



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

# Annual Report

2019/20



GIG  
CYMRU  
NHS  
WALES





## Document Control

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<b>Document Approval</b>	William Oldfield, Medical Director, University Hospital Bristol and Weston Foundation NHS Trust

## Document Abstract

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 April 2019 - Mar 2020. It also looks to the future, providing an overview of plans for 2020/21.

## Document Change Control

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## Introduction from the clinical director

Welcome to the fourth annual report for the South Wales and South West Congenital Heart Disease (SWSW CHD) Network, 2019/20



It is becoming increasingly hard to reflect upon the bulk of last year's activity and the achievements made prior to the advent of Covid-19. The pandemic has clearly been the focus on everybody's mind in recent times and it would be remiss of me not to congratulate all members of the network for their due diligence and resilience, as we face this new challenge. For me it has been very rewarding to see the collective work ethic of the NHS put firmly into action.

The SWSW CHD Network built upon our early initiatives to form a Network of Networks forum supporting established and developing CHD networks around the UK. We set up weekly briefings sharing our experiences and challenges, but most important our solutions in mitigating risks. Working with the British Congenital Cardiac Association (BCCA), the Clinical Reference Group (CRG) for Congenital Heart Services and Royal Colleges enabled rapid dissemination of advice and support for our patients and carers.

This undoubtedly has been an extremely challenging and emotional time for our patients and families alike. Their understanding and patience as we tip-toed through this new "norm" is to be applauded. I sincerely hope that next year our annual report will report on how we have recovered and transformed our service with Digital First technology. I would particularly like to thank our clinical nurse specialists; I know how arduous it has been for you supporting our patients and families through these difficult times.

You will read, further on, that there was a way of life before the pandemic struck and I hope you enjoy reading about the many achievements and contributions from all quarters not least from our Public & Patient Voice advocates who feature as important members of our network board. This report celebrates our achievements whilst recognising the many challenges that help to form our work plan for the future.

Please stay safe.

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

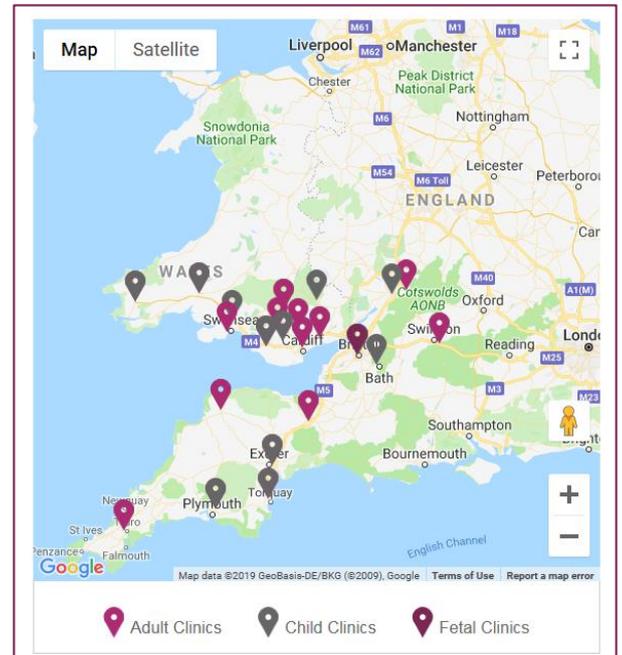
## About us

The South Wales and South West Congenital Heart Disease Network (SWSW CHD) was officially formed in April 2016, following the publication of the national CHD standards. 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.

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 5.5M people, caring for over 6,500 children and 8,000 adults with congenital heart conditions. This network is accountable to NHS England and is hosted by University Hospitals Bristol and Weston NHS Foundation Trust.

Figure1. South Wales and South West CHD network



## Our vision

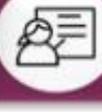
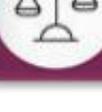
Our vision is to be a network whereby:

- 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
- To ensure it can **demonstrate the value** of the network and its activities





## Our Network Objectives

-  To monitor and drive improvements in quality of care
-  To support the delivery of equitable, timely access for patients
-  To support the education, training and development of the workforce within the network
-  To support improvements in patients and family experience
-  To be a central point of information and communication for network stakeholders
-  To provide strategic direction for CHD care across South Wales and the South West
-  To ensure it can demonstrate the value of the network and its activities



## Network Centres & Staffing

Table 2: South Wales and South West Level 1, 2 and 3 centre service provision		
Level	Hospitals	Service provided
1	<b>University Hospitals Bristol NHS Foundation Trust</b> Bristol Heart Institute (Adult) Bristol Royal Hospital for Children (Paediatric)	<b>Specialist Congenital Heart Disease Surgical Centre</b>
2	<b>Cardiff and Vale Health Board</b> University Hospital Wales (Adult) Noah's Ark Children's Hospital (Paediatric)	<b>Specialist Congenital Heart Disease Centre</b>
3	<p>Please note the Hospitals provide both Adult and Paediatric care unless specified differently below</p> <p><b><u>Level 3 South Wales Hospitals &amp; Health Boards</u></b></p> <p><b>Swansea Bay Health Board</b> Singleton Hospital, Morriston Hospital</p> <p><b>Aneurin Bevan Health Board</b> Royal Gwent Hospital, Neville Hall Hospital</p> <p><b>Cwm Taf Morgannwg Health Board</b> Royal Glamorgan Hospital, Prince Charles Hospital, Princess of Wales Hospital</p> <p><b>Hywel Dda Health Board</b> Glangwili Hospital, Withybush Hospital</p> <p><b><u>Level 3 South West Hospitals</u></b></p> <p>Royal Cornwall Hospitals Trust (Truro)</p> <p>Taunton and Somerset NHS Foundation Trust (Taunton)</p> <p>Northern Devon Healthcare NHS Trust (Barnstaple)</p> <p>South Devon Healthcare NHS Foundation Trust (Torbay)</p> <p>Royal Devon and Exeter NHS Foundation Trust (Exeter)</p> <p>Royal United Hospitals Bath NHS Foundation Trust (Bath)</p> <p>Gloucestershire Hospitals NHS Foundation Trust (Cheltenham &amp; Gloucester)</p> <p>Plymouth Hospitals NHS Trust (Plymouth)</p> <p>Great Weston Hospital NHS Foundation Trust (Swindon)</p>	<b>Local Congenital Heart Disease Centres</b>

## Our 2019/20 Highlights

### Improvements in quality of care

- Clinical pathways developed - Dental & Pregnancy
- Referral criteria for nurse specialists & psychology support developed
- Joint fetal multi-professional meetings with level 1 and level 2 centres
- 7 engagement visits with centres across the network to benchmark CHD standards

### Equitable timely access for patients

- Business case to increase adult CHD care capacity in South Wales
- Transition model for peripheral clinics in development
- Virtual clinics & multi-professional team meetings initiated
- Development of the CHD Network performance dashboard

### Patient and Family experience

- #myquestion Facebook campaign- to increase awareness of support & resources available
- Youth worker appointed to support our young people with CHD across the network
- Young people's evening held to support transition to adult services
- Patient Representative forum held offering peer support and training

### Education and Training

- 13 network training events including inaugural network psychology study day
- Nurse competencies for CHD drafted
- "Lesion of the month" - bitesize education for CHD nurses & training pack for link nurses
- Network Mortality & Morbidity session; well attended and positively received
- First network audit session held - 3 audits presented for shared learning

### Information and Communication

- Biannual newsletters published
- Covid-19 webpage for healthcare professionals
- Covid-19 page for CHD patients & their families
- Monthly national CHD networks forum for rapid dissemination & learning

### Strategic direction

- CHD national peer review – cited as “exemplary network” and highly commended
- Survey and stakeholder session on network priorities over next 5 years conducted
- National CHD networks - led the establishment of Covid-19 response forum
- Continued collaborative working with South West adult and paediatric networks



## Highlights from our centres

**LEVEL 1,  
TERTIARY  
CENTRE,  
BRISTOL**

### Paediatrics

- 4<sup>th</sup> surgeon appointed, meeting national CHD standards
- Proposal to increase nurse specialists to support transition in peripheral clinics (peer review recommendation)
- 85% of patients seen within 3 calendar days post fetal diagnosis, 88% patients also contacted by nurse specialist

### Adults

- Virtual clinics & multi-disciplinary meetings initiated
- Youth worker role established for 16-25 year olds
- Advanced care clinic and Fontan's clinic in development

**LEVEL 2,  
CARDIFF**

### Paediatrics

- Bid to increase peripheral clinic capacity in progress
- Latest set of clinical guidelines published
- Fetal consultant in post, clinics set up & job plan agreed

### Adults

- Phase II business case to increase Adult CHD capacity - final stage of approval
- Commended by National Peer Review team on progress made.
- Audit presented at network clinical governance group

**LEVEL 3,  
SOUTH  
WALES &  
SOUTH WEST**

### Paediatrics

- Cardiac Physiologist led clinics set up in Truro
- Transition clinics set up in Taunton
- Establishment of local PEC clinics in Withybush hospital for Pembrokeshire

### Adults

- Appointment of specialist nurse (Gloucester) and establishment of link nurse role in some centres (adults and paediatrics)
- Funding agreed for ACHD consultant (Truro - recruited in June)
- Anticipated increase of peripheral clinic provision via approval of phase II business case



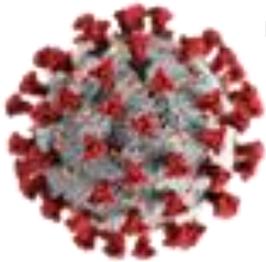
## Nursing Update

by Sheena Vernon, Lead Network Nurse



**2019/20** has been a demanding year for nurses across the network. On top of the daily demands of delivering their service, there has been the requirement to reconfigure their work load to adjust to the changing clinical picture of Covid-19. In March 2020, with the Covid-19 pandemic prevalent, nursing activity across the network was significantly affected as nurses were re-located to different clinical areas such as the paediatric intensive care unit, the adult cardiac intensive care and the cardiac wards to meet service demands. They were also needed to care for and home school their own children at home or shield for their own safety.

The clinical nurse specialist services were quickly re-configured to deal with significantly high volume of telephone advice calls which were needed by patients and families. Face to face meeting was dramatically reduced, and the volume of telephone advice and support increased considerably. On average the paediatric team handled 69 calls per day, with the adult team handling 22 calls per day. Vulnerable patients were telephoned to advise that shielding and advice was sought around issues such as working from home, travel, employment, home schooling and clinic follow-up. There was increasing demand for advice and support in



managing anxiety and low mood in relation to patient's congenital heart disease and Covid-19. The advice given was based on that given by the British Congenital Cardiac Association and Government advice. This was also available on the Covid-19 resource page on the network website ([www.swschd.co.uk](http://www.swschd.co.uk)), which all patients and families were sign-posted to.

The nurses were unable to participate in ward rounds and see patients face to face in the outpatient department due to Covid-19. Many link nurses do not have allocated time for their role, and therefore there is limited opportunity for them to establish the role in their organisation, and to support patients and their families in both outpatient and inpatient settings.

### Clinical nurse specialist teams (Bristol & Cardiff)

The paediatric and adult clinical nurse specialist (CNS) teams from Cardiff and Bristol communicate regularly about the care of mutual patients and their clinical management.

**Level 1 and 2 clinical nurse specialist day**, which takes place every six months, was held in February 2020 and provided an opportunity for clinical up-dates, network progress updates, education, service development and peer support.

The event was well attended and positively evaluated with staff commenting that it is *“very helpful to understand how the other teams are working and share ideas/discuss issues”*.

In addition there is a **Level 1 link nurse group** based in the paediatric and adult service that meet bi-monthly to provide CHD updates, resources, information and education to nurses in clinical areas for patients with CHD.

### Level 3 (Link) and Community Nurses

The biannual level 3 link nurses and community nurse day took place in January 2020 with 16 delegates attending, including community nurses, paediatric nurses and adult link nurses. The was a day for link nurses to network, share practice and understand each other’s services, as well as an opportunity for some teaching and education. The day was very positively evaluated.



**Establishing the link nurse role continues to be a significant challenge** across the network, and has been highlighted by centres during their engagement visits this year. Whilst 70% of Trusts have a named link nurse, we know only 50% of these are actively engaged.

Resources for nursing staff are continually being added to the network website ([www.swswhcd.co.uk](http://www.swswhcd.co.uk)) under the professional’s page. This includes a link nurse resource folder along with a job description, national and international guidelines, toolkits and information to support our nurses. There are opportunities for link nurses to visit level 1 and level 2 centres to understand how the clinical service runs, meet the teams and visit the clinical areas.

Figure 1. CHD nursing in the network





## Patient Representative Update

Following both the NHS England CHD standards (2016) and the Specialised Services Circular (ssc188) guidance, we have involved patient representatives in our network activities since 2016. Since this time, the group of patient representatives has grown and there is regular attendance at each of the network boards. The patient representatives have a standing board agenda item which provides a regular opportunity to comment and feedback to the network board.



We are delighted to have 15 patient representatives currently involved with the network. The group consists mainly of mothers and adult female patients, but we are keen to recruit a more diverse range of representatives and we are actively looking into doing this. There is a job description and a contract for the role.

Annual workshops and training events have been held for patient representatives by the network, and there are further plans for this. Many of our patient representatives have contributed to the network biannual newsletter, the network five year strategy and have also been part of our network panel during the national CHD peer review.

We are keen to further develop the role and involvement of the patient representative in the network. As part of this we conducted a survey to understand that perception of both the network board members and the patient representatives, about the purpose and contribution of patient representative's role within the network. The conclusion of this survey showed that there was widespread commitment to realise the benefits of patient representatives within the network, and that further training and support would be helpful to achieve this, particularly for the network board members and patient representatives.

Looking ahead, the board are looking to develop further training for both board members and patient and family representatives, possibly collaborating with other CHD networks nationally. Work on updating the website pages, which patient and family representatives will be asked to comment and provide feedback on, will begin and the psychology section will be one of the first priorities.

## Education and Training update

A key objective for our network is to support the training and education of our healthcare professionals. In 2019, the network held and supported over 13 training and education events, accessed by a range of multi-professional groups that care for CHD patients across our network. The network plays an essential role in promoting training and education opportunities for all our staff, which we successfully do using a number of communication channels including our network distribution channels, our CHD training and education webpage ([www.swschd.co.uk](http://www.swschd.co.uk)), twitter, and our biannual newsletter. In the midst of the usual programme of training and education, some highlights include:

- Inaugural Network Psychology study day held for all psychologists within the network
- “Lesion of the Month”- bitesize education package for nurses
- 2 x Paediatrician with Expertise in Cardiology study days
- ACHD annual study day
- Nurse competencies drafted
- Link nurses resource folder published

For more information on upcoming training and education days, and for useful CHD and related resources, please visit our website [www.swschd.co.uk](http://www.swschd.co.uk)

## Audit & Research update

Audit and research continue to be important components of the network’s portfolio. In 2019/20 we have been delighted to welcome Helen Wallis, ACHD Consultant in South Wales, into the role of Network Audit Lead. This voluntary role will help establish and run the network audit programme. Helen helped organise our first network-wide audit session with 3 different audits being presented by staff from across the network. This provided a great opportunity to share learning and best practice.



For more details on our audit programme and research in the network please visit [www.swschd.co.uk](http://www.swschd.co.uk)

## Communication and engagement

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 recently in response to Covid-19. Highlights include:

- Set up of Covid-19 webpage on the network website with resources for patients, families and staff. This includes general advice, CHD specific advice and useful resources for wellbeing and mental health.
- Fortnightly conference call established with network members, as well as a weekly national CHD network call. Weekly reporting to Specialist Commissioners and involvement in several regional calls.
- Biannual newsletter for CHD network published and distributed to network members.
- Charity stakeholder event held for all local CHD charities to share what has been happening and to promote collaborative working.
- #My question campaign on the Bristol Royal Hospital for Children and CHD charities Facebook sites. The purpose of this campaign was to address some common queries our patients and families have, signposting them to a number of useful resources on the network website.
- Network five year strategy stakeholder session and survey conducted.
- Patient representative survey conducted with Network Board members and patient representatives.
- Patient stories presented at the Network Board. A recent video production promoting music therapy for a young CHD patient has been picked up by the BBC.



## Focus on Psychology

*“I’ve been helped so much by the psychologist, I was able to focus on myself and my condition in a way I never have before. Thank you”. CHD patient*

The CHD standards recommend that psychology services are provided for a lifespan service. It is recognised that support for patients and their families can often be provided through a range of means (information, clinicians contact, specialist nursing, patient support groups, well-being toolkits).



Following on from the development of over 32 different support and well-being toolkits now available on our website ([www.swswchd.co.uk](http://www.swswchd.co.uk)), in 2019/20 there has been a focus on increasing the awareness of and access to these resources for both clinicians within the network, and patients and their families. We have successfully run nine week #my question Facebook campaign in collaboration with University Hospitals Bristol and Weston to promote these fantastic resources. We have also developed referral criteria for the specialist centre psychology team so it is clearer for clinicians on when to refer.

Key aims for the team has been to upskill and develop the psychology skills of our clinical staff within the network. We have developed psychological skills training packages to enable the specialist centre to offer level 1 and 2 psychological skills training throughout the network. In February 2020, we hosted our first network psychology event, which was well attended and positively evaluated. Our activity levels for 2019/20 are illustrated below;

214 referrals

960 Outpatient slots

84 Surgery/Catheter slots for preadmission



High quality care for patients and families



Upskilling and development of clinical staff



Support and training of psychologists

### Our psychology aims - 2020/2021

- Review support resources with patient reps
- Develop quality metrics for pathways
- Run network psychology study day
- Offer psychological skills training to clinicians across the network
- Continue to support patients, families and staff during Covid-19

## Network governance

The governance of the CHD network is illustrated in figure 2 (page 16). The CHD network board is chaired by David Mabin, Deputy Medical Director and Paediatrician with Expertise in Cardiology, at the Royal Devon and Exeter Hospital. Members of the board include patient representatives, clinical and managerial representation from Level 1 (Bristol), Level 2 (Cardiff) and level 3 (District General Hospitals, South Wales & South West) centres. There are two subgroups that report into the Board (Clinical Governance and Service Delivery Group).

The Network Board is funded by NHS England, and is hosted by University Hospitals Bristol and Weston NHS Foundation Trust. It reports quarterly into NHS England (Specialised Commissioning Operational Group), Welsh Health Specialised Services Committee (WHSSC) and UH Bristol and Weston (Senior Leadership Team, Women's and Children's Divisional Board and Joint Cardiac Board).

A Memorandum of Understanding (MOU) that outlines the terms of engagement for each of the organisations involved in networks is being drafted by NHS England for sign off by member organisations shortly.

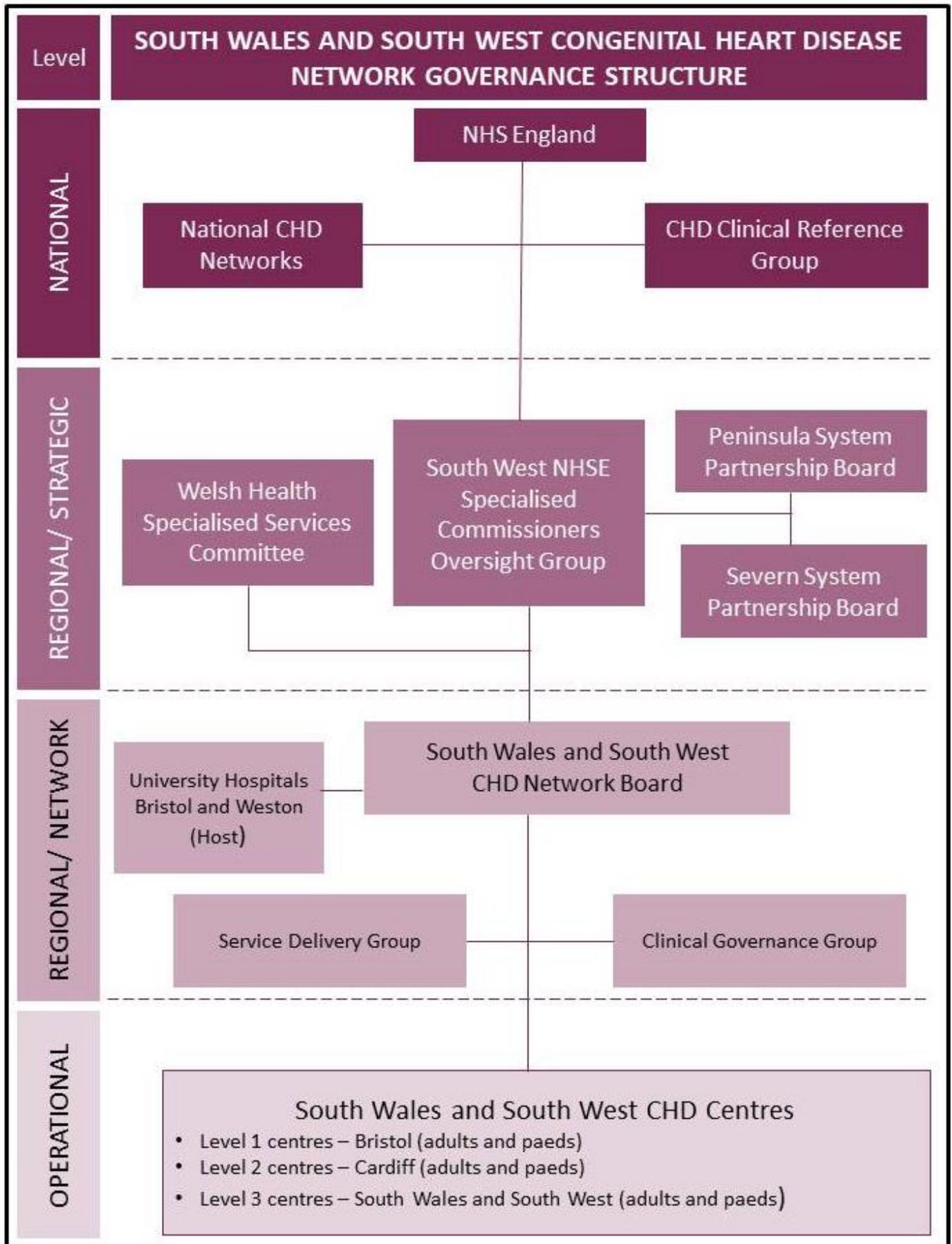
## Network Funding

The network is funded by NHS England and had an annual budget of £173,799 in 2019/20, after overhead contributions to UH Bristol as the host trust. The pay budget was overspent by £3,283, due to pay budget setting at midscale. Non-pay was slightly overspent by £343, accounted for by office moves. The overall budget position was a reported overspend of £3,625 at the financial year end.

In 2020/21 it is anticipated that the non-pay budget will be reduced to reflect a reduction in travel and not holding face to face events during Covid-19.

Network Funding	2019/20
<b>Pay</b>	
Pay total expenditure	£161,653
Pay budget	£158,370
<b>Pay Variance</b>	<b>-£3,283</b>
<b>Non Pay</b>	
<i>IT, phones &amp; office</i>	£6,194
<i>Travel</i>	£1,004
<i>Network events</i>	£3,610
<i>Miscellaneous</i>	£4,964
Non Pay Total Expenditure	£15,772
Non Pay Budget	£15,429
<b>Non Pay Variance</b>	<b>-£343</b>
<b>Total Variance</b>	<b>-£3,625</b>

Figure 2. Network governance arrangements



## Network Risks and Challenges

The top 2 risks/challenges for the CHD network are highlighted below. All network risks are managed through the network board. Further details are available on request. Undoubtedly one of the biggest challenges for CHD in 2019/20 has been follow up backlogs. As with most of NHS services, this now has been amplified as a result of Covid-19. A main focus for centres within the network continues to be on addressing this backlog and mitigating risks associated with increased waiting times for CHD patients in our network.

Top 2 Risks for South Wales and South West CHD Network					
Programme Area	Risk *	Likelihood (1-5)	Impact (1-5)	Owner	Mitigation
Restoration & Transformation	Clinical risks due to delayed appointments and procedures for CHD patients across the network due to Covid-19. Productivity in Outpatients diminished due to Covid-19.	5	3	Provider Trusts	All network members have been asked to escalate any significant clinical risks to the network and within their organisations. All centres have been requested to regularly review and triage their waiting lists. Development of restoration plans for CHD activity – linking in with PIC plans.
Equitable access	Risk that CHD patients in South Wales are not having the same standards of care as the CHD standards are not currently adopted by Wales.	3	3	WHSSC & Network Board	South Wales centres form part of network and report into the network board on performance, escalating any issues. Meeting with WHSSC and Health Boards planned to progress discussion on Wales adopting the CHD standards. Phase II business case drafted and approval awaited to increase ACHD services in South Wales- based on standards delivery.
	*All network risks are managed through the network board.				



## Looking to the future

by **Cat McElvaney, Network Manager**



As expected, our key focus entering into 2020/21 has been to support our centres during the extremely challenging times that Covid-19 has presented us all with since March 2020. This will continue to be our focus in 2020/21; with an emphasis on restoration of activity, alongside progressing work on other key network priorities highlighted in the table below, where possible.

The network will work closely this year with the newly established Paediatric Intensive Care network on the winter planning, to ensure the care of CHD patients and their families is represented in these plans. We will continue to promote the use of digital technology, where appropriate, to enable remote care for our patients and avoid unnecessary travel to hospitals. We will continue to work closely with our commissioning and planning colleagues, both in NHS England and the Welsh Health Specialised Services Committee, to support the ongoing development and improvement of CHD services across the network. We will endeavour to continue with the provision of the extensive training and education programme in our network, using virtual platforms where possible to aid access. Watch this space for our first fetal cardiology webinar series delivered by our Consultant Fetal Cardiologist in Bristol!

Whilst we have set out our key priorities for 2021/22 below, the health and well-being of our network members is critical and we will adapt and respond our plans as needed to reflect this.

Looking beyond 2020/21, we are keen to develop our five year strategy for CHD care within our network, focussing on improving the care and experience for our patients, families and our staff. We are very fortunate to have such engaged and committed members within our network and we will continue to work together to strengthen and improve collaborative working and pathways between centres for the benefit of our patients, their families and our staff.

If you would like further details on our 2020/21 workplan please visit our website on [www.swswchd.co.uk](http://www.swswchd.co.uk)



## High Level System Aims and Objectives - 2020-2021

- 1. Restoration & Transformation:** Facilitate restoration of CHD activity across the network, monitoring % activity restoration, and CHD surgery and interventional waiting list information. Work collaboratively with CHD and PIC networks on winter planning. Transformation of services to support restoration.
- 2. Improvements in Quality of Care:** Develop paediatric disease related guidelines, service developments for advanced care and Fontan's patients. Improve pathway for fetal patients transferring between level 1 and 2 centres. Delivering CHD standards across the network.
- 3. Equitable, time access for patients –** Working with WHSSC to improve access to CHD care for patients in South Wales, promoting models of care that have virtual options where appropriate. Standardising and improving transition pathways across the network, minimising lost to follow up during transfer from paediatric to adult services.
- 4. Education and Training:** Deliver wide ranging and accessible CHD related training to all healthcare professionals involved in the care of CHD patients in the network.
- 5. Information and Communication:** Act as a central point of information and communication for network stakeholders by hosting network events, disseminating key information, publishing regular communications and having a proactive social media presence.

## 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 on 15 September 2020
- Come to our stakeholder day – date tbc.

### Patients and families can:

- Visit our website ([www.swswchd.co.uk](http://www.swswchd.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 – date tbc.

For more information, please visit our website ([www.swswchd.co.uk](http://www.swswchd.co.uk)) or email [rachel.burrows2@uhbw.nhs.uk](mailto:rachel.burrows2@uhbw.nhs.uk). Follow us on twitter @CHDNetworkSWSW