

South Wales and South West Congenital Heart Disease Network

Annual Report 2016/17





Contents

Introduction from the Clinical Director	2
Foreword	3
The CHD Network in Context	3
Our Vision	4
Our Strategy and Work	4
Notable Clinical Progress	4
Funding	4
Network Oversight	5
Nursing Update	6
Assessment against Standards	7
Priority Actions for CHD Standards by Section	8
Communications and Engagement	9
Governance & Monitoring	10
Key Risks and Mitigations	10
Work Plan – 16/17 Review and Plans for 17/18	12



July 2017

Annual Report

Introduction from the Clinical Director

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

First and foremost I am grateful to University Hospitals Bristol NHS Foundation Trust for hosting and pump priming the CHD network team since April 2016 whilst we seek alternative funding streams for the future.

Our primary aim as a network is to bring together the clinicians, commissioners, patient and parent representatives, and other stakeholders to meet NHS England's CHD Standards. Whilst there is a small team coordinating the network, our success is dependent on the commitment and energy of all those involved with CHD services across the region. Accordingly, we have been humbled by the enthusiastic support of all stakeholders from clinical, nursing and managerial staff in all the CHD centres across South Wales and South West England. Importantly we have commissioning representation from both NHS England and NHS Wales agreeing our terms of reference and governance structure. I'm especially grateful to our parent and patient advocates who have used their voice effectively at both board meetings and listening events throughout our first year.

It has been a very busy first year since our launch event in June 2016. Caitlin Marnell, the CHD Network Manager, drew together input from across the network to put in place a robust and challenging work plan. This work has been continued by James Dunn, whilst covering Caitlin's maternity leave. Sheena Vernon, Lead Nurse for the CHD Network, joined us in October 2016, providing a central point to draw together and drive the momentum of the nursing and clinical priorities across the region. We are ably supported by Rachel Benefield, Network Administrator. Finally we made the important appointment of David Mabin as Chairman. He brings a wealth of experience as a senior clinician in paediatrics as well we being an Associate Clinical Dean at the University of Exeter Medical School.

This report sets out the achievements of the network to date, ongoing challenges and importantly our goals for the future. The network team has visited almost all of our Level 3 centres, seeing the progress the centres have already made and quantifying a gap analysis against NHS England's standards for congenital heart disease. This analysis has been central to informing our work plan and ensuring our activities as a team are directed towards supporting centres to meet the standards.

There is much work to do and, I along with my team, look forward to working with our partners across the network in fulfilling our aims and objectives for the coming year.

Dr Andrew J P Tometzki

Clinical Director

South Wales and South West Congenital Heart Disease Network



Foreword

The South Wales and South West Congenital Heart Disease Network brings together clinicians, managers, patients and commissioners across the region to work towards meeting the new standards. The network comprises:

- 18 adult and 19 paediatric providers, covering level 1 (specialist surgical), 2 (specialist medical) and 3 (local centre) services
- over 6,500 children and 8,000 adults with congenital heart problems
- 30 clinics per week, seeing more than 20,000 outpatient attendances per year
- over 40 specialist and link nurses
- 37 paediatricians with expertise in cardiology
- 17 adult cardiologists with specialist congenital interest
- over 425 heart operations



The CHD Network in Context

For well over a decade congenital heart disease has been under scrutiny within the UK. There were long-standing concerns that smaller centres were not sustainable. In 2006 Dr Shribman, National Clinical Director for Children, Young People and Maternity, along with Prof Roger Boyle who was then the National Director for Heart Disease, conducted a workshop on congenital heart services.

In October 2009, Prof Sir Bruce Keogh launched the safe and sustainable review of congenital heart services in the UK. This concentrated on paediatric services alone, despite the advice from clinical advocates who wished that adult congenital heart services be considered simultaneously. This process concluded on July 4, 2012 however this resulted in judicial reviews. Consequently, the Secretary of State requested an independent review. The review concluded that the recommendations were flawed and suggested a rethink encompassing the whole patient journey to include fetal through to adult congenital heart disease. (Ref 1)

NHS England therefore announced in July 2013 that it would embark on a new congenital heart review. After a lengthy period of consultation recommendations were made in July 2015. Service specification standards were published in May 2016. We are now in a period of consultation on the implementation of these standards.

A cornerstone of these recommendations is the formation of a formal network to include a Clinical Lead, Network Manager, and Nurse Lead. As such, in April 2016, University Hospital Bristol established the South Wales and South West Congenital Heart Disease Network to work with clinicians, managers, patients and commissioners across the region to work towards meeting the new standards.





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 Strategy and Work

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

Strategic Direction	To lead providers in meeting the new standards	
Monitor and Improve Quality	To measure and drive achievement of standards	
Timely, Equitable Access	To ensure equity across the region	
Improve Patient Experience	To understand and improve patient experience	
Education & Training	To increase access to training opportunities	
Information and Communication	To be a central point of information	
Value for Money	To maximise the impact of investments in CHD services	

Notable Clinical Progress

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

- Completion and publication of ACHD protocols pregnancy, obstetrics and lesion-specific guidance
- Palliative care pathway work under way
- Paediatric lesions pathways in progress
- Risk & incident reporting processes in place
- Annual M&M / governance meeting in place
- Securing local service provision through SLAs for shared medical input between DGH providers
- Supporting the rationalisation of provision between Gloucester and Cheltenham, supported by parent representatives

Funding

The network is currently funded by University Hospitals Bristol, although alternative funding models are being sought with commissioners.

The pay budget in 2016/17 was over-spent to fund back-fill arrangements for maternity cover. The service expects to be within the pay budget in 2017/18.

The non-pay budget was underspent in 2016/17. There is expected to be a higher degree of non-pay spend in 2017/18, including the design, build and hosting of the network website.

Network Funding	2016/17
Pay	
Pay total expenditure	£139,642
Pay budget	£116,149
Pay Variance	-£23,493
Non pay	
IT, phones & office	£3,328
Travel	£932
Network events	£1,897
Miscellaneous	£645
Non-pay total expenditure	£6,802
Non-pay budget	£16,000
Non pay variance	£9,198
Total Variance	-£14,295



Meet the Team



David Mabin, Network Chair



Sheena Vernon, Lead Nurse



Andrew Tometzki, Clinical Director



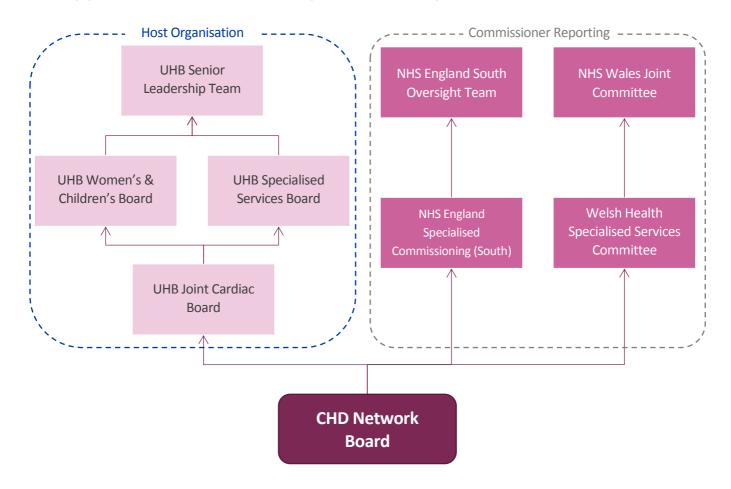
Rachel Benefield, Administrator



James Dunn, Network Manager

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, and commissioners. The Board is accountable to the Joint Cardiac Board in the host organisation, University Hospitals Bristol NHS Foundation Trust (UHB); in NHS England to the Specialised Commissioning (South) ODN Oversight Board; and in Wales to the Welsh Health Specialised Services Committee. This network is unique in that it covers two separate national health bodies i.e. NHS Wales and NHS England. There are fundamental differences in structure and funding. The network is enjoying very positive engagement from both specialised commissioning bodies in both NHS England and NHS Wales.





Nursing Update

The CHD standards dictate that each centre should have a CHD Link Nurse and that patients should have access to a Clinical Nurse Specialist (CNS). Centres have found it difficult to identify nurses within their institutions and to release them from other duties to undertake this role. Some, however, have been able to develop a link nurse role and the network is supporting these to ensure delivery of quality benefits. Network support has included clarifying the expectations of a link nurse in line with the RCN standards and developing a 3 year education programme.

Cardiology training days targeted at paediatric and community nurses have been established hosted by the Faculty of Children's Nurse Education in Bristol. The 15th Annual Regional Adult Congenital Training day is on September 19th 2017. Comparable training days for the paediatricians with expertise in cardiology are planned for February 2018.

There are plans to increase the support that the level 1 and level 2 Clinical Nurse Specialists provide to local centres, both in terms of attending annual young person's clinics, and by providing advice and support for locally based link nurses. Ultimately this is reliant on the local centres identifying, releasing or appointing appropriate members of staff.

The timescales of the action plan for Link Nurses role

Year 1 (2017)	Year 2 (2018)	Year 3 (2019)
- Identify nurse Level 3 centres	- First nurses attending Adult and Paed courses	- All nurse have completed courses
- Clarify support in Level 2/3 centre	- Participate in local clinics	- Local education to up skill other RGN
- Shadowing in Level 1 on ward and OPD	- Explore 'Helpline' options	- Helpline established
- Meet Level 2 CNS teams	- Set up 3-6monthly Link Nurse Meetings	- In patient support established
- Gap analysis 31 surveys from ACHD Day	- Charity funding to support	
- Book onto appropriate course 'Congenital	- RCN competences completed	
Network Nurses' group email for comms,	- Annual transition clinics in Level 3 centres	
training, peer support	supported by Level 1 CNS	

Other nursing work in 2016/17 has included:

- Development of the palliative care pathway
- A fetal service survey
- Gathering patient information for the website
- Taking forward work on transition
- Identifying appropriate cardiac information for the outreach clinics to give to patients and families
- Supporting the Level 1 and 2 clinical nurse specialist teams
- Presenting the work of the CHD network to other associated nursing network (e.g. South West Palliative Care and the Paediatric High Dependency Nursing Network).





Children and young people's cardiac nursing:





Assessment against Standards

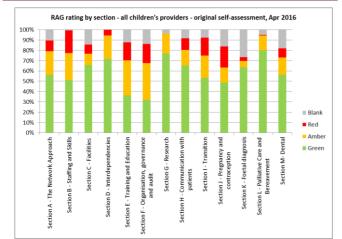
One of the key priorities of the network is to support constituent members to achieve the NHS England Standards. In year one a considerable amount of work has gone into benchmarking each centre against the 200 standards. 28 of 30 centres have now completed the self-assessment. The network has visited 27 of these centres to validate the self-assessment scoring.

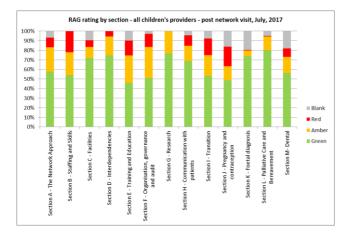
Through the self-assessments, validation visits and workshops we have identified the actions required to meet the outstanding standards. These have been grouped into those that the network will lead, and those that local centres need to address with network support (See Priority *Actions for CHD Standards by Section*). Over the coming months the network team will be writing to each centre providing a breakdown on their outstanding actions and seeking assurance that there is commitment to work with the network partners to achieve these.

Progress to date

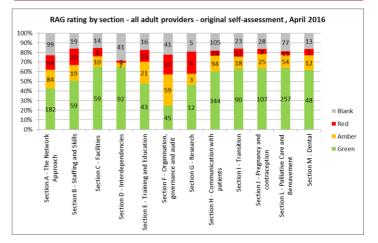
As well as undertaking baseline assessments, in year 1 there has been progress in achieving the NHS England standards through collaborative work at the network meetings as well as action taken locally in each centre. The tables below detail the increase in 'green' standards since the inception of the network.

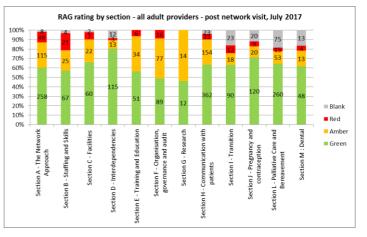
Total Standards for all Adult's Providers	2016	2017	Change	% change
Green	1338	1478	140	10%
Amber	406	414	8	2%
Red	219	150	-69	-32%
Blank	105	26	-79	-75%





Total Standards for all Children's Providers	2016	2017	Change	% change
Green	1586	1688	102	6%
Amber	513	511	-2	0%
Red	285	263	-22	-8%
Blank	255	177	-78	-31%







Priority Actions for CHD Standards by Section

Section	Priority Actions for Network	Priority Actions for Local Centres
Section A - The Network Approach	 Develop guidelines and protocols Support development of national care templates Roll-out telemedicine and remote MDT access 	 Release staff for CPD, remote MDT access Ensure network protocols and approaches are embedded
Section B - Staffing and Skills	 Enable L1/L2 CNS to provide support to link nurses and clinics across network Identify key data for databases 	 Identify link nurses to work alongside consultants in clinics Ensure that basic data (e.g. wait times) can be provided
Section C – Facilities	 Support local centres with business cases Coordinate between centres for access to facilities provided at a network level 	 Ensure facilities can be provided in line with standards and promote these requirements in capital business planning
Section D – Interdependencies	 Ensure that every centre has a pathway access to all relevant services, even where not provided locally 	 Ensure network escalation protocols are adhered to and that non-cardiac services (e.g. A&E) are aware of the 24/7 network support for cardiac patients
Section E - Training and Education	 Deliver planned training for consultants and nurses, including making talks available online Continue to identify additional needs Enable access to MDT for CPD 	 Support staff to attend or access talks online Ensure that staff attend appropriate local non-specialist training and escalate to network if this is not provided locally
Section F - Organisation, governance and audit	 Develop a network audit plan Continue to develop a network database (e.g. of waiting times) 	 Ensure participation in network audits Collect and submit basic data (e.g. waiting times / patient numbers)
Section G – Research	- Work with clinicians involved in research to ensure that access is equitable	 Ensure patients are informed of any research opportunities that arise
Section H - Communication with patients	 Provide access to information and advice through the network website Work with L1/L2 CNSs to provide support to link nurses in peripheral clinics Implement a psychology plan giving criteria-based access to information and support, including web resources, telephone and face-to-face appointments 	 Through link nurses and local clinicians ensure that patients are sign-posted to relevant information on the network website Ensure that patients are given as much information and support locally, and directing appropriately to L1 and L2 services as these are developed
Section I – Transition	- Establish CNS support for a transition clinic in each centre at least once per year	 Ensure a structured approach to transition locally, following a recognised pathway, engaging with local hospital transition nurse
Section J - Pregnancy and contraception	 Share network protocols for pregnancy and contraception 	 Adopt network protocols, promote these across local hospital, and highlight any further training / service needs to network
Section K - Foetal diagnosis	 Understand and address inconsistent fetal pick-up rates Support cases for service investments in UHB and UHW Ensure CNS support for all diagnoses 	 Review local CHD detection rates Assess compliance with Fetal Anomaly Screening Programme (FASP) guidelines Support sonographer cardiac focused training e.g. Tiny Tickers
Section L - Palliative Care and Bereavement	- Develop network palliative care and bereavement pathway	 Adopt network pathway and ensure that patients are given access to local and network support services
Section M : Dental	- Work with dental specialists to develop network guidance	- Ensure that patients are informed of the need for regular dental check-ups. Refer to specialist centres where required



Communications and Engagement

Engaging with our patient and clinical colleagues has been an essential part of our work in the first year. We have undertaken a significant amount of work to ensure that we are involving patients and parents in shaping our work and that we represent the whole clinical network.

Key activities have included:

- Patient and parent representatives as members of the network board
- Newsletter circulated to all inpatients, in clinics and via email
- Visits arranged to 10 peripheral clinics to meet with patients and families in clinic
- Fetal survey undertaken looking at the experiences of all service users across England and Wales for 12 months
- Formed a charity partnership with Above & Beyond
- Developed strong links with patient and parent support groups
- Evening listening and engagement events in Gloucester and Exeter attended by 50+ families. Videos and FAQs posted online
- Hosting an engagement event in May in response to the NHS England consultation
- Patient and parent virtual reference group established to advise on service changes
- Web site due to launch Summer 2017
- Facebook due to launch Summer 2017
- Patient engagement event planned in Cardiff in autumn

In 2017/18 we will continue to develop our methods of engaging with and listening to patients and parents. Central to this will be the launch of our network website, due for late summer 2017. This will be a central resource for patients, parents and clinicians.



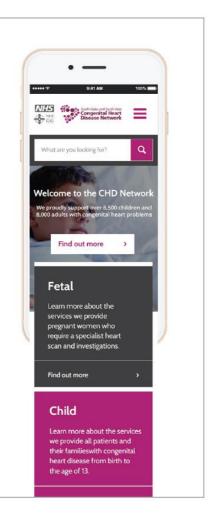


Figure 1 - Mock-up mobile-friendly website design





Governance & Monitoring

In line with the CHD standards, the network has established a governance and reporting structure. Whilst individual providers are still responsible for reporting and acting upon incidents and risks locally, the network reporting structure ensures that learning this can be shared across institutions and that the network can support if multi-provider intervention is required. The structure also gives a clear route of escalation to the network and then to commissioners should organisations be unable to effectively mitigate risks or address incidents internally.

Risks and incidents will be reviewed quarterly at the Network Board meeting. All clinicians are invited to annual Governance and M&M meeting where there is discussion and dissemination of broader learning from incidents and adverse events; aggregate review of mortality and morbidity and learning from this; review of new guidelines & changes in practice; summary of national (NICOR) and local data (waiting times, audits etc.); and forward view of planned audit / research.

Key metrics such as outpatient waiting times, wait for MDT discussion and surgical waiting lists are monitored quarterly. Actions are agreed for those areas that present a concern to the Board.

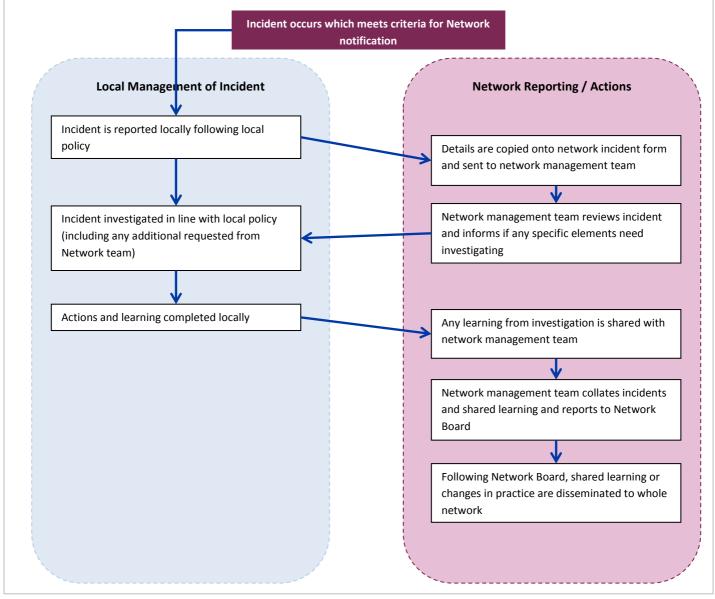


Figure 2 - Reporting & Learning From Network Incidents



Key Risks and Mitigations

Risk	Mitigation
There are long outpatient waits in a number of centres, including Bristol children's service	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)
There are long waits for surgery in Bristol children's service	The board is requesting quarterly assurance from UHB that it has a robust plan in place to meet current and projected surgical demand. The network team has provided assistance with developing capacity plans.
There is a longer term workforce risk associated with a lack of consultants training with expertise in congenital cardiology, particularly in the adult services	The network is undertaking an anonymous survey of consultants' intentions with regard to service provision and retirement. This will enable a true picture of the risk to be shared with commissioners, Trusts and medical training bodies. Where there are known issues the network is working with individual providers to gain commitment to proactive succession planning for CHD medical workforce
The pressures on general paediatric services and general cardiology services in DGHs mean that CHD services struggle to attract investment or recognition from Trust managements. This includes pressure on local clinicians delivering core clinical commitments, as well as on the additional, but essential service coordination, clinical advice and CPD.	The network team has sought to meet with senior clinical and operational managers as part of our site visits to raise awareness of the network and clinical standards. All Clinical Directors have been written to requesting they support protected time for CHD (including non-DCC activities) within clinician job plans. In 17/18 the network will be writing to each centre seeking commitment to work towards meeting the CHD standards. This is also laid out in contractual commitments between NHS England / WHSSC and each provider
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.

Threats	Mitigation
No funding secured from NHS England for core network posts	Through the UHB contract managers, the network will continue to seek funding arrangements, either through NHS England and WHSSC or as a contribution from provider Trusts
No additional funding across network to meet standards	The network will continue to provide innovative solutions to minimise the need for additional investment (e.g. criteria based access to psychology services). Where there is significant risk to the quality of service delivery as a result of a lack of investment the network will use its risk procedures to escalate this to local Trust management and commissioners for re-consideration of funding priorities
Sufficient PICU and ward capacity will be required to ensure Bristol can meet NHS England's requirement for 500 surgical cases by 2021	UHB are actively involved in the national PIC review. It is considered that this may be delayed by the outcome of the NHS England Congenital Cardiac Consultation, so it may be wise for UHB to consider proactive investment in PIC capacity ahead of the publication of the PIC review. The network team are happy to support evidence for any such case.



Work Plan – 16/17 Review and Plans for 17/18

Key Objective	Successes in Year 1 (16/17)	Aims for Year 2 Onwards (17/18)
To provide strategic direction for CHD care across South Wales and the South West	 Established network board, governance structures Gained commitment from English and Welsh commissioners to formally recognise role of network in supporting provider trusts to work towards the national standards Commitment from all provider Trusts to be constituent members of the network and collaboratively work to achieve standards 	 A statement of intent from each provider committing to CHD services, including achievement of standards, development of current workforce and succession planning, addressing service risks and equipment issues Identify an ideal tariff for CHD clinics and work with local services and commissioners to ensure that services are appropriately funded to meet standards. Where block contracts are in place, to support contractual discussions about CHD provision (as above) To have oversight and assurance of delivery of the relevant outstanding actions from the Bristol Independent Review and UH Bristol's action plan with NHS England
To monitor and drive improvements in quality of care	 28 out of 30 CHD centres have self-assessed against the CHD standards 27 out of 30 centres have been visited, or have upcoming visits from the network team to review assessments and support work towards achieving standards Work-streams have been started in key areas including palliative care, pregnancy care, psychology support Clinical protocols for ACHD have been shared and adherence is being audited Network governance and incident reporting structure in place to ensure there is knowledge of and learning from adverse events and risks 	 Continue to use self-assessment data to drive service improvements and share best practice, focusing on those areas (such as transition, psychology, information and support) where the biggest impacts can be made Work with commissioners, independent bodies and providers to ensure standards are met when deficiencies are identified Continue to develop clinical guidance and protocols and promote audit of those protocols already in place to demonstrate improvements Continue to develop a dashboard of key metrics, using this to drive equity in provision, for example of waiting times for treatment Promote the use of the risk and incident reporting processes, sharing learning through board meetings and annual M&M Set up of Network Mortality and Morbidity reviews Delivery of an annual audit programme agreed with members, and reporting outcomes
To support the delivery of equitable, timely access for patients	 Established a network dashboard of wait times, using this to identify and improve long waits Supporting local capacity planning and business cases for investment in services, including (UHB children's service, Truro adult service, Hywel Dda paediatric service) 	 Use newly 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 Implement options for increased access to L1/L2 CNS through telephone / video appointments Demonstrate increased access to L1/L2 specialist psychology for patients from across the network, through telephone / video / f2f appointments, as well as access to information and local support where specialist input is not required Use relationships with clinicians, mangers and commissioners to work with centres to address issues where inequities exist



To support improvements in patient and family experience	 Invited 6 patient / parent reps to join our network Board Run workshops in Bristol, Gloucester and Exeter, with further planned in Cardiff Collated patient information leaflets and shared this with each centre Attended 10 outpatient clinics (children's and adults) to speak to patients about what we can do differently Supported the NHS England public consultation on changes to CHD services 	 Formally launch partnership with Above & Beyond with network website launch. Continue to strengthen partnerships with other charities Support Heart Families South West and other support groups to grow local support groups across the region Use website as single resource to direct patients to support and information. Ensure that every clinician knows about, and directs patients to these resources Through the website, gather patient feedback, both about specific services and the overall provision of CHD care Continue to grow engagement along the lines patients and families want - e.g. evening Q&A sessions, events closer to home
To support the education, training and development of the workforce within the Network	 Set up a Paediatrician with Expertise in Cardiology (PEC) study day for February 2018 Promoted adult congenital study days Established learning needs for link nurses Supported medical job planning to protect time for CHD, including CPD and MDT attendance Mapped the provision of nursing workforce across the network Presented at the all-Wales audit day Presented at the SW palliative care network meeting 	 Support the delivery of targeted training and education to cover - ACHD & paed nurse training, PEC and ACHD study days Undertake a review of medical workforce and develop a forward view, taking account of the risks in succession planning, particularly around ACHD services Use network board events to deliver training or CPD alongside core network business Support development of a programme of research across the Network
To be a central point of information and communication for Network stakeholders	 Established a quarterly newsletter Communicated the network priorities, work plan and Board summaries to system executives 	 Ensure website is key resource for communication to all stakeholders. Use feedback options to guide development of new content Continue to communicate key information to all stakeholders, moving away from paper newsletters towards electronic communication options
To ensure it can demonstrate the value of the Network and its activities	 Rapidly established credibility with commissioners, clinicians and managers Raised the profile of CHD services within provider organisations and commissioners Begun to deliver improvements against CHD standards and to share learning between centres Able to demonstrate improvements towards more equitable access to care across the region Increased understanding of congenital services and pathways in associated networks Created a forum for addressing core issues – e.g. pregnancy services, palliative care and psychology 	 Proactively seek funding opportunities for Network and its stakeholders from different sources e.g. CQUINs, charity, grants etc. Undertake review of Network against relevant 'Value for Money' Framework Continue to seek feedback from stakeholders on value of events etc. Remain within budget and ensure effective use of resources Escalate Network issues appropriately to commissioners, external bodies etc. and ensure action is take when required