



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

South Wales and South West
Congenital Heart Disease
Operational Delivery Network

Annual Report
2021/2022



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Document Abstract	
<p>This annual report for the South Wales and South West CHD Network outlines the background to the network, its vision and key objectives, achievements and challenges, and key updates for the period from April 2021 to March 2022. It also looks to the future, providing an overview of plans from April 2022 onwards.</p>	

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Foreword

Once again, I am delighted to present the annual report which covers 2021-22. I do so with a mixture of emotions; primarily pride in the way in which we have developed a service over the years that I have been in office, but also sadness in that this will be my last annual report as clinical director for the network.

I'm extremely grateful for the support of our host organisation University Hospitals Bristol and Weston. Some of you will know that I approached the Trust executive team ahead of the publication of the CHD standards in 2016 to ask for their investment for a network ahead of central funding from NHS England. We set the bar high nationally and were used by NHS England as a template with regard to ongoing funding structure of CHD networks across the UK. Along the way I have been supported by a strong and committed network team, and we helped other networks start up around the country.



This report further exemplifies the networks achievements. We have certainly come a long way from the blank page we started with in 2016. Strong engagement from clinical and commissioning partners has been pivotal to our successes, as well as dealing with the challenges. Not least of which was navigating the pandemic and the challenge to restore services which is very much an ongoing project. Perhaps more importantly I have witnessed the growing involvement of the patients and parent voice along the way, their input brings into focus where we should place our priorities for the future of the network. I hope we will see more of this going forward.

I hope that you will enjoy reading through the content and be enthused to participate in further developments in the future. I will be keeping a keen interest in the network having been invited to be the Clinical Director for Paediatric Cardiac Services at Bristol Royal Hospital for Children. So it is time to sign off for now and let the new team build on the foundation I am proud to have been part of for the last 6 years.

A handwritten signature in blue ink, appearing to read 'A Tometzki', with a small dot at the end.

Dr Andrew J P Tometzki
Clinical Director
South Wales and South West Congenital Heart Disease Operational Delivery Network



About Us

Background

The South Wales and South West Congenital Heart Disease Operational Delivery Network (SWSW CHD) was officially formed in April 2016, following the publication of the NHSE, CHD standards and specification (2016). This followed on from a long established informal clinical network in South Wales and the South West of England, and a formal partnership agreement with South Wales signed in 2001.

The network brings together clinicians, managers, patient and family representatives, and commissioners from across these regions to work together supporting patients with congenital and paediatric acquired heart disease and their families. It is funded by NHS England and hosted by University Hospitals Bristol and Weston NHS Foundation Trust.

The network covers a broad geographical area of South Wales and South West of England (Aberystwyth to the Isles of Scilly), with a population of approximately 5.5 million people, 1 in every 100 people are born with congenital heart conditions. There have been more adults than children with congenital heart disease since 2002. This network is accountable to NHS England and works closely with the Welsh Health Specialised Services Committee to improve the quality and equity of care for CHD across the region.

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 patients 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

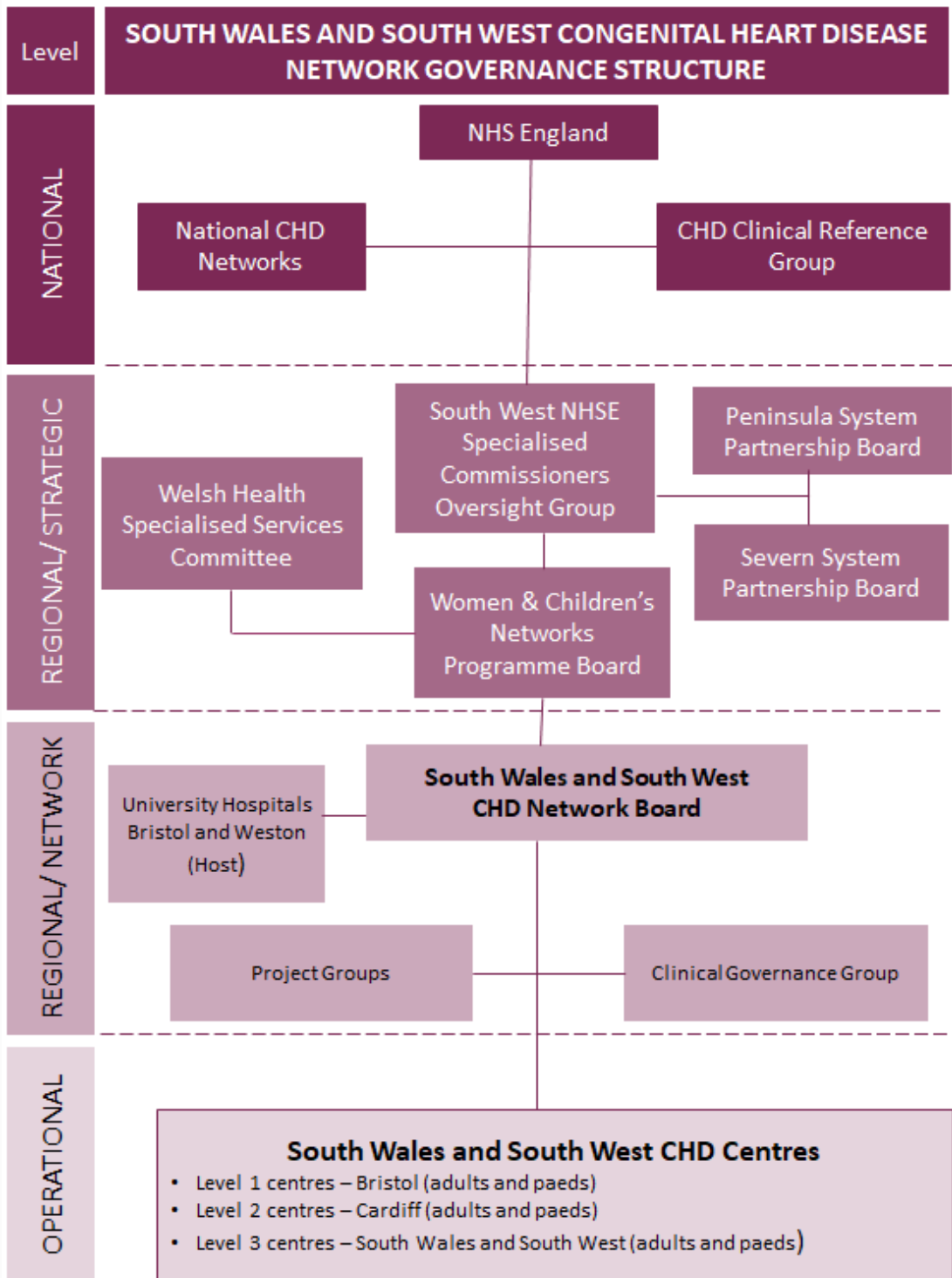


To monitor and drive improvements in quality of care



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:



Meet the Core Network Team (2021/22)



Dirk Wilson

Network Board Chair



John Mills

Network Manager



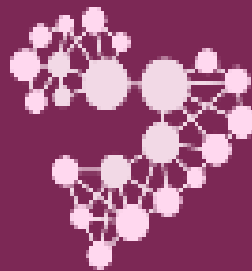
Andy Tometzki

Clinical Director



Sheena Vernon

Lead Nurse



Jess Hughes

Lead Nurse



Ness Garratt

Lead Clinical Psychologist



Rachel Burrows

Network Support Manager



Our Network in Numbers 2021/22

CLINICAL CARE



350

Heart operations



636

Cardiac catheters



c. 15,500

Clinic attendances
(level 1 and 2 only)



1,219

Psychology contacts

OUR NETWORK



Consultants including:

4 Cardiac surgeons

17 Paediatric cardiologists

9 Consultants in adult congenital heart disease

31 Paediatricians with expertise in cardiology (PECs)

16 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:

17 Clinical nurse specialists

68 Link nurses in Level 1 (12), Level 2 (7) and Level 3 centres (49, 3 in paid positions)



Allied Health Professionals staff: c. 100

COMMUNICATION AND ENGAGEMENT



27

Webinars



11

Virtual Study Days



17,654

Website users



470 (↑ 80)

Twitter followers

Visit us: www.swswchdco.uk

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



Key achievements, developments and highlights from 2020/21

CHD national standards self-assessment process in Wales

In 2021/22, in collaboration with the Welsh Health Specialised Services Committee (WHSSC) and the North West, North Wales and Isle of Man CHD Network we supported all level 3 CHD services (12 in total, both paediatric and adult) in South Wales to complete a self-assessment against the NHS England CHD standards, and were impressed by the high level of engagement.

The first aim of the self-assessment process was to understand how centres are delivering the standards. It provided the opportunity for CHD centres to highlight areas that are working well, identify any gaps or concerns, and request any support.

In this process, a CHD national standards self-assessment strategy (Welsh CHD centres) to assess the Welsh centres against the National CHD Standards and specifications was developed by the CHD Network. As part of this, we created a standards template for centres to complete in order to identify an action plan that could be discussed at review meetings with each Health Board.

This template received positive feedback and we have received requests from other regional ODNs to use this for their speciality networks.

Ref	Description	April 2016 Timescale	RAG	Evidence/commentary	Proposed actions	Timescale
L12 (L3)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate	A	Not routinely shared	Ensure information added to patient leaflets	31-Jan-21
M3(L3)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate	A	Capacity issues prevent this		
M6 (L3)	Local Children's Cardiology Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate	R	Referral pathway not in place		

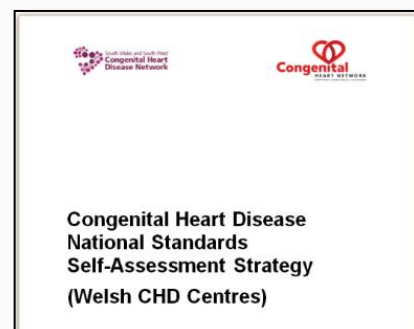
Section	Completion	Green	Amber	Red
A. The Network Approach	100%	61%	16%	23%
B. Staffing and skills	100%	100%	0%	0%
C. Facilities	100%	100%	0%	0%
D. Interdependencies	100%	60%	10%	30%
E. Training and education	100%	100%	0%	0%
F. Organisation, governance and audit	100%	77%	15%	8%
G. Research	100%	50%	50%	0%
H. Communication with patients	100%	67%	29%	4%
I. Transition	100%	82%	17%	0%
J. Pregnancy and contraception	100%	100%	0%	0%
K. Fetal diagnosis	100%	100%	0%	0%
L. Palliative care and bereavement	100%	87%	13%	0%
M. Dental	100%	50%	17%	33%

Overall completion progress: 100%

Once completed, please return this document by email to your Congenital Heart Disease Network Manager and Network Support Manager

The next step is for the network team to produce a recommendation report for WHSSC. This report will provide a summary of the findings of the Self-Assessment reviews to inform WHSSC and the Health Boards about the extent to which services meet the CHD standards to inform further decisions and actions.

It is hoped that based on this report WHSSC will formally adopt the NHSE Standards and Specifications on behalf of the local Health Boards.



The CHD Specification and Standards can be viewed on the NHS England website (correct at July 2021): <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05/>



Peripheral specialist CHD clinic project

In June 2021 the SWSW CHD Network compiled a draft report on behalf of NHS England including recommendations and draft Service Level Agreements with project team members. This was presented to Bristol Royal Hospital for Children (BRHC) and NHS England to discuss next steps.

Background: NHS England in collaboration with BRHC commissioned work to be undertaken by the SWSW CHD Network to review and improve the current specialist paediatric CHD peripheral clinic provision in the South West. There were a number of key aims agreed by both NHS England and BRHC. Over 152 specialist paediatric CHD clinics are delivered across the South West per annum in order to provide care for CHD patients in their local District General Hospitals (DGH's). This enables care to be delivered as close to home as possible and aligns with the CHD standards published in 2016, which recommends provision of specialist clinics locally.

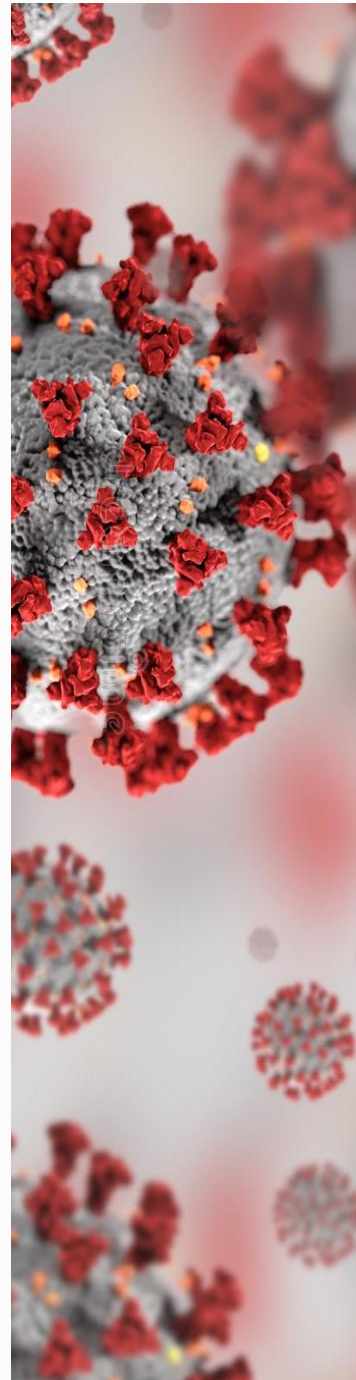
COVID-19 response, restoration and recuperation

The COVID-19 pandemic continues to impact the way our hospitals and community services function. A shared understanding of the challenges each service faces helps us to learn from each other when looking for solutions.

The National Network of CHD Networks meeting has continued to be chaired and supported administratively by the SWSW CHD Network. This has brought a shared understanding of the challenges each network faces, in particular the obstacles in systems that affect cardiac surgery. A few examples are:

- Social distancing in outpatient areas forcing lower numbers of patient that can be seen face to face
- Low nursing resource, particularly in the level 1 PICU.
- Reduced capacity in theatres where other specialities are also facing challenges with their own patient groups.

Some of the positive effects of the COVID-19 pandemic for SWSW CHD Network have been the continued improvements made in digital working. The Network has seen record numbers of participants join some virtual meetings, for example the ACHD day attracted 125 delegates from across the region and beyond, and the paediatric cardiology (PEC) study day attracted triple the number of attendees compared to before the pandemic. Feedback has shown that this is due to ease of access and convenience with no additional travel nor cost. Similarly, this change has continued to improve access to our key network meetings, including the Clinical Governance Group and Network Board.



New CHD Network Board Chair

In June 2021 we were delighted to welcome **Dr Dirk Wilson**, consultant paediatric cardiologist in Cardiff, as our new chair of the Network Board.



“I have enjoyed my first year at the Network Board Chair, working closely with the network team and providers. This role has provided the opportunity to give valuable strategic input, for example helping to develop the network strategy and priorities for the coming years. I have also strived to make the network board meetings even more engaging and focused, by reviewing and contributing to the agenda, with a continued emphasis on the ‘patient voice’ through the patient representatives. Moreover, together with the network team, I support and encourage the quarterly data returns from the level 1, level 2, and level 3 centres to enable better understanding of gaps and risks across the region. The performance dashboards are available on the network website.”

Quarterly Dashboard and Update Report
Level 2 & 3 Centres

Please complete pink fields for the end of the reporting period.

Select from the drop down options

Reporting Hospital

Adults or Paediatrics

Reporting Period Quarter: Year:

Outpatient Performance

	Local consultant	Visiting Specialist
Waiting time (weeks) for new patients	<input type="text"/>	<input type="text"/>

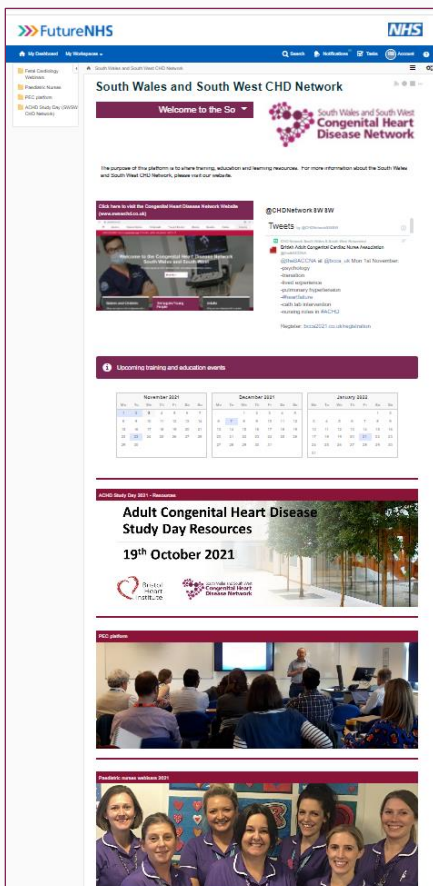


Digital working: Our Future NHS Platform

Over the last year we have further developed our network NHS Future Platform. Being a site for healthcare professionals within the network (who have to register to access this), the platform provides a space to share CHD related webinars, resources and information that may be helpful, primarily for training and education purposes.

The platform is home to the fetal cardiology webinar series; the paediatric nurses webinar series; the network 2021 ACHD study day webinars; the PEC platform; psychology webinars; the physiology platform (currently under development) and much more. These are accessible to all professional groups.

We have also launched chat forums seeking a safe space within professions to have open discussions across the region, and this has particularly been used by the PEC group. The platform is a work in progress and will continue to be developed. Feedback so far has been very positive and plans are already underway to expand this further in 2022/23.



Successes and challenges from around the region

We asked our network members for their top successes (green) and challenges (red) from 2021/22. Here are a few things they highlighted to us.

Challenge:

Lack of physical space in our clinic.: Since COVID-19, various clinic rooms are out of action meaning we have fewer rooms to see patients and our ACHD nurses in particular have to be creative
Royal Glamorgan ACHD

Success:

Successful implementation of physiologist-led clinic for assessment of new-born infants with heart murmurs and consequent reduction in waiting times.
Swansea Paediatric CHD

Challenge:

Outpatient department capacity for face to face appointments – still have reduced footprint in outpatient departments across Wales. Temporary COVID-19 restrictions not lifted yet.
Cardiff Paediatric CHD

Success:

New post appointments: 6th consultant, 3rd sonographer, CNS (transition), Psychology (2nd post), support secretary.
Cardiff Paediatric CHD

Challenge:

Capacity challenges, in particular with young people clinics. Still awaiting decision on a business case for an ACHD nurse
Gloucester ACHD

Challenge:

Planned merger with Yeovil District Hospital is in process. This may have implications on our services and patients across the region
Taunton, ACHD

Success:

Recruitment made for the role of named Paediatric Cardiac Link Nurse
Taunton, Paediatric CHD

Success:

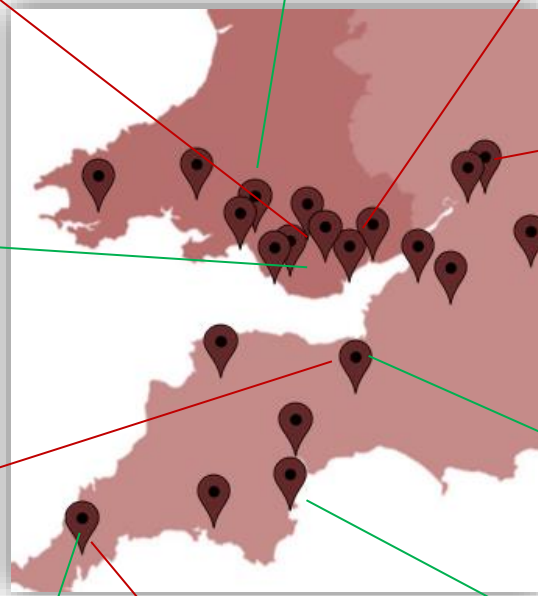
Improving Cardiac scientist capacity and supporting her development
Royal Cornwall, Paediatric CHD

Challenge:

Ongoing delays in accessing timely diagnostic investigations due to backlog caused by the COVID-19 pandemic.
Royal Cornwall ACHD

Success:

Improved links and relationships with the Bristol Cardiac Nurse team and the network.
Torbay, Paediatric CHD



Spotlight on Physiology

Physiology teams play a vital role in the care of patients with Congenital Heart Disease. The CHD Network was keen that physiologists had a space in which they could collaborate and network effectively. A virtual 'Meet and greet' was set up in December 2020 and chaired by Daniel Meiring, lead physiologist from the paediatric team in Bristol. The teams have been meeting quarterly and have had fantastic engagement and enthusiasm from paediatric CHD and ACHD professionals across the South Wales and South West.

Together they have started a physiology section on the Network NHS Futures Platform and are working on improving guidelines and protocols that aid a standardised way of working with patients with CHD.

Daniel Meiring tells us more about the key developments:

- Royal Devon and Exeter and Bristol services have started a pilot in partnership providing a senior imaging physiologist to support the PEC clinics through the provision of echocardiograms.
- In partnership with Health Education England, we have set up a pilot to provide teaching to the physiologists in the Network. This continues to be well supported and two or three physiologists have used this scheme to work towards gaining their BSE congenital heart disease accreditation.
- The weekly congenital heart disease training sessions continue to be well supported by the physiologists from the region, and work is now underway to enable physiologists to lead some of this teaching.
- Work continues on the Network NHS Futures Platform and physiologists from across the region are working collaboratively to share content and ideas of how this can be shaped.
- Staffing and resources remain an issue across the region and the physiology virtual meet and greet has been used to support sharing of ideas and good practice in how to overcome obstacles. In addition, feedback from the virtual meet and greet is being used regionally to support a push to develop a funded national training program in Paediatric Cardiac Physiology.



Nursing update

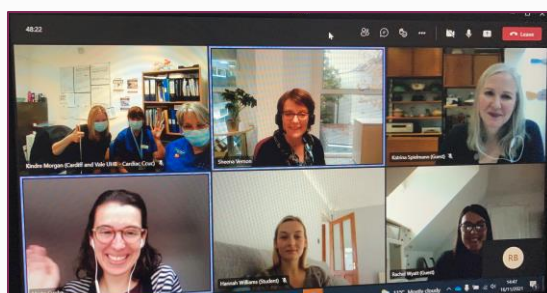
The SWSW CHD Network plays a key role in providing professional leadership, support and resource to the cardiac nurses and link nurses in our region. There were a number of exciting developments in 2021/22.

Taunton became the first District General Hospital in the Network to employ a Paediatric Cardiac Link Nurse with 7.5 hours per week available to attend clinics and provide local support to families. This role is such a valuable source of support and there is now scope to build upon this role including running transition clinics and setting up telephone or e-mail advice services for patients.

Link nurses / CHD nurses with an interest, play a vital role in the cardiac patients journey and the challenge to ensure that the value of these nurses is understood by those commissioning services remains. Some excellent progress was made in the self assessment visits with South Wales Health Boards as mentioned earlier in the report. Many of these centres recognised the gap in their services where nursing was concerned and some have already made progress in identifying a nurse with enthusiasm and passion in the area of CHD. This role is a crucial sign posting role for patients and families to offer clinical advice and support as they move along their cardiac pathway. The next challenge will be seeking funding for these nurses to be given the time they and their patients deserve in order to deliver the CHD standards.

Bi-monthly virtual meetings are held with the Level 3 link nurses. This is an opportunity for them to access clinical, educational and service development advice and support from the Network Lead Nurses. The meetings are very productive and address many day to day issues in Level 3 services. A similar but face to face meeting is held at Bristol Royal Hospital for Children to support all the nursing staff involved in the care of cardiac patients throughout the hospital. Some excellent pieces of work have come from this meeting such as the cardiac workbook for nursing staff across the SWSW CHD Network.

The Clinical Nurse Specialist teams from Cardiff and Bristol meet every six months to discuss both paediatric and adult patient pathways. The aim of this meeting is to facilitate excellent communication between level 1 and 2 to ensure the patient pathway is as seamless as possible. Education, development and SMART targets are part of these meetings. The effort and commitment all the nurse put into their roles is inspiring.



Education to equip nurses and AHPs to care for CHD patients across the CHD Network is an important part of the Lead Nurses role. A number of events have taken this year which are also mentioned on the education page in this report. The Paediatric Cardiac Nurse Specialist team put together a programme of cardiac webinars - each an hour long educational session presented live to delegates and now held on the Network's NHS Futures Platform. These were extremely well received and evaluated and will be repeated in the coming year. The 19th ACHD day was also evaluated very well and 125 delegates attended from across the Network.

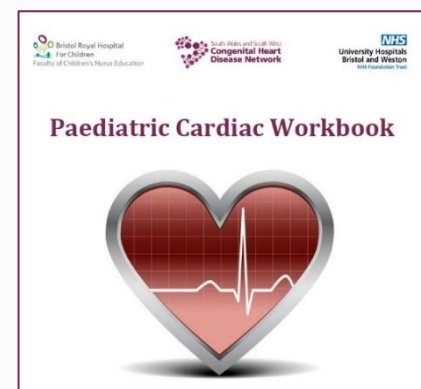


Education, Training and Audit

Education and training

A core objective of the network is to support and promote training and education opportunities for our healthcare professionals. Despite the continued challenges and recovery from the COVID-19 pandemic, the network has continued to achieve this objective. Several events have been supported and taken place with some highlights below:

- Paediatric Cardiac Nurse Specialist 2021 webinar series completed with six webinars delivered live – these were very well received and evaluated. The recorded webinars are published on the Network's NHS Future Platform
- 19th Annual ACHD study day held virtually in October with over 125 delegates from across the region and beyond. The recorded presentations are published on the Network's NHS Future Platform
- Four Paediatrician with Expertise (PEC) days were held virtually with a wide range of presentations.
- Cardiac physiologist quarterly regional virtual sessions with excellent engagement from across the region. Cardiac Physiologists presented an update on regional initiatives at the Network Board in March 2022.
- Two Level 1 and Level 2 Clinical Nurse Specialist events
- Link nurse (level 3) virtual drop in sessions held throughout 2021/22 to enable shared learning and best practice, as well as a link nurse education forum event.
- Paediatric cardiac handbook and nurse competencies development package for nursing staff launched
- 'Lesion of the month' – continued with this monthly bitesize education initiative for all CHD nurses across the network.
- Further development of the Network NHS future platform as a virtual space for staff to share useful resources and information, plus discussion forums and webinars
- Led a rapid development of national CHD e-learning for Health module to be published in May 2022

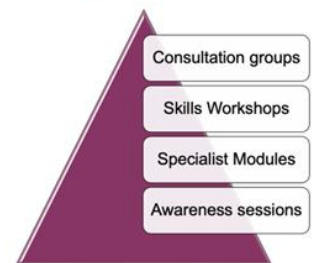


Education, Training and Audit

Education and training highlights continued

- Psychology network day held virtually including a presentation from a regional charity. With 10 attendees from across the region the event focused on supporting clinicians with developing core skills and applying a broad range of psychological models to young people and adults with a cardiac conditions. Also hosted a bite size event ‘providing cardiac psychology in all of our pathways.’
- The network psychology team created a model of psychological skills training to support clinicians across the region to develop their skills and to support patients in distress. Following feedback, the network’s initial bitesize training modules were developed and trialed in level 1 paediatric and adult services. With positive initial feedback, this programme will be developed for the wider network in 2022.
- Fetal cardiology study event held with 170 delegates including clinicians from international centres
- Network wide annual mortality and morbidity session with speakers from across the network – over 45 attendees and positively evaluated.

A proposal – 4 levels of training to offer



For more information on training, education days, and useful resources, please visit www.swswchd.co.uk

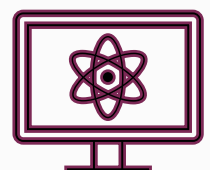
Quality Improvement (Audit)

The network quality improvement programme is an important part of the network’s portfolio, coordinated by Dr Helen Wallis, Network Quality Improvement Lead and ACHD Consultant in South Wales. The SWSW CHD network aims to facilitate the presentation of 2 to 3 audits/quality improvement projects biannually at the network Clinical Governance Group.

This year, two network-wide quality improvement sessions were held virtually with audits presented by different staff from across the network. This provided a great opportunity to share learning and best practice.

In 2021/22, the following quality improvement/audits were presented:

- ✓ Patient experience feedback on virtual clinics (Cardiff Adults)
- ✓ Infective endocarditis audit (Bristol Paediatrics)
- ✓ Right aortic arch project (Bristol Paediatrics)
- ✓ Developing a parental arrhythmia information sheet (Truro Paediatrics)
- ✓ Update on South Wales self-assessment process (both adults and paediatrics)



Feedback on our training events

Through a mixture of surveys, email and debrief conversations, the SWSW CHD network routinely collected feedback from events throughout the year to ensure they continue to meet the needs of CHD staff and services in the region. Our virtual events have been generally very well received, but the limitations of virtual settings was also noted and the lack of informal networking opportunities was a loss compared with previous years.

Meeting online helps us attend more of the network meetings and enables us to join remotely without having to drive long distances for attendance

Network Board - June 21

Excellent presentation. Explained the common practical useful things we must face in critical situations. Helpful in saving lives

PEC day - July 21

As always, patient stories & lived experience are the most powerful aspect of this meeting. As clinicians we can learn so much from our patients & what we can do better

Network Board - March 22

Always a pertinent & worthwhile meeting, with lots of learning points identified

Morbidity and mortality meeting - Sept 21

A really good talk pitched at a good level for people who have some but not extensive knowledge of the topic. Georgia was able to pick out the key issues clearly and succinctly

PEC day - Jan 22

Exploration of some building blocks of psychological intervention including subtle core skills and strategies, and the indirect work of the psychologist in the clinical health setting. Interactive, shared learning experience, and the opportunity to reflect on experiences.

Psychology day - Feb 22

Very worthwhile day with a good mixture of education/ discussion and networking. Allows team building across the network

*Level 1 and 2 Cardiac Nurse Specialist day
Nov 21*



Research update

Research in the network

Enhancing patient care through research is a key objective of the many studies being conducted within the South Wales and the South West Congenital Heart Disease Network. It is widely accepted that a research active culture can bring a host of benefits for patients, clinicians and the NHS. Research drives innovations, enables better and more cost-effective treatments and creates opportunities for staff and patients. In 2021/22 there were a large number of publications within our region.

The CHD research community in the SWSW region continues to be very active and there is much more planned for 2022/23!

Research update from the Paediatric Cardiac Research Team

The last year has been one of highs and lows. We have moved out from the shadow of COVID-19 to reopen cardiac studies and commence new cardiac studies.



The CARDIOCEL study was one of the first commercial studies to be reopened in the Trust. It is a post marketing registry for Cardiocel products used to repair congenital defects. We were the first site to open in the UK and quickly met our target and agreed to over recruit. The study has since changed sponsor and we have been asked to reopen recruitment to cover specific groups of operations still needing to be recruited to.



OMACp (Outcome Monitoring after Cardiac Procedure) has gone from strength to strength with recruitment now standing at around 1500 patients/parents. It has also gone multicentre, with Leicester and Dublin open to recruitment.



A new BHF funded, multicentre, randomised control trial (DESTINY) looking at different types of cardioplegia has started recruitment. The study is comparing the standard cardioplegia (medicine used to stop and protect the heart during cardiac surgery) used in the UK to a cardioplegia used in America. It aims to see whether the American cardioplegia helps children recover faster and with fewer complications. It is run in 4 UK centres, Birmingham, Bristol, GOSH and Leeds.

Along with these successes we have had difficult times. Some of the research nurse posts are funded through the Biomedical Research Centre which was due for renewal of its 5-year funding. Unfortunately, the cardiac component was not successful, and we will lose this funding later this year. This will inevitably reduce our numbers and subsequently our ability to deliver research. We will still have a core group of nurses however and have grant bids in progress to try and replace those posts lost. The team are focused on delivery first class research in Bristol to improve the outcomes for all our patients across the network. Watch this space!

For more details on our research strategy and research in the network please visit www.swswhd.co.uk



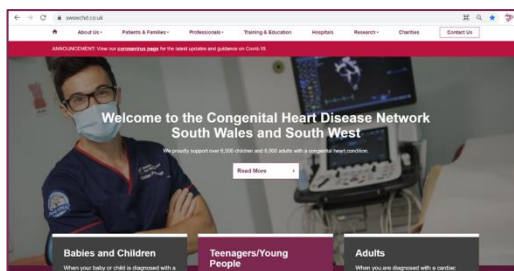
Communication and Engagement

Network communication

The network acts as a central point of communication and information for network stakeholders. With well-established communication channels, we have been able to support our network members and wider teams with rapid and effective communication particularly in response to COVID-19.

Highlights include:

- Led a national network of CHD networks COVID-19 response forum which has continued to run throughout the year with our admin support and our Clinical Director co-chairing this
- Developed and launched a 'demystifying the network' social media campaign in collaboration with network patient representatives and charity support groups to raise awareness of the network and signpost patients/families to website support resources. The featured posts included information about the network, the team, a patient/family story, and information on how to access support



- Arranged a professional photo shoot with the support of patients from around the region who consented to take part, for new high-quality photos to refresh the network website, social media and publications.

- Enhancing the network website – updates include:
 - ✓ New homepage rolling photo banner with refreshed professional photo shoot images of regional CHD patients and staff
 - ✓ Refreshed patient story page and accessibility functions
 - ✓ Arranged a free external audit from website supplier
 - ✓ COVID-19 information frequently updated with resources for patients, families and staff – this includes general advice, CHD specific advice and useful resources for wellbeing and mental health
 - ✓ New accordion (opening and collapsing function); and the development of a new 'events' calendar page for training and education events to be launched in May 2022.
- Redesigned our biannual CHD network newsletters - published and distributed to network members and further afield.



Communication and Engagement

Highlights continued

- Launched a new staff photographic competition as a wellbeing initiative and published photos on the network website. The winning photo (right) with the theme 'February scenes across the network' was taken by Dr Nigel Osborne, Paediatrician with Expertise in Exeter.



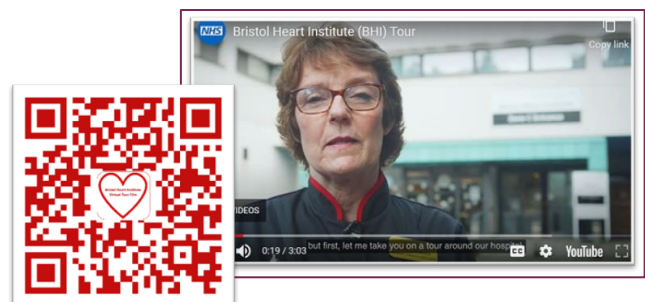
- Relunched a series of patient and family support webinars, including a new webinar on mindfulness, facilitated by the psychology network team. The recorded webinars are now available on the website, and will also form part of new psychology resource QR posters to be launched in Summer 2022 to give families easier access to resources.

1. Living with a cardiac condition – Supporting your child coming into hospital
2. Living with a cardiac condition – Managing the impact of a cardiac condition for parents
3. Living with a cardiac condition – Supporting siblings
4. Living with a cardiac condition – Mindfulness



- The psychology team specifically reviewed resources in the ACHD service in 2021/2022 with adults patient representatives. Following feedback a new resource focussing on support and how to cope as an inpatient was developed.
- Patient stories presented at Network Board – piloted new format of presentation with pre-recorded voiceover: well-received by Network Board.

- Bristol Heart Institute Virtual Tour film created and premiered in October 2021 to support young people during the COVID-19 restrictions and beyond. The film makes the information widely available to all those young people and families who may be seen in peripheral clinics across South Wales and the South West network



- Lead Nurse attended patient engagement training with the Transformation Team and BNSSG CCG



- Increased engagement with patient representatives with a virtual pre-meet before the network board, as well as debriefs. Positively received by patient reps and has led to more active engagement in board meetings. The patient representatives have discussed their specific areas of interest and have supported various network projects.



Patient representatives update'

The network have continued to work closely with our excellent patient and parent representatives to ensure that the patient voice is central to our activities. This team are made up of both adults with CHD and parents of children with CHD, and work closely with the network team to feedback their views on various aspects of the service in both the paediatric and adult CHD services. They are already making plan to welcome more individuals into this group and improve our engagement further in the coming year. Frankie Carlin shares more:

"I have been a Patient Rep since the inception of the role and I can honestly say, that as the years have gone by, we have been taken very seriously by the South Wales and South West CHD Network.

Both as patients or parents of patients, all of our suggestions and points of view have been listened to, acknowledged and validated. It can be quite daunting speaking to consultants, nurses and members of the board, especially via online, but we have always been made to feel welcome, supported and thanked for our input.

This year we have been working particularly on the mental health side of both the patients and the parents of patients.

I was honoured to be asked to sit on the interview panel for a new cardiac psychologist role in Cardiff and I felt this was a real step forward in the appreciation of what a patient needs - to be treated holistically. I will leave you with our guiding principle/strap line that we promote..."



'If a patient is involved, discussions should include a Patient/Parent representative'

Work with charity partners

The SWSW CHD Network collaborates frequently with local charities in the interests of CHD patients in the region to promote activities and support. We are grateful to our charity and support group partners for their support and for promoting the CHD website and resources. In 2021/22, charity partners were invited to include updates in our network newsletter and a charity and support page was further developed on the SWSW CHD network website - www.swswchd.co.uk/en/page/charities - to direct patients and families to further sources of support. The network team and partners regularly support one another on Twitter to raise awareness of CHD and the support available. It is hoped a meeting will take place in September with the local charities and the network team.

In 2021/22 the network promoted the Youth at Heart provision of youth worker support for 15-25 year olds, the Heart Heroes 'I can' project and support hubs across the SWSW region, and much more support. Several representatives of charity partners have fed into the network's 'Demystifying the network' campaign (where we posted weekly posts on the network), and have volunteered their expertise to support the network in improving its website and social media strategy, in order to engage and inform more patients across the region.



Financial Report

The SWSW CHD network is funded by NHS England and was allocated an annual budget of £194,435 in 2021/22, after overhead contributions to University Hospitals Bristol and Weston NHS Foundation Trust as the host organisation.

The end of year statement for the network is shown in the table below. The SWSW CHD network closed the financial year with an overspend of just over £6,000. The overspend was due to long term sickness cover in the team which is in part offset by a reduction in non-pay spend, owing to COVID-19 restrictions preventing travel and face to face network events.

Network funding		2021/22		
	Expenditure	Budget	Variance	
Pay				
Total	£ 193,815	£ 174,747	£ -19,068	
Non-Pay				
<i>IT (inc. website), office</i>	£ 4,930	-		
<i>Travel</i>	£ 85	-		
<i>Training/events</i>	£ 1,418	-		
<i>Miscellaneous</i>	£ 191	-		
<i>Refunds/income</i>	£ 0	-		
Total	£ 6,624	£ 19,688	£ 13,064	
Total				
	£ 200,439	£ 194,435	£ -6,004	



Risks and Challenges

The top risks/challenges for the CHD network are highlighted below. All our network risks are monitored through the SWSW CHD network board. Please note that from April 2022 the CHD network will no longer hold a risk register on the UHBW Datix system, following a change in approach from NHS England. Instead, it will hold a local issues log, which will be reviewed by the network board quarterly and be available on request. Risks will be held on provider or commissioner risk registers as appropriate.

Top Risks for South Wales and South West CHD Operational Delivery Network

Risk / Challenge	Score (1-25)	Owner	Mitigation
Risk that CHD patients come to harm because of delays to appointments and procedures across the network caused by backlogs since COVID-19	15	Provider Trusts	Network has quarterly reporting which enables organisations to report into CHD Network Board. Every organisation has elective recovery back logs, CHD will be part of organisations recovery plans.
The CHD Standards and Specification 2016 NHSE states <i>'Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses whose role will extend across the network'</i> The ACHD service has 3 ACHD CNS unchanged since 2013	12	Provider Trust	Proposal for staffing increase submitted October 2018 and Spring 2022, was not successful. Work load assessed on a daily basis and clinical work prioritised. Education, audit, service development and professional development takes place when possible. ACHD CNS advised to apply for charity funding to support a CNS for 18 months.
Risk that CHD patients in South Wales are not having the same standards of care because the NHSE CHD standards are not currently adopted by services in Wales.	9	WHSSC	South Wales forms part of network and reports into the network board on performance, escalating any issues. Approval in principle by WHSCC and Health Boards to adopt the English CHD standards. Self-assessment visits now conducted with level 3 centres and summary report is being completed to inform this decision.
Risk that network centres will be unable to identify or fund link nurses, reducing quality of service to patients (Note: link nurses may be named but without funded time to deliver the role)	8	Provider Trusts	The network team has met with managers, clinicians and/or senior nurses in each hospital to explore the local options. A link nurse development programme has been put in place. Plans are under way to increase access to level 1 and 2 Clinical Nurse Specialist for those patients in greatest need of support.
Risk that adult CHD service provision will be compromised across the network due to recruitment and retention of specialist ACHD medical workforce	9	Provider Trusts	National drive to increase ACHD staffing across CHD Networks



Our Focus for 2022/23

To ensure the continued development and delivery of CHD services across the South Wales and South West, we will be focusing on the following priorities in 2022/23 (in addition to our core 'business as usual' activities, such as education and engagement):

#1 Post-COVID restoration and recuperation

Continue to monitor CHD activity across the region and work to improve equity of access. Support the restoration and recovery of CHD activity. Signpost access to resources and support for staff wellbeing.

#2 Recruitment in the core Network team

Recruitment of a permanent network manager will become a focus for the months ahead. Securing nursing time in order to make up the shortfall in lead nurse hours, reduced manager hours and succession planning for the clinical director role will also be key to a stable workforce and ensure smooth running of the Network.

#3 CHD standards in Wales & South West of England

Continue to support the adoption of NHSE national CHD Standards and Specifications across Wales by delivering a report to the Welsh Commissioning and health boards.

Our focus will also be to plan for the next phases of self-assessment reviews across the South West of England to measure compliance with the CHD standards.

#4 Patient experience

Work with patient representatives to strengthen their role and embed the voice of the patient further into the network.

- recruit more patient representatives focusing on a sample representative of the CHD population
- plan a patient representative workshop to provide training and resource

#5 Transition between paediatric and adult services

Continue to drive forward the transition pilot project and support the level 1 taskforce to implement transition clinics in some peripheral centres with Level 1 Cardiac Nurse Specialist support. Letters to be sent out in the next phase of the project outlining the offer of the pilot. Centres to be chosen and pilot to start in the coming year



Looking to the future



Saying goodbye to... John Mills

The SWSW CHD Network will see a few changes going into 2022/23.

After more than 10 months as Network Manager for the South Wales and South West CHD Network, John accepted a promotion to a different challenge as Deputy Divisional Director at University Hospitals Bristol and Weston. John led the Network team superbly and will be greatly missed by the core team as well as the patient representatives and wider board members.

What's next?

The hard work that John put in on the WHSSC report and accompanying self assessment process will be continued by the network team who will aim to submit the report along with its recommendations to WHSSC and the Health Boards in June 2022. Our attention will also be turned to continuing our level 3 self-assessments across the South West of England in collaboration with local services and teams.

A key focus for the Network in the next year is recruitment. We are keen to ensure that our next manager brings a wealth of experience and professionalism that will enhance and continue the progress made so far by the network. A huge amount of work has taken place over the past year despite the continuing challenges of COVID-19 and we are grateful to all our network members and partners.

We were very pleased to have Jess Hughes continue her secondment and job share with Sheena Vernon in the Network Lead Nurse role. We look forward to the ongoing work they are doing with network partners. Transition and education being key areas of focus, as well as supporting nurses involved with CHD care across the region.

Our Clinical Director, Andy Tometzki, who has been with the network since its inception is coming to the end of his tenure and a new Clinical Director will need to be recruited in the coming year. This role provides clinical medical leadership across the Operational Delivery Network and is vital to the smooth running of the network. Andy will be a tough act to follow, his experience and leadership has played a major role in bringing together colleagues across the network to improve care for patients with CHD.

Whilst our working this year has remained digital, we have two upcoming events planned that will be held face to face. Our level 1 and level 2 Cardiac Nurse Specialist day will be held in Cardiff and our Network Board and Clinical Governance meetings in July 2022 will be our first hybrid events. We are so excited to meet with colleagues in person again to continue and build upon the fantastic work that has become synonymous with the South Wales and South West CHD Network.





How to get involved

There are many ways to get involved with the network:

Professionals can:

- Express interest in becoming a board member
- Attend one of our training events
- Take part in our virtual annual morbidity and mortality meeting in October 2022
- Come to our stakeholder day – date tbc.

Patients and families can:

- Visit our website (www.swswchd.co.uk)
- Sign-up to our newsletter mailing list
- Apply to become a patient or parent representative for the network
- Attend one of our engagement events
- Come to our stakeholder day – date tbc.

For more information, please:

Visit our website: www.swswchd.co.uk

Follow us on twitter: @CHDNetworkSWSW

Email: rachel.burrows2@uhbw.nhs.uk.



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

