fetal Medicine Consultants
<b>PATIENTS</b>	Referral pathway for fetal cardiology patients from the level 2 fetal cardiology centre in UH Wales to the level 1 fetal cardiology centre in UH Bristol













2022/23 has seen the publication of new guidelines in our Network, as well as updates of pre-existing ones. The lesion-specific ACHD guidelines, originally written in 2016 have been updated, and we have new paediatric guidelines on Fontan and Coarctation of the Aorta.

Our new Fetal Cardiology referral pathway between Level 1 and Level 2 is available on our website.



# Education and Training

A core objective of the Network is to support and promote training and education opportunities for our healthcare professionals. Over 11 Network study events have been delivered in 2022/23 including a range of training and education events for professionals across the region. Here are a few highlights:

 <p>Annual Adult CHD Study Day with over 80 delegates</p>	 <p>Two Clinical Nurse Specialist Away Days (Cardiff, June '22 and Bristol Nov '22).</p>	 <p>Monthly bitesize "Lesion of the month" for nurses.</p>
 <p>Quarterly Paediatric Cardiology Education Forums (recorded webinars on Future Platform)</p>	 <p>Webinar series led by Cardiac Clinical Nurse Specialists.</p>	 <p>Network wide annual mortality and morbidity session (over 45 attendees).</p>
 <p>Fetal cardiology for sonographers study day, hybrid event (Oct '22)</p>	 <p>New transition resource virtual platform.</p>	 <p>Bi-monthly link nurse sessions.</p>
 <p>Transition regional training programme (May '22 and Oct '22)</p>	 <p>National e-Learning for Health introductory CHD modules launched May '22.</p>	 <p><b>e-LH</b> e-Learning for Healthcare</p>

"I enjoyed hearing about some of the social and psychological difficulties patients face. It's great to understand patients' conditions better."  
Physiologist, ACHD study day, Oct '22

"The course was jam packed full of useful information"  
Fetal Cardiology for Sonographers, Oct '22

"Thank you so much I've had an excellent time and learnt so much, can't wait for the next one!"  
Transition study event, May 2022

"A brilliant leadership session. I learnt a lot that I can apply both to my professional and personal life."  
Clinical Nurse Specialist Away Day, June '22

"Excellent, interactive education session with practical approach" Regional Paediatric Cardiology Forum, Jan '23

"Love Jess and Sheena's continued passion and drive to improve our service."  
Clinical Nurse Specialist Away Day, Nov '22

Education resources are available on the Network website ([www.swschd.co.uk](http://www.swschd.co.uk)) and Future Platform



# Nursing update

## Clinical

Supporting nurses in the setting up and running of their services continued with regular meetings with Level 1 paediatric and ACHD clinical nurse specialists and ward teams. The Level 1 and Level 2 clinical nurse specialist days provided an opportunity for teams to share practice, develop cross-site working and participate in team building workshops on leadership skills and resilience. The Level 3 virtual bi-monthly meetings provided advice, and sign-posting support for the increasing numbers of local link nurses.



Clinical support also involved working with Level 1 to set up their Virtual Transition Clinic and launching the peripheral centres Transition Pilot Project. The virtual Young Peoples Open Evening introduces young people and their families into the adult services and takes place 6 monthly. This was well attended and evaluated in May.

## Network

Facilitating patient stories for the Network Board and implementing some of the patient recommendations were key focus areas this year. Our patient representative work has been refreshed with meetings for interested patients and parents and this has been followed up with informal interviews. A job description and contracts are available.

The Lead nurses work closely with our local charities and Youth Worker, Xander Patel-Cook, in developing services for our young people and supporting teams across the Network.

## Education

Education included planning, preparing, and delivering our rolling programme of two Transition half-days of study. We have also supported the Paediatric Cardiac Study Day, Paediatric A&E sessions, an NHSE seminar and a West Midlands CHD Network day.



We are currently involved in planning the main programme for the British Congenital Cardiac Association conference in November 2023 including the paediatric presentations for the Congenital Cardiac Nurses Association (CCNA) and adult presentations for the British Adult Congenital Cardiac Nurses Association (BACCNA).

Three CHD modules have been created in collaboration with Health Education England and E-learning for Health with the paediatric one co-written by our Lead Nurse Jess Hughes.



# A Year in the Life of our Allied Health Care Professionals

## Physiology

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



NHS England CHD Standards state: “all local children’s cardiology centres must have a cardiac physiologist with training in congenital echocardiography”.

With only one (of the 9) Level 3 services compliant with this standard across the South West of England, the **Congenital Echocardiography Training Project** set out to address this in November 2021. With financial support from Health Education England and led by Owen Burgess, the Cardiac Physiology team at BRHC delivered a pilot congenital echocardiography training project, enabling physiologists in peripheral hospitals to deliver paediatric echo locally.

The British Society of Echocardiography’s congenital echo accreditation process was selected as the required standard with training taking two to three years. So far Taunton, Plymouth, Torbay and Barnstaple have been involved. The long-term aim is to support all centres within the Network to be compliant with this standard.

## Psychology

By Dr Vanessa Garrett, Principal Clinical Psychologist, Bristol Royal Hospital for Children & Dr Anna McCulloch, Consultant Clinical Psychologist, Cardiff and Vale University Health Board

We continue to offer psychological assessment and interventions for psychological distress, treatment decision-making and coping with changes in health status, both in person and virtually. We have welcomed Ellen and Nicole to our psychology network team across the Network.



## Service Developments

In Wales, we have completed three outdoor ACHD wellbeing groups, with wonderful feedback and thank the Cardiff and Vale cardio-thoracic directorate for funding this project and our nurses and patients who made it possible.

In Bristol, we developed the ACHD website and ‘tips and tricks on the ward’ patient information leaflets. We are grateful to the patient representatives who have supported us in designing projects.

## Staff training

We continue to offer yearly continuing professional development events to colleagues across the Network, including training on psychological safety, transition and trauma-informed care and to national groups on congenital heart disease and its psychological impact.



## Pharmacy

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

Over the last year, I have been lucky to have had many opportunities locally, regionally and nationally, representing paediatric pharmacists and engaging in exciting new projects, including helping to develop Health Education England CHD Modules, being appointed to the Clinical Reference Group for CHD and being a national speaker for Paediatric Pharmacists on Paediatric Cardiology. There has been an agreement to set up a national group for Paediatric Cardiology Pharmacists to share practice nationally, working with industry, to produce more paediatric friendly medication formulations.



## Research update

By Dr Giovanni Biglino, Associate Professor in Bioengineering, Bristol Medical School & Research Lead, SWSW CHD Network

Professor Caputo (British Heart Foundation Professor in Congenital Surgery based in Bristol), following renewal of BHF Chair, continues to lead a programme of research including clinical trials and tissue engineering research.

The OMAC trial is actively recruiting patients'/mothers' samples across three sites (Bristol, Dublin, Leicester), with 440 patients recruited in Apr 22-Mar 23. Ethical and health research authority approvals have been granted to the Surgical Paediatric



Congenital Anomalies Registry with a long-term follow-up (Surgical-PEARL) study, which aims to establish a multicentre prospective fetal, child and biological parent cohort of congenital anomalies potentially requiring surgical (CAPRS) interventions. From 2022 to 2027, Surgical-PEARL aims to recruit 2,500 patients with CAPRS alongside their biological parents from up to 15 UK centres.

Bristol is also leading the Paediatric Brugada Registry (a national initiative for risk assessment and management), designed to collect information related to the expression of Brugada syndrome. Results will help identify risk markers and set a line of treatment in young patients with Brugada syndrome.

In November 2022, new Research Priorities in CHD were launched at the British Congenital Cardiac Association annual meeting. I sat on the steering group that coordinated this James Lind Alliance Priority Setting Partnership. The CHD Priority Setting Partnership identified the Top 10 unanswered questions about CHD in adults and children. The priorities have been published and plans are being put forward, at national level, to address these priorities.

Professor Caputo and I continue to grow the 3D Bio-Printing Lab, now hosted in the Bristol Royal Infirmary, with state-of-the-art 3D printing equipment and virtual reality equipment for the visualisation of CHD anatomy. The group is internationally recognised for 3D printing research, now sitting on the newly formed European 3D Printing in Hospitals Special Interest Group. The team has been awarded three MRC Impact Acceleration Awards. Bristol also continues to lead on research in exercise physiology in CHD patients, under the leadership of Professor Graham Stuart.



# Quality Improvement & Audit Programme

By 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 four of these projects presented at the Governance meetings held virtually in July 2022 and January 2023. These projects reflected both paediatric cardiology and ACHD practice in both England and Wales and across Level 1, 2 and 3 centres:



**Review of congenital ECHO services within Level 3 centres. Owen Burgess, Bristol Royal Hospital for Children**

The CHD standard B8 states that 'Each Local Children's Cardiology Centre must have a cardiac physiologist with training in congenital echocardiography'. This audit assessed Level 3 centres against this standard and identified variable compliance. A pilot congenital echo training project was established in Taunton and other centres, with the hope that this would be a long-term funded project encompassing all Level 3 centres (see page 14).

**Evaluation of Compliance with dental pathway for children referred for cardiac surgery. Zoe Jordan, Bristol Royal Hospital for Children.**

This project highlighted suboptimal compliance with the dental pathway and recommendations were to raise awareness of its existence and to ensure that an urgent dental referral is made after a JCC discussion/referral for cardiac surgery.

**Results of ACHD Pilot Wellbeing Group. Dr Anna Mcculloch, UHW Cardiff**

The 'Orchard Project' enabled ten ACHD patients in the Cardiff area to be supported to undertake outdoor / green space activities in a supervised and supportive setting over a six-week period. There was clear evidence of improved mental wellbeing with a positive effect on general fitness and an improved confidence to be able to undertake more physical activities at home. The aim is to continue to provide these sessions long-term and to establish a similar project for patients in West Wales.

**Paediatric exercise tolerance testing (ETT) in Level 3 centres. Dr Megan Harty, Dr Nigel Osborne, Royal Devon University Hospital**

This quality improvement project assessed understanding of 'How to safely perform an ETT' amongst local paediatric registrars and then extended this survey to all medical personnel involved in paediatric cardiology in the Level 3 centres. They produced a clinical guideline for performing an ETT and a patient information sheet. The hope is to standardise practice across the Network.

**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

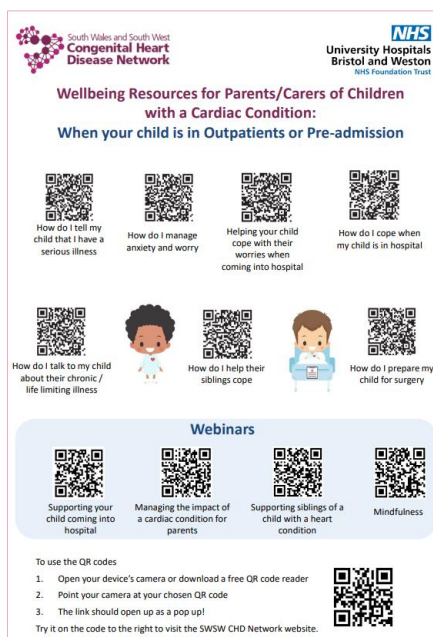
The Network acts as a central point of communication and information for stakeholders. With well-established communication channels, we have been able to support our members and wider teams. Here are a few highlights:

Developed a Website Outline Strategy and Future Platform 'how to' guide, circulated to Board members with positive feedback



Developed and launched a new 'Events' calendar on the Network website, linking to the Future Platform resource pages for healthcare professionals

Produced our biannual CHD Network newsletter



Designed and promoted a new series of four wellbeing QR code posters for patients and families

Promoted QR code posters, designed by BRHC clinicians to signpost to BHF leaflets, on 'understanding your child's heart' and 'understanding your heart' (for parents and young people) across the Network -

Launched the psychology recorded webinars for parents/carers on 'living with a cardiac condition'



# Communication and Engagement



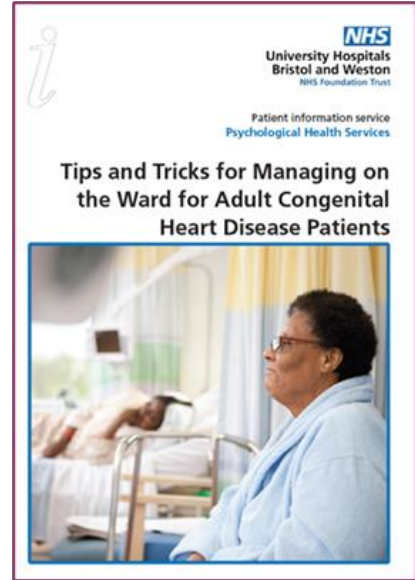
## What is a JCC or MDT?

By Jess Hughes, Network Lead Nurse

Developed 'What is the JCC or MDT?' information resource for patients and families in response to feedback, in collaboration with patient representatives

Website 'Latest info' provided communications during winter pressures

Published a new patient information leaflet: 'Managing on the Ward', developed by ACHD psychologist with support from patient representatives



Tour of Bristol Heart Institute



You cardiac surgery journey - films



Leaflets and Information for Adults



Adult CHD Clinical Nurse Specialist Teams

Refreshed and redesigned 'Information for Adults' patient support page on the Network website, with support from the ACHD clinical nurse specialists.

Launched Cardiff level 2 paediatric and ACHD service 'check-ins' meets to enhance support

Increased engagement with patient representatives with a virtual pre-meet and debrief around Network Board meetings. Positively received and led to more active engagement

Staff photographic competition as a wellbeing initiative (Sep '22 and Mar '23). Photos published on Network website.



September 2022 - CHD Network Photographic Competition

Theme: 'summer scenes across the network'



March 2023 - CHD Network Photographic Competition

Theme: 'Birds Eye View'



# Communication and Engagement

## The patient/parent voice

By Nicola Morris, Network patient/parent representative



As patient and parent reps we have had a busy year!! In June 2022 we were involved in the interviews for the Network Manager which was a huge privilege, and it has been great to see how Louise has moved into the role and hit the ground running.

As a small patient/parent group we are keen to encourage others to share views and ideas to the SWSWCHD Network. In March 2023 we held an online meeting with prospective patients and parents which went well. We shared information about what is involved in being a patient/parent rep and they were able to ask us questions. This session was followed up with interviews with the Network team, so we hope to have a few more volunteers soon.

From a personal perspective I have continued to develop links with the charity Heart Heroes and am now able to visit and give support to families on Dolphin Ward (cardiac unit at Bristol Royal Hospital for Children) as a Family Support Worker. This is a dream come true, being able to support families when they need it the most, as their child is going through heart surgery. I must thank the hospital and Kelly from Heart Heroes for making this happen.

Finally, I have recently been interviewed and been successful in securing a Patient and Public Voice (PPV) role on the National CHD Clinical Reference Group!! I am sure I am slightly mad, but this seems a huge honour and will enable me to feedback to NHS England the reality of care and treatment for our Heart families and patients. I will keep you posted on how this develops ...

## Work with charity partners

The SWSW CHD Network collaborates frequently with local charities in the interests of our patients. We are grateful to our charity and support group partners for their support and for promoting the Network website and resources. In 2022/23, they were invited to include updates in our network newsletter and develop their page on our website:

[www.swswhd.co.uk/en/page/charities](http://www.swswhd.co.uk/en/page/charities)



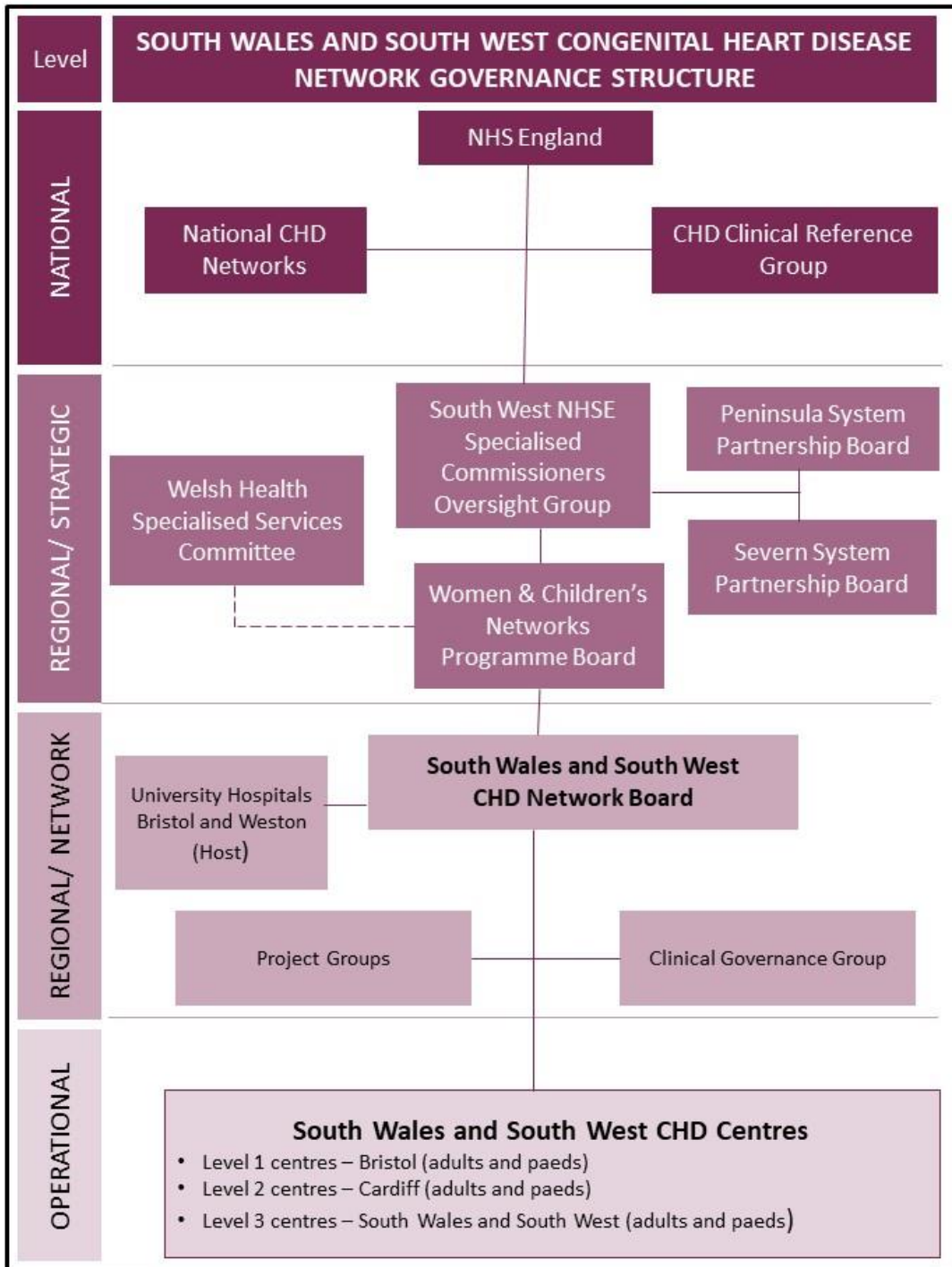
The Network team and partners regularly support one another on Twitter to raise awareness of CHD and the support available. We held two local Charities and Support Groups Update Events (Oct '22 & Mar '23).

The charity Aortic Dissection Awareness UK launched a new patient information booklet on planning pregnancy with aortic disease, which has been distributed nationally, written by our Clinical Director and a patient with aortic disease.



# Network Governance

The oversight of the SWSW CHD ODN 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

From April 2022 we no longer hold a risk register following a change in approach from NHS England. Risks are held on provider or commissioner risk registers as appropriate. Instead, we have an Issues Log, which is reviewed by the Board quarterly.

In January 2023, the CHD Network Board and Clinical Governance Group signed off new processes for risk, issues and incident management. The top issues/challenges from April 2022 until March 2023 are highlighted below.

Issues / Challenge	Mitigating action
Delays to and cancellation of appointments and procedures across the network	<ul style="list-style-type: none"> <li>Renewing focus on elective recovery in 2023/24 workplan, working with individual providers to support action and share good practice. Monitoring and reporting via regional and national meetings and Board.</li> <li>Network meetings with centres who are flagging concerns.</li> <li>Providers are risk stratifying patients to mitigate risk.</li> <li>Managers are taking action to mitigate the risk to staff wellbeing.</li> </ul>
Cancellation of paediatric cardiac operations due to PICU capacity	<ul style="list-style-type: none"> <li>Working with centres and the PIC ODN to support improvement in operational flow</li> <li>Escalating regionally and nationally where appropriate.</li> </ul>
Lack of investment in services in South Wales	<ul style="list-style-type: none"> <li>Local Health Boards to agree to fund clinical activity in line with NHSE Standards and implement Level 2 Phase III Business Case.</li> <li>Meet with L3 centres, Health Boards, Cardiac Network for Wales to work towards implementing the key recommendations from L3 self-assessments.</li> </ul>

## Financial Report

The SWSW CHD network is funded by NHS England and was allocated an annual budget of £197,596 in 2022/23, after overhead contributions to University Hospitals Bristol and Weston NHS Trust as the host organisation. The end of year statement is shown below. Variance was largely due to the manager vacancy.

Network funding		2022/23		
		Expenditure	Budget	Variance
Pay	Total	£ 184,219	£ 188,814	£ 4,595
Non-Pay*	Total	£ 7,674	£ 8,782	£ 1,108
<b>Total</b>		<b>£ 191,893</b>	<b>£ 197,596</b>	<b>£ 5,703</b>

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



# Our focus for 2023/24

In addition to our core 'business as usual' activities, such as education and communication, our workplan will be focussing on:

1	Performance data & elective Recovery	Continue to monitor activity across the region, working to improve equity of access. Support the recovery of activity including surgical delays, outpatient backlogs. Using performance data to support workforce planning.
2	CHD standards in Wales & South West of England	Continue to support the adoption of NHSE Standards across South Wales via self-assessment meetings with Health Boards and plan for the next phase of self-assessments across the South West of England.
3	Delay in transfer audit project	Bristol and Cardiff to monitor delays in transfer between centres to better understand issues with patient flow.
4	Transition and transfer between paediatric and adult services	Continue to drive the L3 transition pilot project. Support L3 centres to enhance transition, sharing good practice and learning via meetings and events. Audit Lost to Follow Up from paediatric to adult services. Implement new transfer of care pathway.
5	The communication of patient information across the Network	Task and Finish Group to improve patient related communication from L1 to L2 and L3 centres to improve patient safety and care.
6	Image sharing	Implementing processes for ensuring smooth flow of images across the Network, particularly from Wales to England.
7	Patient experience	Support new patient and parent representatives and develop a variety of opportunities for engagement in initiatives, to enhance patient and carer experience of CHD services.

## Upcoming key events in 2023/24

- British Congenital Cardiac Association annual conference, Bristol, 13-14 Nov 2023
- National Network of CHD Networks, Bristol, 15 Nov 2023
- Stakeholder day 2024





## 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
- ♥ Come to our Stakeholder Day

### Patients and families can:

- ♥ Visit our website ([www.swschd.co.uk](http://www.swschd.co.uk))
- ♥ Sign-up to our newsletter mailing list
- ♥ Become a patient/parent representative
- ♥ Attend an engagement event
- ♥ Come to our Stakeholder Day

### For more information, please:

Visit our website: [www.swschd.co.uk](http://www.swschd.co.uk)

Follow us on twitter: @CHDNetworkSWSW

Email: [rachel.burrows2@uhbw.nhs.uk](mailto:rachel.burrows2@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.



