



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

Annual Report

2017/18



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Annual Report

Introduction from the Clinical Director

Welcome to the Annual Report for the South Wales and South West Congenital Heart Disease (CHD) Network, 2017/18.

I am truly proud of the work that has flourished over the last year from a wide variety of stakeholders. We have achieved our primary aim to bring together clinicians, commissioners, patient and parent representatives, and other stakeholders to meet NHS England's CHD Standards. I am continually grateful for the support, advice and comment from our parent and patient advocates. Their voice and shared experiences continue to be an important focus for our future work.

Our second year has been no less busy than the first. We welcomed back Caitlin Moss, our Network Manager, who returned following maternity leave. So, it was time to say goodbye to James Dunn who covered Caitlin's absence and we wish him well in his next adventure. The seamless transition is testimony to their attention to detail and professionalism, and I am grateful to them both.

This report sets out the achievements of the network, ongoing challenges and importantly our work plan for the future. I think it important for me to highlight some key achievements. We passed a major milestone in launching our network website. This was a momentous event after a huge amount of work by the core team to bring this together. This is, however, an ongoing project and so your input to keep it current and relevant is extremely important to us. Please take time to regularly review its content and comment on ways in which we can improve upon it for all our stakeholders.

The expansion of the psychology team with a focus on network-wide solutions, as well as the development of a palliative care toolkit, are similarly impressive developments.

We now have a proactive governance structure built around network relevant incident and risk reporting. This is helping to identify common themes which will direct solutions in partnership with stakeholders and other parallel agencies. We have experienced positive engagement with regard to workforce planning in our Level 3 centres, maintaining and improving upon on local standards of care.

I am very pleased to see core members of the team invited to national specialist groups and taskforces where we have been able to share our experiences with NHS England directly and other evolving networks. We have been delighted to work more closely with other CHD networks from around the UK as well, sharing ideas and challenges.

University Hospitals Bristol NHS Foundation Trust have continued to host and fund the CHD network team, as we awaited decisions on the future of central funding, for which I am very grateful.

There is still much work to be done for us to achieve the 2021 NHS England standards. The team looks forward to nurturing the relationships and enthusiasm we currently enjoy with all our partners across the network in the year to come.



Dr Andrew J P Tometzki

Clinical Director

South Wales and South West Congenital Heart Disease Network



OUR NETWORK IN NUMBERS

Congenital Heart Disease Network
South Wales and South West





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 Core Team



Caitlin Moss

Network Manager



Andrew Tometzki

Clinical Director



Sheena Vernon

Lead Nurse



David Mabin

Network Chair



Rachel Benefield

Administrator



Vanessa Garratt

Lead Psychologist

Meet our Network Clinicians

We have over 100 clinicians working to provide CHD care across the South Wales and South West region. Here is just a small selection of them. On our website, you will find details of many more clinicians within the 'Hospitals' section, if you'd like to find out more.



Notable Clinical Progress

The full details of our progress and plans are detailed in the Work Plan – Review and Plans section. Key successes include:

- A regional lifespan specialist **psychology service** was launched
- Our **website** was launched with detailed information for families, parents and clinicians on how to get emotional support
- A network **palliative care toolkit** was launched
- Development of **paediatric drug protocols**
- Network-wide **adult lesion-specific guidance** was issued
- **Risk and incident management** processes were embedded
- The first network **Governance and M&M meeting** was held, with risks, audits, and learning from morbidity, mortality and complaints discussed
- A network **audit programme** was developed
- **Video conferencing** to weekly Joint Cardiac Conference meetings from remote sites has been facilitated in paediatrics
- Delivery of multiple **training events** for network clinicians with excellent attendance and extremely positive feedback, including the inaugural PEC training day in February 2018
- Dedicated **transition clinics** were set up at the Level 1 Paediatric Centre (Bristol Royal Hospital for Children)

One of the key priorities of the network is to support constituent centres to achieve the NHS England Standards for Congenital Heart Disease Care. In year one, considerable work was undertaken to understand a baseline of where each centre was against the standards for the level. In year 2, our focus has been supporting our centres to make progress against the standards. The three key areas where progress has been made across the region against the standards are:

1. Development of support services for patients, including access to a specialist CHD psychology service

Sections B and F of the standards highlight the need for a specialist psychology service for CHD patients, which can be accessed by patients across the network. The Level 1 Centre now has a comprehensive lifespan service, consisting of 3.8 whole time equivalent clinical psychologists. A tiered approach to support has been developed, which includes access to 24/7 support information online via the network website through to specialist 1:1 support for those with the greatest need. Psychology has been embedded into several congenital clinical pathways such as fetal, cardiac catheter, cardiac surgery, inpatient and outpatients. Through the website and new service, all network clinicians can signpost or refer their patients to the right type of support, at the right time.

2. Information for patients and families

The standards require that networks must provide age-appropriate written and/or electronic information to patients and their families/carers, covering the full range of social and health-related advice. Our new website has been designed with the needs of patients and their families at its heart. Online, patients can now find: leaflets and written clinical information; guidance on how to find the right emotional support for a range of different needs; details on how to get involved with the network as well as many other things. (www.swschd.co.uk)

3. Development of a network-wide palliative care toolkit

The palliative care toolkit was written in response to section L of the CHD Standards which calls for individualised palliative care and bereavement support. There are twelve sections within this standard which cover both children and adults for Level 1, 2 and 3 centres.

The toolkit offers practical guidance to professionals caring for a patient with congenital heart disease who it is felt would benefit from the support of palliative care or end of life care, whether at the present time or in the future. Early palliative care improves quality of life by focusing on living well with deteriorating health.

As congenital heart disease is a life-long condition, this toolkit is a lifespan document and refers to the patient who may be a fetus, newborn baby, child, young adult or adult. The toolkit is not a decision making tool but an aid to timely care which is applicable across the network for all those involved in patient care and supporting families.



Highlights from our Centres

Level 1 Adults:

- Appointment of new ACHD psychologist Michelle O'Keefe and launch of ACHD psychology service
- New network-wide lesion-specific protocols developed
- New locum consultant appointment
- Audits begun including an audit of transition between adult and paediatric services in the Level 1 Centre
- Multiple training courses planned and delivered for ACHD professionals
- Development of an emerging adult ECMO service

Paediatrics:

- New consultant appointment
- Reduction in waiting lists for surgery and outpatients
- Delivery of new transition clinics at the Bristol Royal Hospital for Children
- Detailed demand and capacity work undertaken to advise on adequate capacity
- Strategic business case underway for the expansion of the Bristol Royal Hospital for Children, including the PICU

Level 2 Adults:

- Palliative care workshop delivered
- New intranet pages developed
- Digital transfer of echocardiogram images through IEP established
- Patient engagement and education event delivered in Bridgend
- Working with WHSCC to develop long-term case for additional funding in to Welsh services (Phase II)
- Service Level Agreement signed with Level 1 Centre
- Delivery of exemplary transition clinics in Wales
- Significant improvements to the cardiac MRI service
- Ongoing delivery of cardiac pregnancy service

Paediatrics:

- Funding for additional consultant time embedded in service to increase capacity and reduce waiting lists
- Regular attendance of consultant at Joint Cardiac Conference at Level 1 Centre, both face to face and via telemedicine links
- Trialling 'Careflow' communications tool to support closer working with Level 1 Centre
- Process in place for electronic link between Cardiobase and Welsh Clinical Portal (all letters and reports will be accessible to all clinicians across Wales)

Level 3 Adults:

- New Consultant Cardiologists with ACHD expertise in Torbay and Plymouth
- Audit of outpatient follow-up versus network guidelines begun in Torbay
- Development of link nurse role around the region

Paediatrics:

- Bacterial endocarditis audit undertaken in Barnstaple
- Consultant Paediatrician with Expertise in Cardiology (PEC) appointments in Truro, Plymouth and Cwm Taf
- Development of link nurse role around the region
- PECs from around the region using telemedicine facilities to join Joint Cardiac Conferences at Level 1 Centre
- Service Level Agreements put in place across L3 centres in South West to support centres with PEC staffing issues

Communications 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:

- Launching our new website: www.swswhcd.co.uk and promotion of the website amongst a broad range of stakeholders
- Launching the NHS England led patient reported experience online survey throughout the Level 1 centre in Bristol: Chdpatientsurvey.co.uk
- Supported a patient engagement and education event in Bridgend
- A network Twitter account was launched (@CHDnetworkSWSW)
- Patient and parent representatives have continued to be members of the network board and engaged with our work in other ways
- Network newsletters have been circulated to all inpatients, in clinics and via email to our patient email database
- Working in partnership with several charities including: Youth@Heart, the British Heart Foundation and Above & Beyond
- Expanding databases of our stakeholders across the region and delivering targeted communications for different groups
- Continuing to develop strong links with patient and parent support groups
- Visits to a number of peripheral clinics to meet with patients and families
- The team have attended and presented at multiple forums across the year including: Wales and West Acute Transport for Children (WATCH), the South West Children's Palliative Care Network, the High Dependency Children's Nurses Network and University Hospitals Bristol's Clinical Strategy Group
- The team have participated in national forums such as: the Clinical Reference Group for Congenital Heart Disease, the NHS England Task and Finish group on CHD networks, British Adult Congenital Nurses Association meetings and others



Network Team Funding

The network team was funded by University Hospitals Bristol in 2017/18, although for the next financial year NHS England will take over direct funding. In 2018/19, funding is expected to be delivered for the network team via a CQUIN payment¹.

The pay budget was overspent in 2017/18 due to maternity cover and staff in post being on higher points on banding scales than originally budgeted for. This has been flagged to the relevant finance team for the financial year 2018/19, as without adjustments to the budget, the latter overspend is unavoidable.

Non-pay was underspent by £2,192, despite the costs of the design and build of the network website. This offsets part of the overspend in the pay budget, leaving the budget overall at an overspend of £5,294.

| Network Funding | 2017/18 |
|-----------------------------|---------------|
| Pay | |
| Pay budget | £141,959 |
| Pay expenditure | £149,445 |
| Pay Variance | £7,486 |
| Non pay | |
| Computer software/license | £3,423 |
| Travel | £2,590 |
| Network events and training | £5,011 |
| Miscellaneous | £2,784 |
| Non-pay total expenditure | £13,808 |
| Non-pay budget | £16,000 |
| Non pay variance | £2,192 |
| Total Variance | £5,294 |

¹ Commissioning for Quality and Innovation

Network Oversight

The network is governed by a Board which has representatives from across the level 1, 2 and 3 centres, including clinicians, nurses, managers, patients and parents. Commissioners from both NHS England and the Welsh Health Specialised Services Committee (WHSSC) both participate in the Board. The Board was accountable to the Joint Cardiac Board and Senior Leadership Team in the host organisation, University Hospitals Bristol NHS Foundation Trust (UHB) and in NHS England to the Specialised Commissioning team (South). This network is unique in that it covers two separate national health bodies i.e. NHS Wales and NHS England, across which there are fundamental differences in structure and funding. The network has continued to experience very positive engagement from both specialised commissioning bodies.



Key Network Risk and Issues

| Risk/Issue | Mitigation |
|---|--|
| There are long outpatient waits in a number of centres. | The board is monitoring waiting times quarterly and seeking assurance from local centres that plans are in place to address these. Where required the network has supported with capacity planning and will oversee proactive solutions to staffing gaps (e.g. through joint appointments or SLAs). Issues have also been escalated to commissioners where appropriate. |
| Risk of cancelled paediatric cardiac operations due to PICU capacity pressures. | The Board supports the expansion case for the PICU at the BRHC. The network Manager is giving practical support to the BRHC management team in developing the strategic business case for the expansion of the Children's Hospital, including the PICU. |
| There is a risk of inferior ACHD care being provided to patients in some parts of South Wales due to inequitable investment in services. | Concerns have been flagged to the Welsh Health Specialised Services Committee (WHSSC) around this risk. The network is working with WHSSC to support further investment into those centres that require additional MDT and capacity investment. |
| Risk to long term sustainability of CHD care in region due to lack of medical workforce in future/lack of succession plans. | The network undertook a survey of consultants' intentions with regard to service provision and retirement, which highlighted an issue around sustainability of the medical workforce. The risk was discussed by the Board and a number of actions agreed, which included escalation of these concerns to relevant national training bodies such as Health Education England and the relevant SACs. |
| There are several risks around recruitment to posts around the region for Consultants with a special interest and expertise in CHD. | The network is working with centres to ensure and support interim plans to ensure services are maintained. |
| There is a risk that University Hospitals Bristol cannot secure funding from commissioners for the CHD network. | The Level 1 Centre (University Hospitals Bristol) directly funded the network team for its first two years of operation. In May 2018, commissioners confirmed they would directly fund the CHD networks for the financial year 2018/19 with other funding mechanisms likely to be agreed in future years. This risk will therefore be closed. |
| Some local services are currently unable to release nursing staff to develop as CHD link nurses, meaning some of the core quality elements of the standards will be difficult to deliver. | The network team has produced clear guidance on the link nurse role and a 3-year training plan. We will continue to engage with nurse managers to support the identification of suitable staff. The network will actively support those link nurses that have been identified to ensure their value can be demonstrated within their Trust and across the network. |

Nursing Update

Having now identified link nurses in the majority of centres, there has been a focus on communicating with them, particularly around education opportunities, clinical updates and new guidelines. Activities have so far focused on nurses from the Level 1 and 2 centres. The aim has been to develop communication and relationships between the entire clinical nurse specialist teams for both adults and children. A day was held on 30th January for the level 1 (Bristol) and 2 (Cardiff) teams to present individual aspects of their service so each team was able to fully understand their colleagues' services in order to facilitate smooth working between the centres. The remainder of the day was spent looking at some of the standards in depth. The day was well evaluated as being useful and, in particular, time spent meeting the broader teams and sharing best practice was considered valuable. A second day is to be held on 3rd July and Welsh Level 3 nurses will be invited to this day.

Education days on paediatric congenital heart disease for paediatric nurses have been established and hosted by the Faculty of Children's Nurse Education in Bristol. These are two linked days throughout the year. The initial event on 25th May had 52 delegates and 'what you need to know about the network' was presented by Sheena Vernon, our network Lead Nurse. The second day will follow in the autumn. The 16th Annual Adult Congenital Heart Disease Study day for nurses and AHPs will take place on 2nd October. A comparable training day for paediatricians with expertise in cardiology is being planned for November 2018. Education resources and national events are posted on the network website on a regular basis.

Work has also been undertaken with the paediatric nurses in the Level 1 Centre in Bristol. The purpose of this work is to communicate with all nurses delivering cardiac care in the fetal clinic, neonatal and paediatric intensive care units, the ward, cardiac catheter lab, cardiac theatre and the cardiac obstetric service. Raising the profile of the network, the website and its resources, in order that nursing staff are able to direct patients and families to it, is a key goal of this work. Nurses will benefit from the education resources and opportunities being promoted by the network, and will share other specific resources and opportunities from their clinical areas so that all the nurses in the network can benefit.

Presenting about the work of the network at away days for teams including the PICU, Dolphin Ward, Outpatients and paediatric Clinical Nurse Specialists has also been helpful in raising awareness. Education on the process of transition has been a priority, as clinics are set up in Level 1 and 2 centres, and to the broader network through the board meetings.

In Taunton, nursing input has been around the development of the Clinical Nurse Specialist role in terms of training and support. Annual teenage and young adult clinics with Level 1 support is the aim for the Level 3 centres.

A key part of the nursing work for the network has been supporting and engaging with charity partners and support groups, in particular Youth@Heart and Heart Families South West, writing clinical protocols and developing the website.





Work Plan – 2017/18 Review and Plans for 2018/19

| Key Objective | Successes in Year 2 (2017/18) | Aims for Year 3 (2018/19) |
|--|---|---|
| To provide strategic direction for CHD care across South Wales and the South West | <ul style="list-style-type: none"> - Embedded network board and governance structures - Renewed commitment to CHD services in one L3 Centre following escalation of concern that service was to be decommissioned - Led oversight of ongoing actions from Independent Review of Children’s Cardiac Services in Bristol - Escalation of concerns around medical workforce to national bodies with positive engagement - Core team engaged with national specialist groups and taskforces | <ul style="list-style-type: none"> - Write to each Trust in the network with headlines from self-assessments, key agreed actions /next steps and highlight benchmarked position - Support Centres to understand current income for services. With commissioners, understand what appropriate tariffs/income should be - Continue to engage with Clinical Reference Groups, Academic Health Science Networks, NHS England etc. - Host national CHD networks 'Get Together' and suggest get together with local (non-CHD) networks - Consider how to work differently with our L3 centres to put them at heart of network activities - Have continued oversight and assurance of delivery of the ongoing actions from the Bristol Independent Review and University Hospitals Bristol’s action plan with NHS England |
| To monitor and drive improvements in quality of care | <ul style="list-style-type: none"> - Centrally addressed key gaps in the standards through establishment of network-wide regional psychology service, palliative care toolkit, and information and communication for patients through the new website - Several new clinical guidance documents delivered - Self-assessment visits undertake with Level 1 and 2 Centres, paediatrics and adults - Network audit plan generated - Project initiated on discharge communications between Level 1 Centre and regional centres - Key elements of the nursing strategy taken forward | <ul style="list-style-type: none"> - To support the development of a suite of paediatric guidelines (drug, disease-related and procedures) - Develop dental offer in line with standards - Continue to support Level 1 & 2 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 - Deliver annual network M&M - Write up nursing strategy. Take forward key elements, namely: closer working between L1 and L2 CNS teams; direct engagement with known L3 link nurses and senior nurses/matrons; encourage L3s to pursue funding for a dedicated link nurse - Support improvements in communications to the network following discharge from Level 1 centre. Includes improving paper process but also scoping Careflow opportunity - Continue to support progress against agreed actions in recommendations 4 & 5 of the IR, including: Fetal working group, benchmarking against Level 1 centres, audit of Welsh mothers - Refresh network governance structure and documentation following changes to Board structure and relationship with commissioners - Grow audit programme and ensure audits are presented to network to disseminate learning |



| | | |
|--|---|--|
| <p>To support the delivery of equitable, timely access for patients</p> | <ul style="list-style-type: none"> - Fetal diagnosis rates audit initiated. - Workshop held on image sharing around the region - New regional lifespan specialist psychology service launched - Transition clinics launched in the Bristol Royal Hospital for Children - Palliative care toolkit launched - Quarterly network performance dashboard delivered | <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. Support centres to develop telemedicine facilities where desired, including access to legacy funding - Monitor outcome of bid for increased CNS resource to improve access to L1/L2 CNS via telephone and/or outreach clinics - Continue to promote awareness of and access to regional service. Monitor activity and evaluate year 1 of service - Evaluate new transition clinics at BRHC. Consider peripheral transition opportunity - Create summary reference document of palliative care toolkit - Continue to produce quarterly performance dashboard - Review centres' submissions and offer support and/or seek assurance/escalate concerns when continued 1. lack of engagement or 2. unacceptable performance - Develop network-wide transfer and repatriation policy - Work with Centres and commissioners to support Phase II investment in Wales - Begin work to understand loss to follow-up rates - Support Bristol Royal Hospital for Children with strategic outline case for expansion, including the PICU |
| <p>To support improvements in patient and family experience</p> | <ul style="list-style-type: none"> - Continuing to build partnerships with charities to the benefit of patients - Continuing to collaborate with support group partners - Supported a patient engagement and education event in Bridgend | <ul style="list-style-type: none"> - Map charity stakeholders and clarify relationship/opportunities - Continue to build on existing relationships with patient/family representatives. Develop patient representative role and training. Co-develop structure and purpose of role within network. Recruit further representatives - Continue to support and advise local support groups. Try to encourage equitable access across the region - Continue to embed and publicise national CHD survey in Level 1 Centre. Communicate results when available and encourage action to address any areas for improvement - Support centres with local patient engagement events and try to encourage events that allow equitable geographical access across the region. Consider offering some training to centres on how to deliver patient engagement |
| <p>To support the education, training and development of the workforce within the network</p> | <ul style="list-style-type: none"> - Delivery of a programme of network training events and signposting to non-network training events through our website - Undertook regional review of medical workforce and succession plans - Developed relationships with research partners - Presented at multiple forums | <ul style="list-style-type: none"> - Finalise high level training and education strategy for relevant professional groups (events, frequency, signposting etc) - Support the delivery of targeted training and education to cover - ACHD & paediatric nurse training, PEC and ACHD study days. Support development of echo training offer - Consider training for PECs/adult Cardiologists with an interest alongside business update in form of a new way to engage L3s. Develop online or video training material for primary care professionals e.g. GPs, HVs - Continue to support recruitment of medical workforce as needed. Continue to engage with relevant regional bodies on big picture (HEE, SACs). Develop promotion material to support recruitment into the region - Continue to build relationship with partners in research. Seek information on current research to develop a network central directory of research across the region |



To be a central point of information and communication for network stakeholders

- Delivered paper and electronic network newsletters
- Launched new network website
- Delivered targeted communications for various stakeholder groups across the network

- Continue to promote website to stakeholders. Ensure annual review/update of website. Consider further developments based on feedback/feasibility
- Meet with interdependent teams to encourage collaboration and build relationships
- Deliver two newsletters per year. Continue to get out and about at events, meetings and visits. Continue to use email databases for targeted communications. Deliver large annual stakeholder event

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

- Successfully sought funding for network events
- Sought feedback on all network events and listened to suggestions on how to improve (events generally extremely well evaluated)
- Delivered annual report for 2016/17
- Successfully escalated issues to appropriate in order to be collective voice of network and to influence strategic decisions
- Able to demonstrate improvements towards more equitable access to care across the region.
- Leading the way on UK-wide collaboration of CHD networks

- Proactively seek funding opportunities for network and its stakeholders from different sources e.g. CQUINs, charity, grants, tariff, commercial sponsorship of events etc
- Continue to seek feedback from stakeholders on value of events and activities
- Remain within budget and ensure effective use of resources
- Reinvest existing budget into the team following reduction in Manager/Nurse WTE
- Hold team away day to reflect on 17-18 progress, understand future opportunities and threats, and develop 18-19 work plan
- Complete Annual Report
- Escalate network issues appropriately to commissioners, external bodies etc. and ensure action is taken when required



Our Patients and Staff

Peter's Story²: Although Peter had been offered surgery in the past his anxieties had meant that each time it was offered he had felt unable to cope and had cancelled the operation. His past experiences of hospital had meant that he had lost trust in medical professionals and felt traumatised by his experiences.

Network ACHD Clinical Psychologist Michelle O'Keefe saw Peter for two sessions before he was due to have surgery. During these sessions they explored the pros and cons of having surgery and ways he could manage his anxiety. At this time Peter was feeling calm and ready for surgery. Unfortunately, on the day of surgery he became very distressed, worrying that he would not make it through the procedure. This was understandably very upsetting for him, his family and the staff on shift that day. As Peter was being taken into the catheter lab he told the team he could not go through with it.

Peter and Michelle used this as a learning experience and developed a treatment plan aimed at understanding and helping him manage the particular thoughts that were contributing to his anxiety. They also created a support plan involving strategies that he and staff could utilise to support him at the time of surgery. This plan was shared with his family, the surgical team and ward staff. Positively, Peter was able to have his surgery in December 2017. In January 2018, Peter said he was feeling physically and emotionally stronger and was proud of himself for having been able to go through with the surgery.

Amy's Story: I was born with a collection of complex and severe heart defects. In my 18 years, I have been in hospital over 20 times, had 15 operations, three of which were open heart surgery and have been in intensive care five times. I have three impressive scars and my friends like to think that my pacemaker practically makes me a robot. A portion of my life has been spent in and out of hospital, taking horrible medicines and having numerous needles poked in me, but that portion of my life has only been and will only be a tiny portion.

I was very lucky to be born to amazing and supportive parents who have always treated me as if I was any 'normal' child. They have never stopped me from trying anything that I wanted to try



and allowed me to set my own boundaries, within reason. I have tried ballet, football, tag rugby, netball, athletics, golf and even surfing. I have been lucky enough to travel to, France, Spain, Portugal and even New York City. Between the time of me turning 16 and 18 I felt like I had grown up a lot. I had held down a part time job as a waitress for two years, learnt to drive, had my own car and

even got a place at the University of Southampton, where I am currently studying.

I suppose what I'm trying to say is although living with a heart condition has not been without its struggles, I deal with it. I am not brave, bravery is where you have a choice to act strong, what choice did I have? And I'm not normal, I have endured things that no child/young person should have to endure, but I am resilient, and I know more than most that life is a gift. Because of that mindset I have chosen to live as any normal 18 year old would, I'll make mistakes and I'll learn from them and I'll find my limits, and yes it is this mindset that gives my cardiac liaison nurse a meltdown every time I ring her asking her if it is safe for me to do whatever 'crazy' thing I've thought would be a good idea for me to do now, but it is my life and I have fought for it so I'm going to live it in the way I deserve. Like a normal 18-year-old.

Becky Lambert, Staff Nurse, Taunton and Somerset NHS Foundation Trust: I'm proud to have been a nurse for 30 years, have never wanted to be anything else and love the nurse-patient relationship; drawing alongside people at difficult times and being part of a team that makes a difference in their lives.



I first became involved in Adult Congenital Heart Disease (ACHD) three years ago when I was asked to help at our bi-monthly joint clinic with a visiting consultant from Bristol. My interest was sparked, and I started attending the excellent study days in Bristol. Dr Curtis, our visiting Consultant in ACHD based at the Bristol Heart Institute, has also always been willing to teach me in clinic.

I was invited to the network launch in June 2016, which I attended with some trepidation, never imagining that my involvement would continue to this degree. At some point, I found myself volunteering to sit on the board, as a Level 3 and a nursing representative. The meetings have been well-led, patient-focussed and the group has been fundamental in making inroads into improving patient care and professional communication across the network.

The network has supported me to set up a nurse role in Taunton, bringing us in line with the NHS England standards and starting to provide an equitable service for our local patients. I currently have one day per week as an ACHD nurse and am setting up the role from scratch, with support from the network team. The aims of the role are to provide advice and support to patients (both inpatient and outpatient) and their families, deliver staff education and support, undertake audit and evaluate the service to meet the changing needs of the patient group. I am excited to be the ACHD nurse for Taunton and am looking forward to continuing to develop the service and my knowledge to the benefit of our patients.

² Patient's name has been changed for privacy reasons



Delivering Continual Progress

What are the top areas that Centres should 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?

- Consider taking up the offer of legacy funding from the University Hospitals Bristol team if your Trust does not have **telemedicine** facilities in place
- Work with the network's IT champions at the Level 1 Centre to ensure **image sharing** links are as good as they can be, and understand where future opportunities are
- Understand what **income** your service receives for CHD work from commissioners, and work with the network team to ensure this is appropriate
- Seek support in your Trust for the development of a **link nurse role**
- Make use of the network **palliative care toolkit** and develop a local directory of services for your patients
- Promote and signpost patients to the new network **website** so they can access online information and support 24/7
- Refer patients appropriately to specialist **support services** for CHD psychology when it is required
- Ensure **waiting lists** are being managed effectively and undertake **demand and capacity planning** for your service if they are too long – the network team can help with this
- Make use of network and other **training opportunities** for staff
- Ensure one **annual audit** of clinical significance is completed each year
- Escalate any relevant **risks** to the network team and engage with network **incident management** processes to ensure learning is shared
- Work with our Lead Nurse to make sure **transition** is well-managed in your service
- Support your patients to be **dentally fit**, all of the time

How to get involved

There are many ways to get involved with the network:

Professionals can:

- Express interest to become 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 M&M on 11th September, 2018 in Taunton
- Come to our stakeholder day on 10th July 2018 in Bristol

Patients and families can:

- Visit our website
- 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 on 10th July 2018 in Bristol

For more information, please visit www.swswhcd.co.uk or email Rachel.Benefield@uhbristol.nhs.uk