



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

South Wales and South West
Congenital Heart Disease
Operational Delivery Network

Annual Report
2020/2021



GIG
CYMRU
NHS
WALES

NHS
England



Document Control

Document Control	
Document Type	Annual Report
Document Status	DRAFT
Document Owner(s)	South Wales and South West CHD Network Board
Document Author(s)	CHD Network Team: Cat McElvaney, <i>Network Manager</i> (until June 2021) John Mills, <i>Network Manager</i> (from June 2021) Andy Tometzki, <i>Network Clinical Director</i> Sheena Vernon, <i>Network Lead Nurse</i> Jess Hughes, <i>Network Lead Nurse</i> Rachel Burrows, <i>Network Support Manager</i>
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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 2020 to March 2021. It also looks to the future, providing an overview of plans from April 2021 onwards.</p>	

Document Change Control				
Date of Version	Version Number	Lead for Revisions	Type of Revision	Description of Revision
13/05/21 – 03/06/21	0.1 – 0.4	Cat McElvaney / Rachel Burrows	Content	Draft all sections
29/06/21 – 12/07/21	0.5 – 0.8	John Mills / Rachel Burrows	Content and formatting	Updated all sections
13/07/21	0.9	Andy Tometzki	Content	Foreword written
13/07/21	1.0	John Mills	Content and formatting	Research and audit – content. Proofed and finalised all sections
06/08/21	1.1 – 1.2	Rachel Burrows	Content	Minor corrections/adjustments to text



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Foreword

I am delighted to present the 2020/21 South Wales and South West CHD Network Annual Report. This report shares our achievements within the Network over the past year, and reflects on the work programme going forward. This has been a most difficult period of time for our stakeholders, especially those patients and families we serve.

We've all been affected in one way or another, personally and professionally. Our lead nurses were redeployed to adult and paediatric intensive care units at a time when our paediatric inpatient service was extremely busy and much of our adult service moved to virtual clinics. We now face the daunting task of restoration back to normality as national lockdown measures ease.

Despite this we report continued growth and development within our network. Indeed we formed and hosted a national network of CHD networks forum to share issues and mitigation plans with NHSE commissioning groups on COVID related topics.

Our core network team has seen some important changes. Lead nurse Sheena Vernon, who has been with the SWSW CHD network since its inception in 2016, has partially retired and has now been joined by Jess Hughes, who brings a wealth of experience from her paediatric cardiac clinical nurse specialist background, particularly with regard to transition care to adult services. I would like to thank Prof David Mabin who stood down in March after four successful years as the inaugural Chair of the Network Board. We now welcome Dr Dirk Wilson as his successor, who many of you will recognise as a senior paediatric cardiologist in Cardiff.

Sadly, our Network Manager, Cat McElvaney, leaves us as she takes on a new post in the Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group. I would like to thank her for guiding the whole team and wider network with superb leadership. Cat has much to be proud of. John Mills joins us for 2021/22 and has a hard act to follow!



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

Dr Andrew J P Tometzki

Clinical Director

South Wales and South West Congenital Heart Disease Operational Delivery Network



About Us

History and geography

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 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. 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, caring for over 6,500 children and 8,000 adults with congenital heart conditions. 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

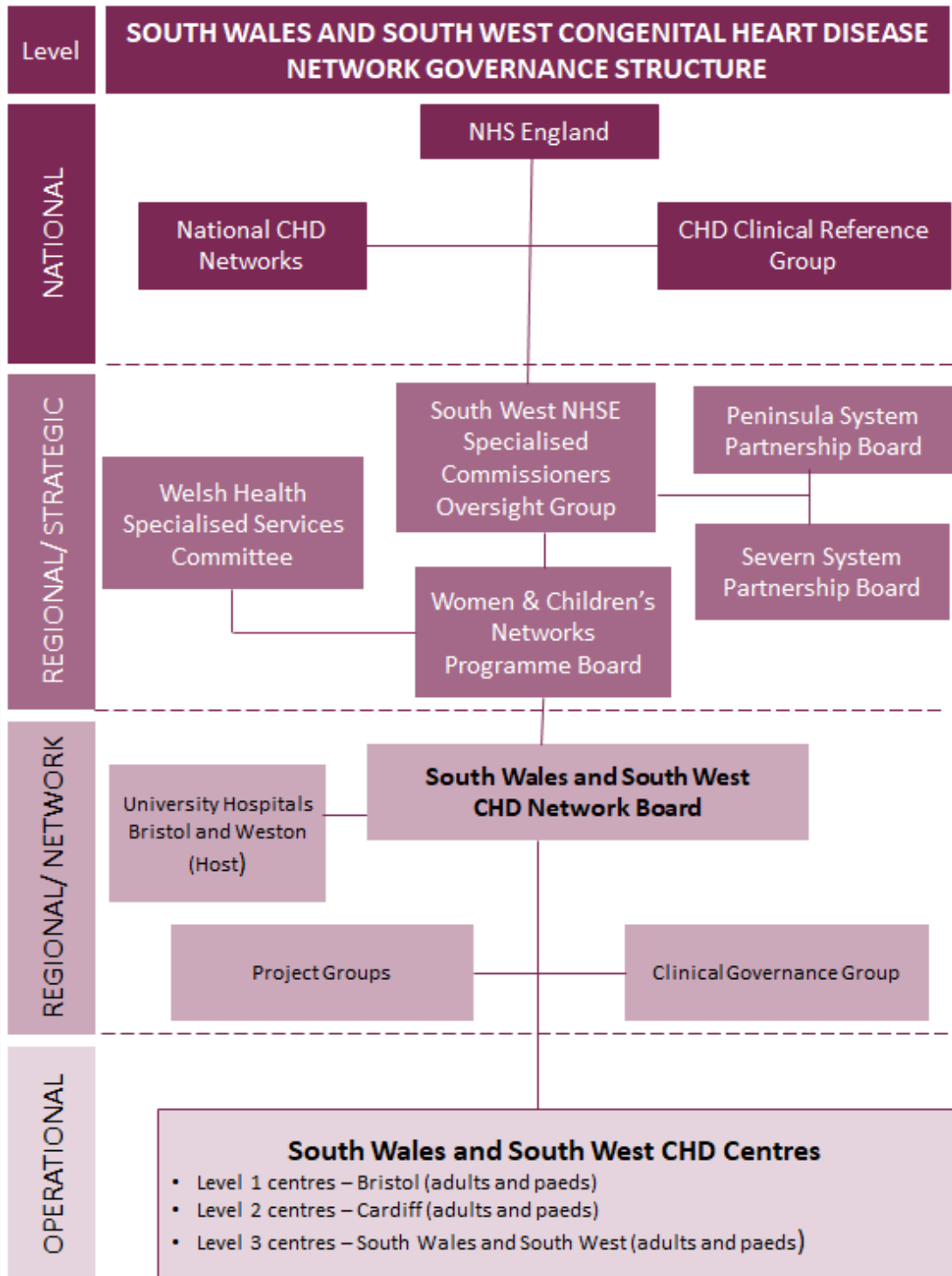


To monitor and drive improvements in quality of care



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 Network Team (2020/21)



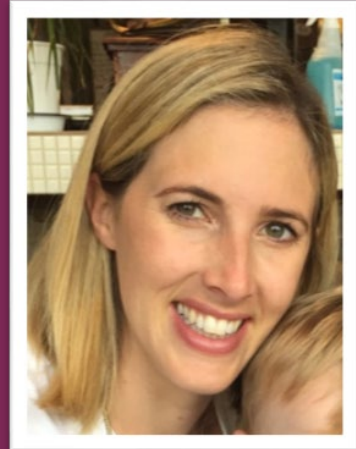
Cat McElvaney
Network Manager



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 2020/21

CLINICAL CARE



317

Heart operations



547

Cardiac catheters



c. 14,000

Clinic attendances
(level 1 and 2 only)



1,145

Psychology contacts

OUR NETWORK



Consultants including:

4 Cardiac surgeons

16 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)



Allied Health Professionals staff: c. 100

COMMUNICATION AND ENGAGEMENT



9

Webinars



8

Virtual Study Days



17,654 (↑ 11,640)
Website users



390 (↑ 192)
Twitter followers

Visit us: www.swswchdco.uk

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



Key achievements, developments and highlights from 2020/21

COVID-19 Response, Restoration and Recuperation

The escalating SARS-CoV-2 coronavirus pandemic necessitated a dramatic change in the network workplan and priorities at the start of 2020/21, focusing on whatever could be done to assist the local, regional and national NHS response. At times of greatest need, this included redeployment of our network lead nurses to support adult and paediatric intensive care services. Thankfully, as a network we were able to support the continuation of CHD services throughout this difficult year.

Collectively, the SWSW CHD network led and supported a number of COVID-19 initiatives as the year progressed:

- Established and led a national 'network of CHD networks' weekly calls to disseminate information rapidly and coordinate response across the UK, and advise NHS England;
- Shared vital information, discussion of clinical cases and learning regionally and nationally;
- Developed regional triage guidance to support decision-making in tertiary clinics;
- Published a COVID-19 information page on the SWSWCHD website to direct patients, families and professionals towards the latest guidance, including wellbeing support;
- Contributed to the development of paediatric inflammatory multisystem syndrome disease specification and treatment strategies.
- Collaborated with the British Congenital Cardiac Association, Clinical Reference Group, Royal College of Paediatrics and Child Health and other stakeholders to develop guidance / FAQ's for CHD patients during the pandemic;
- Supported the Paediatric Critical Care network with winter planning for the South West region;
- Supported regional centres with recovery plans and monitoring of patient backlogs.



Digital working

The pandemic required a rapid acceleration in digital working, and our network was no exception. We adapted quickly to virtual communication platforms and off-site working in order to continue delivering much of our core network activities. Our planned face to face events were necessarily cancelled but many of these were successfully moved online, to become virtual study days and webinars. We adjusted our website and launched an additional space using the FutureNHS Collaboration Platform to provide access to resources for CHD professionals across the region.



Our move to virtual communication platforms enabled wider access to the level 1 paediatric CHD joint cardiac conference (multi-disciplinary team meeting), since clinicians across the region could join more conveniently. Similarly, this change has improved access to our key network meetings, including Clinical Governance and the Network Board. Despite the COVID-19 restrictions, the SWSW CHD network was able to adapt effectively and will likely keep some of these changes going forward.



Standardising and improving care across the network

The SWSW CHD network plays a key role in improving quality and equity of access to CHD care in the region. In 2020/21 the network supported WHSSC to develop a CHD service specification for Wales, and formed plans to enable Welsh centres to adopt the NHSE CHD standards, which will continue in 2021/22. A number of guidelines, pathways and protocols were developed within the region, including a *retrieval, transfer and repatriation protocol* for neonates, children and young people with suspected or confirmed congenital heart abnormality ; a *pregnancy pathway* for pregnant women with CHD; and a relaunch of a dental pathway for patients requiring cardiac surgery, in a project which increased awareness, identified gaps and implemented improvements. Further work was begun to revise paediatric guidelines for *Fontan circulation*, *coarctation of the aorta* and *inherited cardiac conditions*.

A number of improvements to clinical services also launched in 2020/21. Referral criteria was developed for the paediatric clinical nurse specialist services and shared across the region. ACHD nurse specialists in Bristol began an *Advanced Care clinic* for patients with complex CHD, with a future evaluation of this service planned for 2021/22. A cardiac physiology-led ECHO clinic launched in Truro, with a similar service being planned in Bristol.

A network of paediatric pharmacist contacts has also been generated across the region to make it easier for pharmacists to communicate, feed into network agendas and get advice and guidance from level 1 and 2 centres when necessary. This should improve awareness and access to guidelines that have been developed to aid seamless care of our patients across the Network.

Spotlight on Psychology

Whilst cardiac care and the surgical program continued during the pandemic, lifespan psychology services needed to adapt to provide continued inpatient and critical care support but also remote support for clinics and outpatients services not able to be delivered in the hospital. The service has remained full, service orders continued to increase and activity remained high.

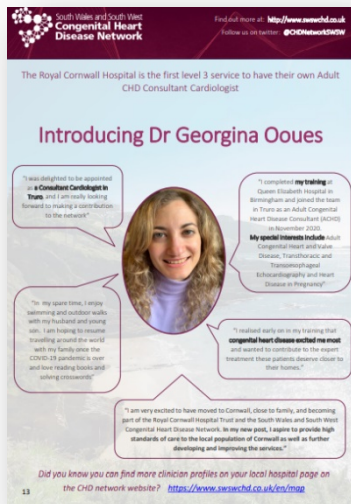


Key adaptations and developments to enable the service to continue included:

- Converted to virtual platform for individual and multidisciplinary consultations
- Produced four webinars: (1) Coming into hospital (for parents to support selves and children); (2) Preparing for surgery; (3) Supporting siblings; (4) Managing stress (for parents)
- Delivered a training day for all psychologists providing psychological care to paediatric or adult CHD patients in the South West or South Wales.
- Scoped and mapped a four tiered model of psychological skills training for network clinicians, with plans to pilot this training in 2021/22
- Delivered a regional online public engagement event to answer families' questions concerns around service adaptations during COVID and to understand information and support needs.
- Launched a network wide social media '*my question*' campaign to raise awareness of psychology toolkits and resources to support families
- Developed a network patient and public involvement program of engagement and support for key programs of work, including the promotion of the SWSW CHD network website, sources of support, and guiding the network social media strategy



Expanded Adult CHD services across the network



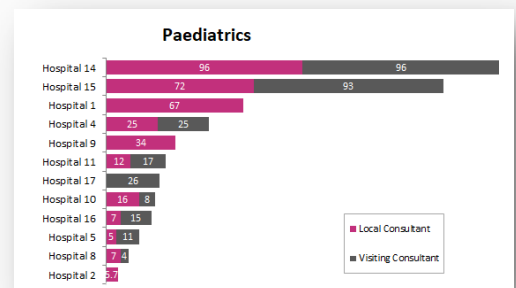
The SWSW CHD network celebrated the appointment of Dr Georgina Ooues to The Royal Cornwall Hospitals NHS Trust, which became the first Level 3 centre in the country to have a dedicated ACHD Consultant, improving access to CHD expertise for adult patients in the South West peninsula.

We also supported WHSSC to develop a proposal and 'Phase 2' business case to increase ACHD capacity in South Wales. Funding received so far has enabled the expansion of the ACHD service in South Wales with the recruitment of several new clinical and support posts. This will lead to increased tertiary service capacity across South and West Wales, and, once Covid-19 restrictions start to ease, will lead to a reduction in waiting times for CHD patients, along with an expanded range of dedicated services available, including psychology.

Enhanced performance reporting

The Network Board has a role in monitoring the performance of centres within the network, with a particular focus on reducing variation in quality and access. The performance report is used to provide assurance to the board and highlight any areas that are performing well or areas that may need support.

The board can then identify and share good practice or take supportive action. In early 2021, we launched an enhanced set of templates and dashboards to make it easier for services to report on their performance and to improve the quality and relevance of reports. We are developing and assessing a graphical dashboard, enabling a quick visual way to notice trends, hot spots and areas of best practice. This will improve our ability to benchmark services within the network.



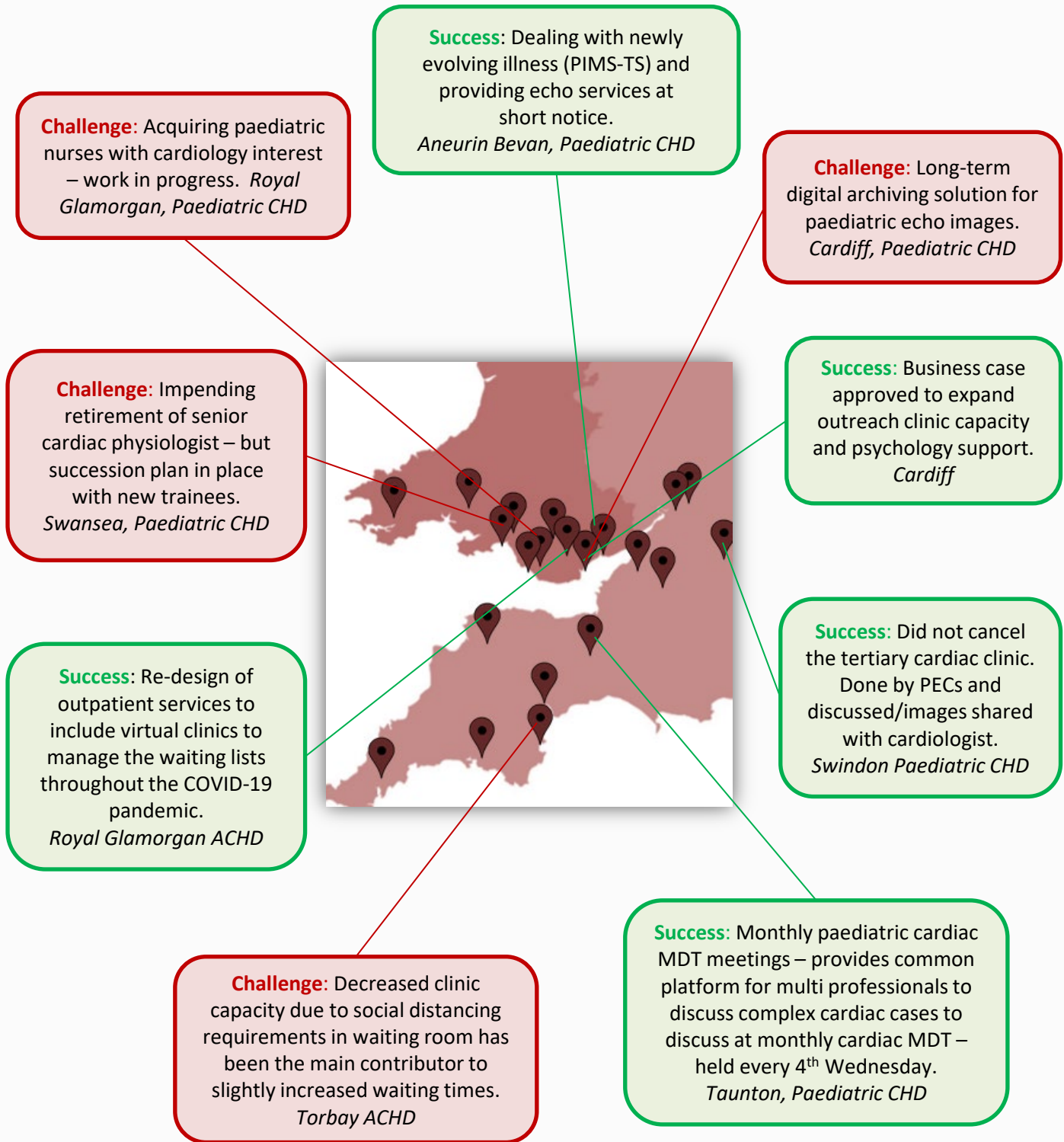
Opportunities for networked working

Use of virtual platforms has increased the opportunities for collaboration and joint working across our region, overcoming geographical barriers. In addition to the virtual network teaching/training sessions and board meetings, this included virtual project groups; facilitating virtual 'Meet and Greet' sessions for cardiac physiologists and CHD link nurses across the region, promoting networking, broadening contacts and sharing perspectives. The network team also supported joint meetings between Fetal Cardiology teams in South Wales and the South West to improve understanding and increase collaboration between centres. Level 1 (Bristol) multidisciplinary team meetings were held virtually, which enabled clinicians from across the network to join the meeting, including both the Bristol and Cardiff Clinical Nurse Specialist teams. This is strengthening working relationships, improving communication and continuity for patients. In quarter 4, the network developed and launched a collaboration space for Paediatricians with expertise in cardiology (PECs) on its FutureNHS Platform, designed as a central platform for regional PECs to share resources and information, alongside a discussion forum and events calendar. The SWSW CHD network manager also established an informal forum with other South West Operational Delivery Networks (such as Surgery in Children and Paediatric Critical Care) to facilitate shared learning, improved communication and efficient use of NHS resources.



Successes and challenges from around the region

We asked our network members for their top successes (green) and challenges (red) from 2020/21. Here are a few things they highlighted to us.



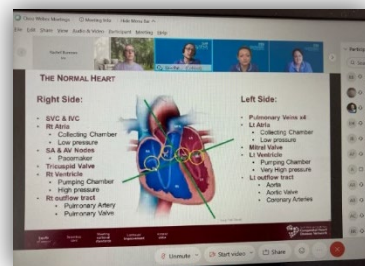
Education, Training and Audit

Education and training

A core objective of the network is to support and promote training and education opportunities for our healthcare professionals. The past year has brought with it unprecedented challenges with the COVID-19 pandemic affecting all aspects of our clinical services. In response to the pressures of COVID-19, the network shifted to delivering a variety of programmes of education and training online. This new way of learning has enabled a significant increase in network participation in events as this overcomes the constraints of geographical distance.

Some highlights include:

- 18th Annual ACHD study day held virtually in October- with over 90 delegates from across the region
- Psychology training days and webinars
- Level 1 and 2 Clinical Nurse Specialist meeting
- Fetal cardiology webinar series – these popular recordings are stored on our network NHS Future Platform and attracted international interest with over 200 delegates registered – email SWalesSWCHD-manager@future.nhs.uk for access!
- Cardiac physiology meet and greet sessions with excellent engagement across the region
- ‘Lesion of the month’ – bitesize education for CHD nurses and training pack for link nurses
- Virtual sonographer training session for district general hospitals delivered by the fetal cardiology team to help improve rates of antenatal detection of CHD
- Network wide annual Mortality and Morbidity session; well attended and positively evaluated
- Paediatrician with Expertise in Cardiology (PEC) study day
- PEC platform created on the network NHS Future Platform as a virtual space for regional PECs to share useful resources and information, plus a discussion forum and events calendar



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

Audit

The network audit programme is an important component of the network's portfolio, coordinated by Dr Helen Wallis, Network Audit Lead and ACHD Consultant in South Wales. The SWSW CHD network aims to facilitate the presentation of 2 to 3 audits biannually at the network Clinical Governance Group. Although audit was deprioritised for much of 2020, as services adjusted to 'living with COVID-19', existing audits started to be progressed and new ones were designed. This year, two network-wide audit 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 2020/21, the following audits were presented:

- Neonatal Ectopic Beat Management (Cardiff Paediatrics)
- Transfer and Transition (Taunton)
- Dental Care Access in Cornwall (Truro)
- Patient experience feedback survey on telephone consultations (Cardiff Adults)



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.

“The cases were really thought provoking and the audit was a perfect example of a standard that was assessed and found to be lacking... and improvements made.”
M+M Sep 2020

“Attending virtually worked really well. The link to attend was easy to follow and the video stream also worked well. I could hear the presenters clearly and the slides were good.”

Psychology day Feb 2021

“I have had a look at these webinars and they are brilliant. I would really like to share them with the other teams in our East Midlands Network. Well done! Really good!”

Fetal Webinar series (summer 2020)

“Excellent virtual meeting. Missed the networking but I found it easier to take notes and photos of slides which consolidated my learning”

ACHD day Oct 2020

“I learned more about ACHD. There were very good presentations. **Very well put together.** Delivered by **experts** in their fields.”

ACHD day October 2020

“Generally a fantastic experience. You definitely feel as though you are at a meeting and can interact. The obvious disadvantage is that you are speaking to a screen of initials rather than actual faces, which is slightly off putting as you cannot get any facial clues from your audience as to whether they are following you or have switched off... “
‘M+M Sep 2020

“Attending online is so much easier as it saves time, travel and money.”

Cardiac Physiologist, Dec 2020



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 2020/21 there were a large number of publications within our region, including a Cochrane systematic review of [physical activity interventions for people with CHD](#), and papers on [genetic counselling in inherited cardiomyopathy](#) and [implantable cardioverter-defibrillator devices in paediatric hypertrophic cardiomyopathy](#). Active research fellows led projects such as exercise prescription in teenagers and human-computer interaction in patient self-monitoring. Other new and ongoing research programmes included an evaluation of sudden cardiac death victims, funded by the *British Heart Foundation*, and a study of aortopathy and exercise, funded by *Above and Beyond*. The CHD research community in the SWSW region continues to be very active and there is much more planned for 2021/22!

Research update from the Paediatric Cardiac Research Team

The pandemic brought with it many changes and we needed to find different ways of working, balancing the need for research recruitment against valuable PPE. By collaborating with clinical staff already on the paediatric intensive care unit, patients could be informed about and recruited to studies without using additional PPE. We managed to continue recruiting to the OMACp (Outcome Monitoring after Cardiac Procedure) study during the pandemic. The study went on pretty much undisturbed, recruiting between 40-60 patients/parents a month. This gathered data and samples from cardiac patients during normal clinical care to improve our knowledge of risk stratification and patient outcomes.



The research team also received update training and were on standby to support front-line services, and later assisted as vaccinators on adult and paediatric COVID vaccine trials. Later in the year, the research team was able to finish the set up of a commercial study, CARDIOCEL, which looks at long-term follow up of CARDIOCEL products used to close holes in the heart. This was done quickly and Bristol became the first UK site in this study to open.

It is fair to say that we have all had our difficult moments during the pandemic, but it has shown just what a bedrock of clinical care research is and how impressive teams have been collaborating, using transferable skills and pushing boundaries to help us all through the past 12 months. Whatever the future brings it will, as always, have the singular aim of improving outcomes for our patients and their families.

*Karen Sheehan RGN RSCN MSc
Cardiac Research Sister at Bristol Royal Hospital for Children*

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



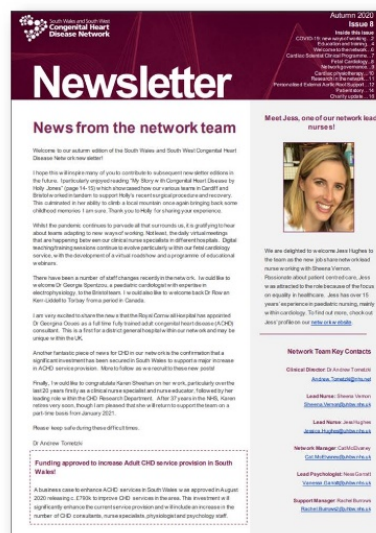
Communication and Engagement

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.

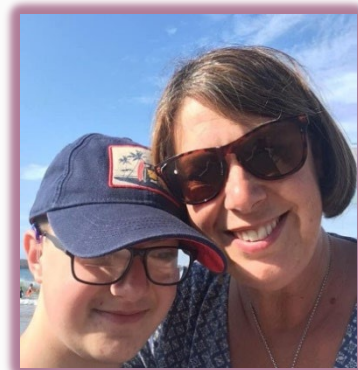
Highlights include:

- Enhancing the COVID-19 webpages 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.
- Led the establishment of 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. Weekly reporting to Specialist Commissioners and involvement in several regional calls.
- Biannual CHD network newsletters published and distributed to network members.
- Trial online 'listening event' in Gloucester supported by the network.
- Survey of patient experiences of virtual appointments.
- Patient and family support webinars facilitated by the Level 1 centre psychology team.
- Working in collaboration with support groups and charities to raise awareness of the network and signpost to website resources.
- Patient stories presented at the Network Board.
- Patient representative survey presented to the Network Board members and patient representatives.
- Increased engagement with patient representatives with a virtual pre-meet before the network board, as well as debriefs. The patient representatives have discussed their specific areas of interest and have supported various network projects promoting the guiding principle that if a project is about a patient, a patient representative should be involved.



Patient representatives update

The Patient/Parent rep team are made up of both adults with CHD and parents of children with CHD, and we work closely with the network team to feedback our views on various aspects of the service that we receive in both the paediatric and adult CHD services. We are made to feel very included and our views are taken seriously resulting in closer working relationships between clinicians and the patient reps. Through regular briefing meetings before and after the Network Board Meetings we are able to share our views and thoughts and we have developed a strap line:



*Nicola Morris (right)
with Calum Morris, 15*

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

As Patient/Parent reps we are working on a range of different projects including promotion of the network through social media and mental health support. It is great to feel our views are valued and that the Network is responsive to our suggestions working with us to make changes to improve the support patients and families receive on their CHD journey.

Nicola Morris, Parent Representative

Increasing patient involvement in the Network Board

The network team were keen to understand the perception of the role of the patient and family representatives' contribution to the Network Board and so conducted a survey in March 2020. The aim was to identify what further work needed to be done around the role. Sheena Vernon presented the key messages from the 19 board member and 4 patient representative responses to the June 2020 Network Board. Overall, the results indicated the work with lay representatives has started well and there is a common commitment to fully realise their benefits, provide training and support, and enhance joint working and involvement of patient representatives in projects within the network. Recommendations included further training and development for the patient representatives but also for the board. Support was provided to patient representatives on how to introduce themselves at the board meetings, and they are encouraged to flag any abbreviations, jargon or terminology that they don't understand or feel is insensitive.

Work with charity partners

The SWSW CHD Network collaborates frequently with local charities in the interests of CHD patients in the region. We are grateful to our charity and support group partners for their support and for promoting the CHD website and resources. In 2020/21, 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.swswhd.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.

In 2020/21 the network promoted the Children's Heart Federation 'Think Heart' campaign, the Youth at Heart provision of youth worker support for 15-25 year olds, the Heart Heroes support hubs across the SWSW region, and much more. Several representatives of charity partners have fed into the network's 'My Question' campaign (where we posted answers to frequently asked questions), 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 £186,304 in 2020/21, 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 underspend of just over £18,000. There was a small underspend in the pay budget related to a short gap in our lead nurse establishment, ahead of Jess Hughes starting in post. However, the underspend was largely driven by a reduction in non-pay spend, owing to COVID-19 restrictions preventing travel and face to face network events.

This small saving goes a little way to mitigating the huge costs to the wider NHS in this unprecedented year.

Network funding		2020/21	
	Expenditure	Budget	Variance
Pay			
Total	£ 167,072	£ 169,736	£ 2,664
Non-Pay			
<i>IT (inc. website), office</i>	£ 3,709	-	
<i>Travel</i>	£ 10	-	
<i>Training/events</i>	£ 1,195	-	
<i>Miscellaneous</i>	£ 100	-	
<i>Refunds/income</i>	£ -3,895	-	
Total	£ 1,119	£ 16,568	£ 15,449
Total			
	£ 168,191	£ 186,304	£ 18,113



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. Further details are available on request. Undoubtedly one of the biggest challenges for CHD in 2020/21 has been outpatient follow up backlogs, which was amplified by the disruption cause by COVID-19. A main focus for centres within the network continues to be on addressing these backlogs and mitigating risks associated with increased waiting times for CHD patients in our network.

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 COVID-19 and subsequent backlogs.	15	Provider Trusts	Network members are 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. Continued development of restoration plans for CHD activity – linking in with PIC plans.
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 centres form part of network and report into the network board on performance, escalating any issues. Network has met with WHSSC and Health Boards to progress discussion on Wales adopting the CHD standards. Phase II business case approved to increase ACHD services in South Wales.
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	Under review	Provider Trusts	Concern escalated to Clinical Reference Group for Congenital Heart Services and the British Congenital Cardiac Association , to be considered and addressed nationally. Meeting set up in July 2021 with key Network stakeholders to explore regional risk and mitigation strategies, such as use of different staff groups.



Our Focus for 2021/22

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 2021/22 (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 CHD standards in Wales	Support the adoption of NHSE national standards for CHD across Wales by: <ul style="list-style-type: none">- Developing a standard process for self-assessment against these standards- Completing a gap analysis of Welsh CHD services against these standards- Support the progression of business cases to attain these standards
#3 Transition between paediatric and adult services	Pilot project has begun to implement transition clinics in some peripheral centres with Level 1 Cardiac Nurse Specialist support. Transition taskforce formed in order to support the Level 1 centre in this project and take it forward.
#4 Peripheral clinics	Produce standardised protocol for the governance of tertiary CHD clinics in Level 3 centres and support the Level 1 centre to roll this out across the region.
#5 Adult CHD workforce	Work with Clinical Reference Group for Congenital Heart Services and local CHD centres to develop a workforce strategy for ACHD services, to ensure the continuity of adult services across the region. Continue to develop and support Level 3 nursing services clinically and with ongoing education.



Looking to the future



Introducing... John Mills

The SWSW CHD Network will see a few changes going into 2021/22. After more than two years as Network Manager for CHD in the South West and South Wales, Cat has accepted a secondment to a different challenge, and a promotion to Head of Locality within the Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group, at least for the next 12 months. It is clear to me, even from a few weeks in post, what a positive, driving force Cat has been within this network. I joined the network in June 2021 and very much hope to live up to Cat's legacy!

I am not the only new face for 2021/22, at the start of the year the network appointed Dr Dirk Wilson, Paediatric Cardiologist in Cardiff, as the new Chair of the Network Board. As a core network team, we look forward to working closely with Dirk to ensure that our network continues to deliver value and improvement for CHD services and patients across the region.

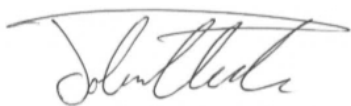
'Meet' Dirk Wilson!
www.swswhd.co.uk/en/staff/30

What next?

For me, working on this annual report has really emphasised the tremendous amount of work that the SWSW CHD Network has achieved in the last year, having an impact nationally as well as locally. It has also highlighted the fantastic passion and dedication of individuals and teams across the region, who make up the network itself, and who are determined to make CHD care in the South West and South Wales the best it can be.

My own priority for the next year is to keep this momentum and continue the great work that has already begun, while making the most of new ideas and new ways of working open to us. Our workplan for 2021/22 is ambitious, but it needs to be if we want to tackle the big challenges facing CHD services. After the lessons of 2020, we recognise we may also need to be flexible in our priorities to respond to the unpredictable, ensuring that the health and wellbeing of our patients and services comes first. All this will not be easy, but this network is well-placed to deliver this valuable work.

Digital working is here to stay. For now, this will be the primary mode of delivery for our network activities, including the excellent education and training programme in our network. However, we hope that some return to in-person events may be possible before the year is out. I look forward to meeting you then.



Dr John G. Mills
Network Manager, SWSW CHD ODN



Congratulations, Cat
You will be missed!





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 September 2021
- 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
- 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**

