



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

Annual Report

2018/19



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Annual Report

Introduction from the clinical director

Welcome to the third annual report for the South Wales and South West Congenital Heart Disease (SWSW CHD) Network, 2018/19.

It has been a particularly busy year for the team for a variety of reasons. There have been core changes to the team. Caitlin Moss left us for her new role as deputy divisional director for strategy and planning, women's and children's services at Bristol Royal Hospital for Children. I am delighted to welcome Cat McElvaney, who takes the helm as our network manager, bringing a wealth of experience. Our administrative support has also been enhanced by the appointment of Morwenna Bugg. Yet again I was pleased to experience a seamless transition during these personnel changes as our work continued without interruption.

I am pleased to be reappointed to serve as clinical director for the next three years. Within the network, we have seen a number of senior consultants retire, whilst we welcome the next generation. Nationally, we continue to be heavily involved in the formation of a "network of CHD networks" community throughout the UK since launching the concept in 2017.

NHS England (NHSE) has recently declared us an operational delivery network. This is an important milestone for us as well as for the other CHD networks emerging around the country. We continue to provide mutual support to these networks and learn from each other as we develop.

We, along with all the congenital heart networks throughout the UK, prepared for an NHSE peer review of our level one and level two services. I would like to thank and congratulate all the contributors who helped to collate the evidence we were asked to provide. This was a mammoth but worthwhile task. I was also very proud to hear colleagues voice how the network team had made a positive impact to services in South Wales and South West England. We were delighted to hear preliminary comments describing our network as an exemplar. A NHSE report by the quality surveillance team will be published later this year.

I am particularly grateful to our senior dental colleagues, Mick Allen and Rosie Power, for their excellent work on developing a dental pathway for our patients across all ages within the entire network. This has been a key piece of work and I congratulate them for this major contribution.

We continue, first and foremost, to be guided by our patient experiences and outcomes and Frankie Carlin is no exception. Please read her story on page 17 and perhaps, like her, become inspired to get involved yourself. We will be enhancing patient and public voice involvement with specific training sessions in the coming year.

There is still much work to be done for us to achieve the 2021 NHS England standards. The team looks forward to continuing the positive and collective engagement with all our partners across the network in the year to come.

This report celebrates our achievements whilst recognising the many challenges that help to form our work plan for the future.



Dr Andrew J P Tometzki
Clinical director
South Wales and South West Congenital Heart Disease Network

Background

The South Wales and South West Congenital Heart Disease Network (SWSW CHD) was officially formed in April 2016. The network brings together clinicians, managers, patient and family representatives, and commissioners from across South Wales and South West England to work together supporting patients with congenital and paediatric acquired heart disease and their families. The network covers a broad geographical area of South Wales and South West England (Aberystwyth to the Isles of Scilly), as outlined in figure one, with a population of approximately 5.5M people. This network is accountable to two separate commissioning bodies: NHS England and NHS Wales.

The network comprises:

- 17 adult and 19 paediatric providers, covering level one (specialist surgical), level two (specialist medical) and level 3 three (local centre) services
- over 6,500 children and 8,000 adults with congenital heart conditions

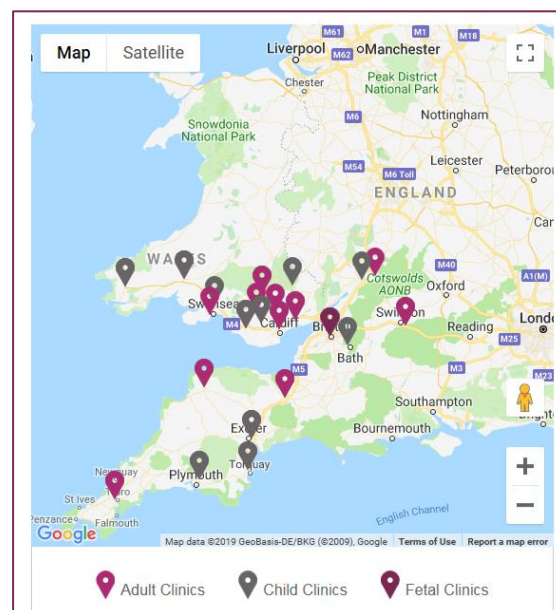


Figure one: South Wales and South West CHD network centres

Our vision

Our vision is to be a network whereby:

- Patients have **equitable access** to services regardless of geography
- **Care is provided seamlessly** across the network and its various stages of transition (between locations, services and where there are co-morbidities)
- **High quality care** is delivered, and participating centres meet national standards of CHD care
- The provision of **high quality information** for patients, families, staff and commissioners is supported
- There is a strong and **collective voice** for network stakeholders
- There is a strong culture of collaboration and action to **continually improve** services

Our objectives

Our objectives were developed in collaboration with stakeholders from across the network and underpin a detailed work plan overseen by the network team. They are:

- To provide **strategic direction** for CHD care across South Wales and the South West
- To monitor and drive improvements in **quality of care**
- 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 ensure it can **demonstrate the value** of the network and its activities

Meet the network management team



Pictured left to right: Dr. Andrew Tometzki (CHD network clinical director), Dr. Vanessa Garrett (clinical psychologist) (top row), Cat McElvaney (CHD network manager), Sheena Vernon (CHD network lead nurse), Morwenna Bugg (network support manager) (bottom row).

The network management team was established in April 2016, comprising initially of the network clinical director, network manager and administrator, with the network lead nurse joining the team in October 2016. In 2018, a new role of network support manager, following a skill mix review of the network team, was created and recruited to. This has enabled us to place greater focus on enhancing communication and engagement within the network. The key priorities and work of the network team is determined by the network board. It is responsible for ensuring that the activities of the network staff are in line with agreed network priorities and are working towards the achievement of CHD standards.

Our network clinicians

We have a large number of clinicians providing CHD care across the South Wales and South region. This will include:

- Three cardiac surgeons
- 16 paediatric cardiologists and 39 paediatricians with expertise in cardiology
- Seven cardiologists in adult congenital heart disease and 19 cardiologists with a special interest in adult congenital heart disease (ACHD)
- 14 clinical nurse specialists and 40 link nurses
- Four specialist clinical psychologists

To find out more about the clinicians in our network, please visit the "Our hospitals" section of our website (www.swswhcd.co.uk).



OUR NETWORK IN NUMBERS 2018/19

South Wales and South West Congenital Heart Network

CLINICAL CARE



450

heart
operations



648

cardiac
catheters



c.23,000

outpatient
attendances



1547

psychology
contacts

OUR NETWORK



CONSULTANTS INCLUDING

3 cardiac surgeons

16 paediatric cardiologists

7 consultants in adult
congenital heart disease

32 paediatricians with
expertise in cardiology

19 adult cardiologists
with specialist
congenital interest



NURSING STAFF INCLUDING

14 clinical nurse specialist

40 link nurses

17 ADULT AND 19 PAEDIATRIC CENTRES

covering level 1 (specialist surgical),
2 (specialist medical) and 3 (local
centre) services



Adult Clinics Child Clinics Fetal Clinics

COMMUNICATION AND ENGAGEMENT



18

network meetings
and events



14

patient
representatives



6014

website
users



198

twitter
followers

VISIT US: WWW.SWSWCHD.CO.UK FOLLOW US: [@CHDNETWORKSW](https://twitter.com/CHDNETWORKSW)



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

Key successes

The full details of our progress in 2018/19 and plans for 2019/20 are detailed in the work plan – review and plans section on page 14. Our key successes in 2018/19 include:

Clinical

- Cohesive and comprehensive joint preparation for the **national CHD network peer review** (June 2019) by the network, level one adult and paediatric services and level two adult and paediatric services
- Development, approval and publishing of several **paediatric and adult CHD protocols**, recommended by NHS England for CHD and required for the national CHD peer review
- **Network wide dental standards for CHD care for adults** developed, approved and published. Paediatric CHD dental standards close to completion
- Excellent progress has been made in delivering **network drug protocols** for paediatric care
- Positive evaluation by patients of families of new transition clinics at Bristol Royal Hospital for Children (BRHC.) **Transition evening** for patients and families held at the Bristol Heart Institute (BHI), with around 50 people attending. Transition protocol updated and approved
- **Network nursing strategy** finalised and being implemented across the network, further nursing progress updates can be found on page 13
- **Link midwife** identified to participate in cardiac obstetric clinics
- **Network audit lead** in place (cardiologist based in Wales) and network audit programme to share learning and best practice in progress
- Network **morbidity and mortality meeting** held with 25 attendees from multi-professional groups around the region.

Patient, charity and support group engagement

- Continued development of **patient representative role** within network. Event for patient representatives held and positively evaluated. Patient representative role description and application form developed
- The network team worked with the local level three paediatricians supporting their **patient engagement evening** for Gloucester families in conjunction with the local parental support group
- Continued to build **partnerships with local and national charities** and support groups with a **CHD Charity day on 3 October** held to facilitate joint working between local cardiac charities
- Development and recruitment of a **youth worker role** for the BHI and broader region, supported by the charity Youth@Heart.



Research and education

- **Network training and education strategy** approved and implemented
- Continued development of resources for professionals on the **network website** and signposting to national and international training events (<https://www.swswchd.co.uk/en/page/training-and-education>)
- Delivery of multiple training events for network clinicians with excellent attendance and evaluation
- **Draft network research strategy** developed, including a programme of research activity, and shared with Network Board in March 2019.

Highlights from our centres

Network centres report to the network board on progress against delivery of the CHD standards for their areas. Highlights from these reports for 2018/19 are outlined below.

Level one: Bristol, specialist surgical centre

Adults

- Quality improvements in ACHD service, including pilot in ACHD cardiac rehabilitation, exercise ACHD echo service, Fontan associated liver disease pathway
- ACHD journal club established, which provides weekly communication between clinical and research teams
- Wide-ranging ongoing audit programme in progress for shared learning and best practice
- Same day outpatient clinic letter generation
- IT improvements, such as evolve (electronic patient record)
- Youth worker role recruited to adult service

Paediatrics

- New cardiology consultants recruited
- Approval to recruit to fourth surgeon post
- Additional clinics set up in Weston General Hospital and South Bristol Community Hospital
- Set up of Clinical Nurse Specialist anticoagulation service
- Received highest ever data quality indicator of 99% for reported clinical outcome and quality (NICOR) data
- Reduction of cardiac surgery waiting times an overall list

Level two: Cardiff, specialist medical centre

Adults

- Implementation of phase two of the South Wales ACHD service supported and included in the 2019/20 commissioning plan
- New cardiology outpatient department commissioned to support the ACHD service
- New cardiac MRI scanners in use, which provide greatly improved quality, enabling appropriate cardiac MRI scanning, image analysis and reporting
- Text reminder service implemented, resulting in a significant reduction in “did not attend”(DNA) rates (from 18% in 2017 to 10.5% in 2018)
- Investment in image exchange portal to enable electronic transmission of echo images to level one centre
- Systems developed and implemented to reduce patient lost in repatriation process to local health boards.

Paediatrics

- Organisation and delivery of successful Welsh paediatric and Welsh fetal cardiovascular network education conferences
- Recruitment of consultant to enhance fetal cardiology services
- Text reminder service implemented, resulting in a significant reduction in “did not attend”(DNA) rates (from 9.7% in 2017 to 6.6% in 2018)
- Reduction of referral to treatment waiting times within Cardiff and Vale University health board from 23 weeks in 2016/17 to 13 weeks in 2018/19
- Successful introduction of Careflow app, allowing Cardiff clinicians to view progress of Welsh patients admitted to Bristol Royal Hospital for Children
- Business case accepted in principle for Cardiff and Vale based clinical psychologist
- Teenage clinics successfully established at the Noah's Ark Children's Hospital



Adults

- New ACHD consultant in post in Taunton
- Transition clinics set up in Taunton with establishment of link nurse role
- Developing and establishing link nurse role in level three centres across network
- Improved tracking of ACHD patients in general cardiology clinics

Paediatrics

- New consultant paediatrician with expertise in cardiology started in Plymouth
- Progressing cardiac link nurse 0.1 WTE in Torbay
- Reduction in waiting times for new patients in Taunton
- ECHO machine available at all times in Taunton paediatric department
- Physiologists in Taunton able to attend at least two clinics a month to support the PEC
- Urgent patients can be seen within one week on the paediatric assessment unit in Swindon. New patients whose cases are urgent are expedited for the visiting cardiologist
- Improved image storage under progress in Truro
- Recruitment drive in Truro to appoint consultant in substantive position to cover extra clinics provided by local paediatrician with expertise in cardiology (PEC) and paediatric cardiologist

Communication and engagement

Communicating and engaging with our patient and clinical colleagues has been an essential part of our work in our third year of operation. Key activities have included;

- Stakeholder engagement event held with multi-disciplinary team attendance from across the network
- Patient representative group established, inaugural event held which was very positively evaluated
- Promotion of CHD website (www.swswhcd.nhs.uk) via posters, charity and support groups, and on clinic letters
- Network bi-annual newsletters published and circulated widely
- Weekly tweets with network updates, news from charity and support groups, and promotion of education and training events
- Event held for all local CHD charities and support groups to help facilitate relationship building and joint working
- Regular meeting established with NHS England specialist commissioners and welsh health specialised services committee (WHSSC), and attended by network team, level one and level two CHD clinical leads and managers
- Participation in a number of national forums such as the clinical reference group for congenital heart disease, British adult congenital nurses association meeting, national CHD networks group and the patient reported experience leads meeting
- The network team has attended and presented at a number of events and groups including the paediatric cardiac study day for community and ward nurses, paediatric critical care advanced module, WHSSC audit day, Cardiff patient engagement day and a number of team days including Dolphin ward and neonatal intensive care team away days.



Network team funding

The network team is funded by NHS England specialised commissioning. The pay budget was marginally underspent in 2018/19 due to gaps in recruitment into substantive posts. Recurring costs are expected to be in-line with the annual budget plan. There was an offset relating to non-pay budgets where there was a reported overspend of £799. The overall budget position was a reported underspend of £1,804 at the financial year end.

Network Funding	2018/19
Pay	
Pay total expenditure	£152,845
Pay budget	£155,448
Pay Variance	£2,603
Non Pay	
IT, phones & office	£9,980
Travel	£1,038
Network events	£2,826
Miscellaneous	£2,955
Non Pay Total Expenditure	£16,799
Non Pay Budget	£16,000
Non Pay Variance	-£799
Total Variance	£1,804

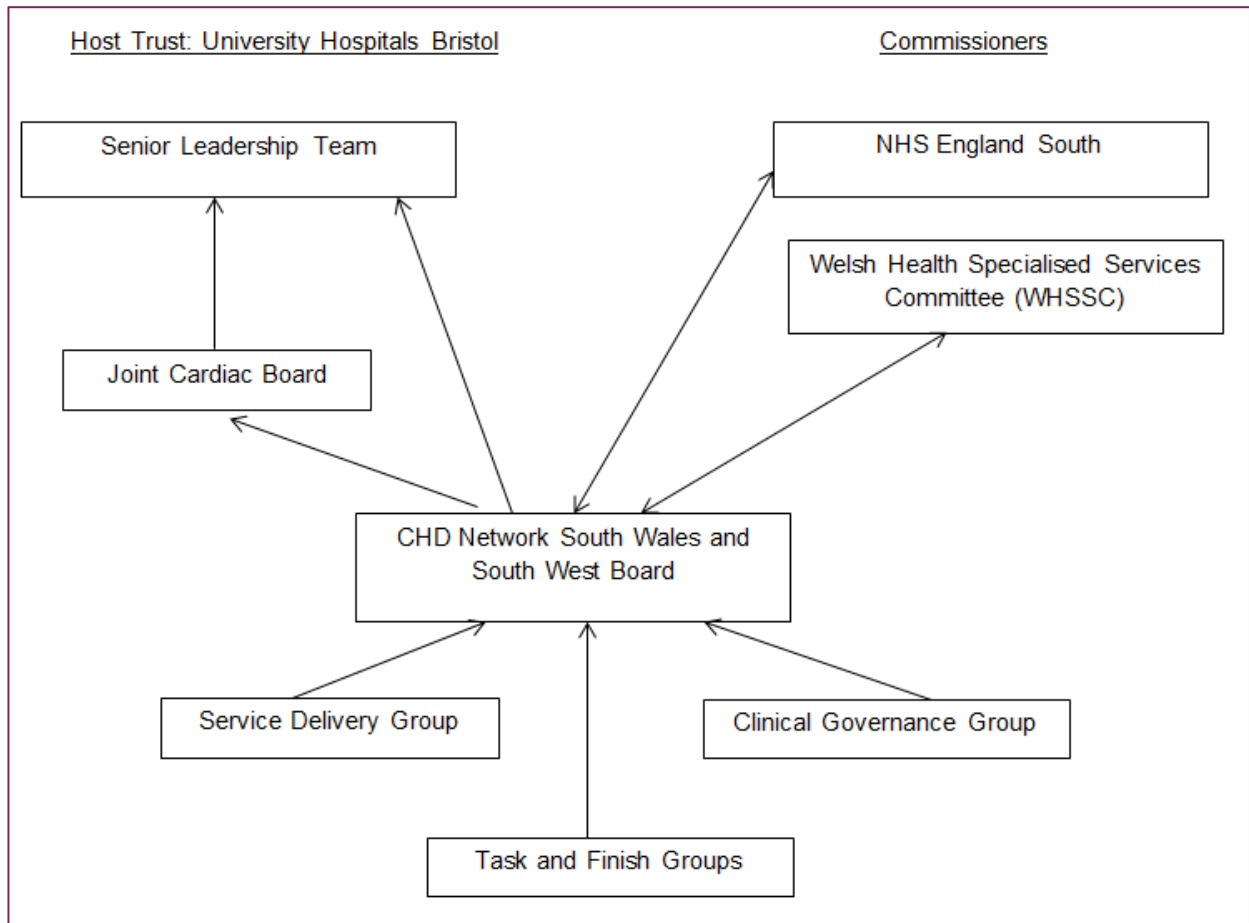
Update on network governance

The network is governed by the South Wales and South West (SWSW) CHD Network Board, which has representatives from across the level one, two and three centres, including clinicians, nurses, managers, patients and parent representative and commissioners. In 2018/19, it was agreed by the network board to change the configuration and governance of the network to include two subgroups; the network service delivery group (SDG) and the network clinical governance group (CCG). Each of these groups has key roles and responsibilities as outlined in the table below. The change in governance structure for the network was implemented to provide more opportunities for detailed discussions and more focussed work, to use members' expertise and interest more, and overall to have greater accountability within the network. This new structure will be evaluated by network members for effectiveness a year post implementation (October 2019).

Division of responsibilities for CHD SWSW Network groups		
Network board	Network clinical governance group	Network service delivery group
Overall responsibility Escalation of concerns Risk management Strategic direction Performance assurance Centres, commissioners, charity etc. updates	Education and training programme Incident management and learning Annual mortality and morbidity Audit programme Clinical pathways, protocols, guidance Patient leaflets and pathways	Standards & self-assessments performance and capacity Workforce issues The website and other technology projects Patient engagement and support groups Finance/tariffs



As illustrated below, the network board remains accountable to the joint cardiac board and senior leadership team at University Hospital Bristol NHS Foundation Trust (UH Bristol) as the host organisation; in NHS England to the specialised commissioning (South) oversight group; and in Wales to the Welsh health specialised services committee. This network covers two separate national health bodies: NHS Wales and NHS England. The network meets with representatives from both commissioning groups in a quarterly review meeting and at the Network Board to review key clinical quality outcome measures, progress against plan and any escalated risks and/or issues.



Key network risks

The network risk are recorded on the datix risk management system of its host organisation, University Hospitals Bristol. Risks are assessed and reviewed, and mitigations agreed, at the network board.

	Risk	Mitigation
1	Long-term workforce risk associated with a lack of consultants training with expertise in congenital cardiology, particularly in the adult services	Local clinicians are flagging the issues to their trust management teams, supported by network. Risk discussed at network board and actions agreed including to continue to link in with Health Education England and the CHD clinical reference group to understand any national strategy to address this.
2	Risk that network centres will be unable to identify or fund link nurses, reducing quality of service to patients	The network team working with local hospital teams to explore options. Draft finance guidance completed to help support trusts to develop this role. A link nurse development programme has been established.
3	Risk of cancelled cardiac operations due to paediatric intensive care unit (PICU) capacity pressures	A strategic outline business case for the Bristol Royal Hospital for Children (BRHC) expansion, including Paediatric Intensive Care Unit (PICU), was approved by UH Bristol in March 2019 to proceed to a full business case with more detailed costs and options. It is anticipated that the project could take five years or more to complete, and that planning permission will be a key challenge given the space constraints around the site.
4	Risk of inferior care being provided to patients in some parts of South Wales due to unequal investment in services	The 2019-22 WHSSC integrated commissioning plan has prioritised additional investment in the South Wales adult congenital heart disease service provided by Cardiff and Vale University health board. WHSSC is working with colleagues at Cardiff and Vale University health board to finalise the business case and it is anticipated that this will be submitted to WHSSC in July 2019. This investment will support the ACHD service in meeting the CHD standards.
5	Risk of not meeting the congenital heart disease standard for care around interventional cardiologist case numbers	Data on procedures and clinical outcomes is submitted to NICOR and reviewed on a regular basis by level one centre and NHS England to ensure clinical quality and patient safety. In 2019/20, specific actions and mitigations for the provider and commissioner have been agreed and these actions and mitigations will be jointly reviewed at the NHS quarterly CHD meeting.
6	Risk of failure to deliver of CHD standard relating to image sharing between organisations in the network	Survey has been conducted to scope out current IT system provision for image sharing across the network to understand feasibility of making improvements and working towards the standard.

Nursing update

In 2018/19, work has continued to **support link nurses** across the network, **developing resources** for them to use in the peripheral clinics. There still remains a challenge for link nurses to have allocated time for their role, which limits the opportunity for some to make progress and develop the role to support patients and families in outpatient clinics and during inpatients stays. Working in collaboration with Yorkshire and Humber's CHD Network, a **link nurse job description** has been written and presented at a national CHD network day. A **link nurse resource folder** has also been developed which contains national and international guidelines, toolkits, workbooks and information to support transition of patients to the adult services. This resource will be continually developed. There are opportunities for link nurses to visit level one and two centres to understand how the clinical service runs, meet the team and visit clinical areas.



Pictured; Sheena Vernon, Network Lead Nurse

The clinical nurse specialist (CNS) teams have been focussing on providing care at the fetal clinics, delivering a comprehensive transition service across from Bristol Royal Hospital for Children to the Bristol Heart Institute, and in the young people's clinics in a number of level three centres. Work is ongoing to increase the CNS team numbers across the network. A **level one and two CNS day** takes place every six months with the most recent one held in January 2019. This provided an opportunity for teams to discuss their recent challenges and achievements; to get updates on preparation for the forthcoming peer review, a session on joint working between Dolphin ward and Pelican ward and an update on local charity activity. The day was well evaluated, with those attending finding it particularly beneficial to network and share best practice.

The **Bristol Royal Hospital for Children cardiac link nurses meetings** take place bi-monthly and enables all nurses caring for cardiac patients to discuss clinical issues, share best practice and ideas. Outcomes of that meeting have included work by the neonatal intensive care (NICU) nurses to design a, '**calling card**' with the contact details of the cardiac clinical nurse specialists on it. This can be left for parents if they are not with their baby when the nurse visits, making it easier for the parents to then make contact with them if needed. Transfers of babies from NICU to Bristol Royal Hospital for Children can often cause significant anxiety for new parents. To help support parents during this time, the NICU nurses are drafting a leaflet for parents, explaining how the transfer of their baby will take place. The link nurse meeting has also provided an opportunity to raise awareness of the CHD network workplan, and of the CHD Network website (www.swschwcd.nhs.uk) and resources, so nursing staff are able to direct patients and families to the appropriate help and support.

Education opportunities and other specific resources from clinical areas are shared so that all the nurses in the network can benefit. A similar meeting takes place in the Bristol Heart Institute, where nurses from all clinical areas meet on a regular basis to discuss similar issues, sharing learning and best practice. In 2018/19, we have benefited from our **link cardiac midwife** who has supported the cardiac antenatal clinics, providing additional advice, information and support to mothers with congenital heart disease. In Taunton, the ACHD nurse has been able to provide support to the ACHD clinic and also has worked with the paediatric link nurse to support the **first transition clinic** in the children's services. It is hoped this model will be replicated in Exeter this year.

This year, a number of education opportunities for nurses have included attending **cardiac courses** and the **community and ward nurse days** delivered by the faculty of children's nurse education in Bristol, and the adult congenital heart disease study day, which over 90 people attended. In 2018/19, a key role for a number of nurses has also been involvement in supporting local cardiac charities with the aim of raising their profile in clinical areas and supporting more joined-up activities between these groups.

Work plan – 2018/19 review and plans for 2019/20

Key objective	Successes in year 3 (2018/19)	Aims for year 4 (2019/20)
To provide strategic direction for CHD care across South Wales and South West England	<ul style="list-style-type: none"> - New network governance structure implemented - Engagement with key national and local groups including Clinical Reference Group (CRG), British Adult Congenital Cardiac Nurses Association (BACCNA), British Congenital Cardiac Association (BCCA), CHD national networks group and local non-CHD group - Draft finance guidance produced for centres - Support provided to develop and complete the successful strategic outline case for expansion of the BRHC, which would include a PICU expansion. - Quarterly review meetings with NHS England and WHSSC established 	<ul style="list-style-type: none"> - Strengthen engagement with level three centres with visits to include update of self-assessments, priorities and challenges - Formal commitment from participating network member organisations / memorandum of understanding - Support centres to understand current income and appropriate tariffs for provision of CHD services - Continue to engage with clinical reference groups, NHS England, WHSSC - Actively participate in national CHD networks event and local (non-CHD) networks meeting - Evaluation of network governance structure and implementation of network board agreed outcomes
To monitor and drive improvements in quality of care	<ul style="list-style-type: none"> - Several paediatric and adult CHD protocols, recommended by NHS England for CHD are now complete - Excellent progress made in delivering network drug protocols for paediatric care - Nursing strategy finalised and being implemented across the network - Network-wide dental standards for CHD care for adults completed and paediatrics being finalised - Network-wide clinical incident shared learning session at network clinical governance group in March 2019 - Network audit lead in place (a cardiologist based in Wales). Work is underway collating audit information across network with plan to share completed audit results at future network clinical governance meetings - Network morbidity and mortality meeting held in Taunton in September 2018, with 25 attendees from multi-professional groups around the region - very positively evaluated - Task and finish group set-up to focus on improving discharge communications from the level one centre in Bristol to regional partners, aiming to improve current processes and timeliness of correspondence 	<ul style="list-style-type: none"> - Implement recommendations of national CHD network peer review - Agree requirements for paediatric disease-related guidance and paediatric drug protocols - Finalise paediatric dental pathway - Continue to support level one and two centres to address amber and red standards - Continue to capture risks on network register and take action to manage or mitigate risks - Promote incident reporting processes. Ensure any learning from incidents is shared - Continue to support improvements in communications to the network following discharge from level one centre - Set up and facilitate fetal working group, with clear terms of reference and action plan - Support network audit lead to run network audit programme with minimum of two audits per annum presented to network to share learning - Continue to deliver annual network mortality and morbidity event - Take forward key elements of network nursing strategy, namely; closer working between levels one and two CNS teams; direct engagement with known level three link nurses and senior nurses/matrons



To support the delivery of equitable, timely access for patients	<ul style="list-style-type: none"> - Published psychology toolkits available on network website - Palliative care toolkit published on the network website - Support provided to Welsh adult CHD teams to complete phase II business case for WHSSC. Case approved in principle. - Transition protocol has been developed and approved - Continued work to strengthen transition processes within the network - Network performance dashboard regularly reviewed and discussed at network board 	<ul style="list-style-type: none"> - Use published fetal datasets to understand variations in fetal identification and implement actions to address these - To develop better mechanisms for sharing patient information, images and access for MDTs. - Continue to promote awareness of, and access to, regional psychology service and available resources - Evaluate transition clinics at BRHC and young adult clinics in BHI. Consider peripheral transition opportunity. Scope out feasibility of monitoring lost to follow-up ratios - Continue to produce quarterly performance dashboard. Review centres' submissions and offer support and/or seek assurance or escalate concerns - Finalise network-wide transfer and repatriation policy - Continue to support level two centre and commissioners to support phase II investment in Wales
To support improvements in patient and family experience	<ul style="list-style-type: none"> - Supported successful patient engagement evening for Gloucester families in conjunction with the local parental support group - PREMs surveys promoted across the level one centre to increase response rate (currently on-hold nationally) - Work undertaken to support Youth@Heart with the development of a youth worker role for the BHI and broader region - Continued development of patient representative role within network – meeting for patient representatives held in November 2018 and positively evaluated. Job description and application form developed - CHD Charity day held in March 2019 to facilitate joint working between local cardiac charities 	<ul style="list-style-type: none"> - Continue to work with charity stakeholders and support groups, clarifying relationship and opportunities. Try to encourage fair access across the region - Continue to build on existing relationships with patient representatives. Develop programme of activity. Recruit further representatives - Support centres with local patient engagement events and try to encourage events that allow equal geographical access across the region
To support the education, training and development of the workforce within the network	<ul style="list-style-type: none"> - Network training and education strategy approved and implemented - Continued development of resources for professionals on the network website and signposting to national and international training events - Annual training day held for paediatricians with expertise in cardiology and annual ACHD study day held - Draft network research strategy developed and programme of research activity shared with network board in March 2019 	<ul style="list-style-type: none"> - Support the delivery of targeted training and education to cover: ACHD and paediatric nurse training, PEC and ACHD study days. Continue to signpost training and education events to network members in line with strategy. Continue involvement with development of national nurse e-learning packages - Continue to support recruitment of medical workforce as needed. Continue to engage with relevant regional bodies on big picture for e.g. Health Education England.) Develop promotion material to support recruitment into the region - Finalise network research strategy. Continue to build relationship with partners in research, seeking information on current research to populate the network central programme of research activity across the region and to update network members



To be a central point of information and communication for network stakeholders	<ul style="list-style-type: none"> - Bi-annual SWSW CHD newsletters completed - SWSW CHD network website updated (https://www.swswhd.co.uk/) and Twitter account launched (@CHDNetworkSWSW) - Successful network stakeholder day held in July 2018 in Bristol, with over 50 attendees from various stakeholder groups across the region. Positive evaluation received 	<ul style="list-style-type: none"> - Continue to promote website, updating and improving as required. Continue with weekly tweets. Consider setting up Facebook account - Meet with interdependent clinical teams to encourage collaboration and build relationships - Deliver two newsletters per year - Continue to represent network at events, meetings and visits - Continue to use email databases for targeted communications - Deliver large stakeholder event every two years (next one July 2020)
To ensure it can demonstrate the value of the network and its activities	<ul style="list-style-type: none"> - Cohesive and collaborative preparation between the network level one and two centres for national CHD peer review - Successfully escalated issues in order to be collective voice of network and to influence strategic decisions - Annual report for 2017-18 completed - Successful core team away session held - Sought feedback on all-network events and listened to suggestions on how to improve (events generally well evaluated) - Network remained in budget 	<ul style="list-style-type: none"> - Proactively seek funding opportunities for network and its stakeholders from different sources, such as CQUINs, charity, grants, tariff, commercial sponsorship of events - Continue to seek feedback from stakeholders on value of events and activities - Remain within budget and ensure effective use of resources - Hold team away day to reflect on 2019-20 progress, understand future opportunities and threats, and develop 2020-21 work plan - Complete annual report - Escalate network issues appropriately to commissioners and external bodies and ensure action is taken when required

Our patients and staff

Frankie Carlin, network patient representative

I was born with aortic valve problems and throughout my life I have had yearly appointments with a cardiologist. Over the last 20 years, I have undergone two open heart surgeries - the last one, a Ross Procedure performed in February 2017 in Bristol, was particularly brutal.



It was very complex and, as a 'redo', recuperation was even harder. I had to undergo many procedures before and after both surgeries.

I can honestly say that without the support of the cardiac nurses in Cardiff, I wouldn't have recovered as quickly as I did from my recent surgery. Their constant support was invaluable, both before and after the operation. Bethan, the cardiac nurse, was in the room with us when we were being told about the complexity of the operation and the other options that were available. We were bombarded with a lot of information and after the consultation were a bit 'befuddled'. To be able to discuss it with Bethan, straight after the meeting and in follow-up phone calls, was invaluable and meant I didn't have to worry about 'wasting' the consultant's valuable time, whilst still being able to manage my own health.

This was to be the pattern throughout my visits to the hospital. Whenever I needed information, the nurses were there. No question was too trivial, and if they didn't know the answer, they would return my call or email as soon as they found out. ***They treated me as a person and not just a patient. I cannot emphasise enough how important this is when you are undergoing such a serious operation that is totally overwhelming.***

To not have to introduce and explain yourself every time you meet or phone someone is fantastic. To also have people

who know your case, family, and circumstances is fabulous and helps with the whole treatment process.

From getting to know the nurses, I was asked to be a **patient representative** for the South Wales and South West CHD Network. I was delighted to take on this role and feel it's a huge honour to participate in meetings and give a patient's view. I have been a huge advocate for **cardiac patients being treated holistically**, as I feel that when you start to feel better physically is when you start to struggle mentally - and there was nowhere for me to turn. The cardiac nurses did what they could but there was no-one to be referred to. Through being part of the network, I have been able to suggest counselling throughout a patient's journey, which has been listened to. We have also tried to come up with ideas on how to 'spread the word' about the network and the continuing role of a patient representative. I have met and become friends with other patient representatives, which has been a bonus.

I am now back at work and trying to enjoy life to the full with my fantastic family and friends.

Susie Gage, lead paediatric cardiac pharmacist, Bristol Royal Hospital for Children.

I have been working as a paediatric pharmacist for the last 14 years. During this time, I have specialised in paediatric cardiology, cardiac surgery, general surgery, supported theatres and I can often be seen on the Paediatric Intensive Care Unit.



As a clinical pharmacist on the paediatric wards, I have a different role to what people may think is the 'traditional' role of the pharmacist. I am based on the wards and I am lucky to be part of the multi-disciplinary team; attending ward rounds.

On the wards, I check all medication prescribed; assessing the suitability of the formulation, the dose prescribed for the

appropriate indication, reviewing kidney and liver function for dose alterations, check for any drug or food interactions and suggest appropriate therapeutic drug monitoring. My main role is providing medicines information and education for nursing, medical staff and parents. In the last year I have become a non-medical independent prescriber, meaning I can prescribe medication for patients on the ward and for outpatients; this is a role I am hoping to develop further.

I was invited to attend a network meeting by Dr. Andy Tometzki, about a year and a half ago, and **I was inspired by the attitudes of members to improve the service across the network.** I was impressed by the inclusive nature of the network board and the desire for seamless care across the network with patients at the centre of decision. Since that meeting, I have become part of the network governance group and have been involved in the development of paediatric medication protocols for the network. I've been asked to present at various network days and I have been involved in subgroups to drive forward the service and outcomes of the network, whilst considering patient safety. Attending these meetings and speaking to clinicians around the region, has highlighted areas that could be improved. These include development of more guidelines in response to governance issues, better communication regarding medication supply problems and access to medications for patients in the community via their GP or local pharmacy. We hope that by co-ordinating this work it **will reduce duplication throughout the network, provide more seamless care and improved communication links locally, regionally and nationally,** as well as ensuring everyone has access and knowledge of the work that is being carried out.

Mick Allen, Consultant, special care dentistry, Aneurin Bevan University health board

I am a consultant in special care dentistry working with Aneurin Bevan University health board community dental services. I also work as a dental strategy advisor to Cardiff and Vale University



health board and work with Wales Government. Special care dentistry is best described as caring for adults who cannot access dental care in the conventional sense because of one or more impairments which may be physical, mental, emotional, intellectual, societal or medical. There are similar dental specialists and consultants who work with children and young people. In respect of congenital heart disease, our role is to provide clinical care for more complex patients, often at the request of, and in liaison with, their cardiologist and to provide advice and leadership for other dentists who may want support in managing their patients who have congenital heart disease.

The aim is to ensure correct management is provided by the right person, at the right time, in the best setting and as conveniently as possible for people. This may be by a dentist in a high street practice, a dentist within the community dental service, a specialist or consultant in a hospital or a community dental clinic. Other members of the dental team such as nurses with enhanced skills and dental therapists will be involved in providing preventative dental care. Dental managed clinical networks are being established to help provide these services.

I became involved with the CHD network because I enjoy a good working relationship with my cardiology colleagues and I have an interest in managing people with CHD and other associated conditions. My role has been to establish a small, specialist dental team, with my paediatric dentistry consultant colleague, Rosie Power, and to develop **dental care pathways.**

We have worked with the CHD network clinical director and the CHD network team to meet the described standards for dental services in relation to congenital heart disease. **These pathways should provide a framework for planning services for commissioning bodies, advice for dentists and help for patients.**

I see the future role of the dental team as being ready to provide updates to the care pathways as guidance changes and develops and also to provide an expert dental resource for the CHD network. The pathways will need to be evaluated and this will involve feedback from patients and dental teams in future.

Delivering continual progress

There are a number of key areas for centres to focus on in the coming year to continue to drive progress against the standards and continue to improve the quality of care we offer as a region to CHD patients

Link nurses	<ul style="list-style-type: none"> • Seek support in your Trust for the development of the link nurse role
Waiting list management	<ul style="list-style-type: none"> • Manage waiting lists effectively. Undertake demand and capacity planning for your service if required (We can support with this!) Complete your network performance report and flag up any issues
Education and training opportunities	<ul style="list-style-type: none"> • Make use of network and other training opportunities for staff
Escalate risks, issues and incidents	<ul style="list-style-type: none"> • Escalate any relevant risks or issues to the network team and engage with network incident management processes to ensure learning is shared
Image sharing	<ul style="list-style-type: none"> • Work with the network's IT contacts at the level one centre to ensure image sharing links are as good as they can be, and understand where future opportunities are
Annual audit	<ul style="list-style-type: none"> • Ensure one annual audit of clinical significance is completed each year and shared. Participate in network annual mortality and morbidity event
CHD resources	<ul style="list-style-type: none"> • Access CHD resources as required, including network protocols, dental pathways, specialist psychology support, online wellbeing toolkits and support • Direct patients, families and staff to the CHD Network website (www.swschwcd.nhs.uk).

How to get involved

There are many ways to get involved with the network:

Professionals can:

- Express interest in becoming a member of our board or join one of our task and finish groups'
- Attend one of our training events
- Take part in our annual morbidity and mortality meeting on 8 October 2019 in Bristol
- Come to our stakeholder day in July 2020 in Bristol.

Patients and families can:

- Visit our website (www.swschwcd.co.uk)
- Sign-up to our newsletter mailing list
- Become a patient or parent representative for the network
- Attend one of our engagement events
- Come to our stakeholder day in July 2020 in Bristol.

For more information, please visit our website (www.swschwcd.co.uk) or email morwenna.bugg@uhbristol.nhs.uk