

Introduction to the Congenital Heart Disease Network, South Wales & the South West

Cat McElvaney – Network Manager

11th February, 2020

Buzz word bingo!- shout "BINGO" when you get a full house!

CLINICAL ENGAGEMENT	STRATEGY	GOVERNANCE
TRANSITION	ODN	NHS ENGLAND
PATIENT ENGAGEMENT	LESION OF THE MONTH	SWSW

Aims for the Session

- **Operational Delivery Networks (ODNs)- what are they?!**
- **Congenital Heart Disease Networks – national & regional**
- **Objectives of the CHD network**
- **Achievements & Risks**
- **Priorities 2020/21**
- **2020 and beyond**

Operational Delivery networks- what are they?

- Launched in April 2013 following the publication of the NHS England strategy to sustain and develop clinical networks, [Developing Operational Delivery Networks: The Way Forward](#).
- ODNs are established across England within geographical areas around clinical pathways.
- ODNs are focussed on coordinating patient pathways between providers over a wide area to ensure access to specialist resources and expertise.

Existing networks

- Adult critical care
- Neonatal critical care
- Major trauma
- Burns care
- Paediatric Neurosciences
- Congenital Heart Disease

In progress

- Paediatric surgery
- Paediatric Critical Care
- Paediatric Oncology

Purpose of networks- as per NHS England guidance

- Ensure effective clinical flows through the provider system through clinical collaboration for networked provision of services
- Take a whole system, collaborative provision approach to ensure the delivery of safe and effective services across the patient pathway, adding value for all its stakeholders
- Improve cross-organisational, multi-professional clinical engagement to improve pathways of care
- Enable the development of consistent provider guidance and improved service standards, ensuring a consistent patient and family experience
- Focus on quality and effectiveness through the facilitation of comparative benchmarking and auditing of services, with implementation of required improvements

CHD Networks – an overview

- 11 CHD networks across the country
- SWSW CHD- One of the first official CHD networks in the country !
- Established officially in April 2016, in response to CHD standards
- Building on existing well established clinical network
- Accountable to two separate commissioning bodies; NHS England and NHS Wales.
- Designated Operational Delivery Network and funded by NHS England since April 2019
- Changes in progress with ODN governance, South West- led by Peter Wilson



Why?

The purpose of the network is to bring together clinicians, managers, patient/family representatives and commissioners across South Wales and the South West to work together supporting patients with congenital and paediatric acquired heart disease and their families

The Standards

- Section A: **The network approach**
- Section B: **Staffing and skills**
- Section C: **Facilities**
- Section D: **Interdependencies**
- Section E: **Training and education**
- Section F: **Organisation, governance and audit**
- Section G: **Research**
- Section H: **Communication with patients**
- Section I: **Transition**
- Section J: **Pregnancy and contraception**
- Section K: **Foetal diagnosis**
- Section L: **Palliative care and bereavement**
- Section M: **Dental**



CHD standards- Psychology

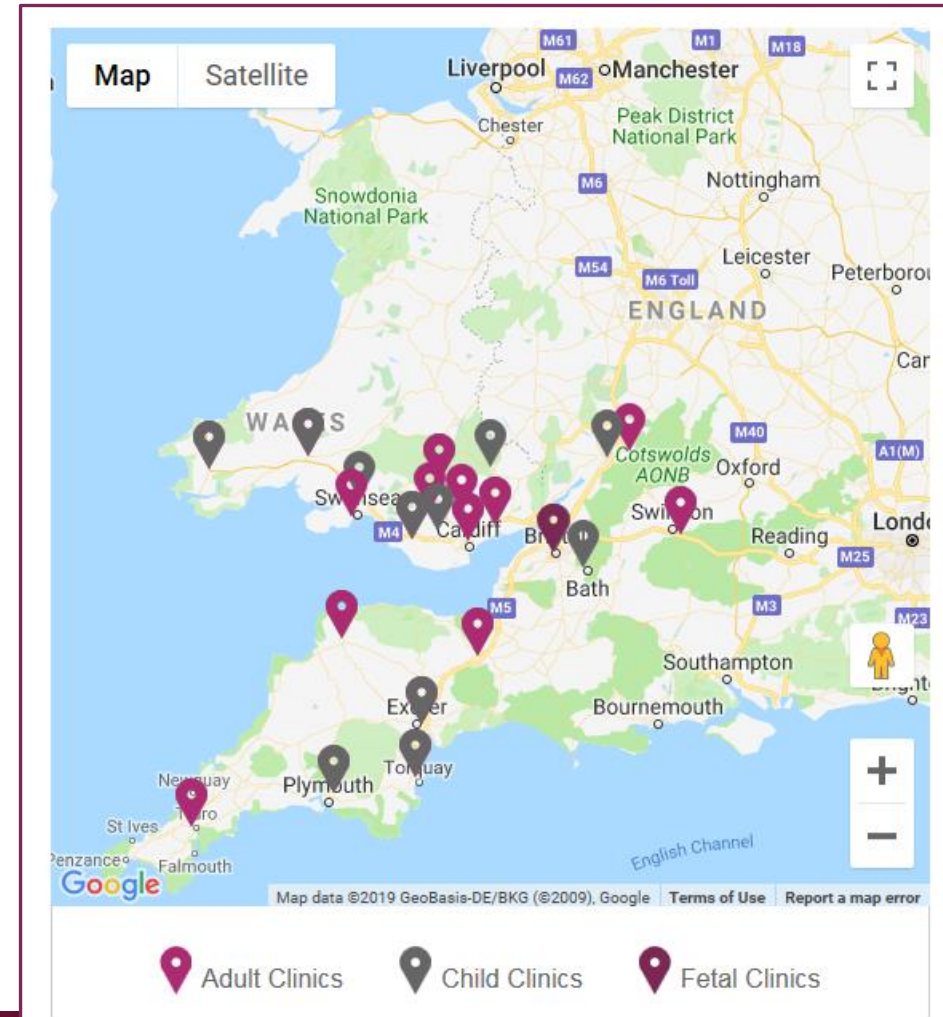


More later!...

Network catchment area, boundaries and patient flows

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 23,000 outpatient attendances per year
- over 40 specialist and link nurses
- 39 paediatricians with expertise in cardiology
- 17 adult cardiologists with specialist congenital interest
- c.450 heart operations take place each year



Hub and Spoke Operational Delivery Network Model

- **Level 1 Centre** – UH Bristol
- **Level 2 Centre** – UH of Wales (Cardiff) – interventional cardiology
- **Level 3 Centres**

South West: Royal Cornwall – Truro, Musgrove Park – Taunton, N Devon – Barnstaple, S Devon – Torbay, Royal Devon & Exeter, Cheltenham & Gloucester, RUH- Bath, Great Western- Swindon

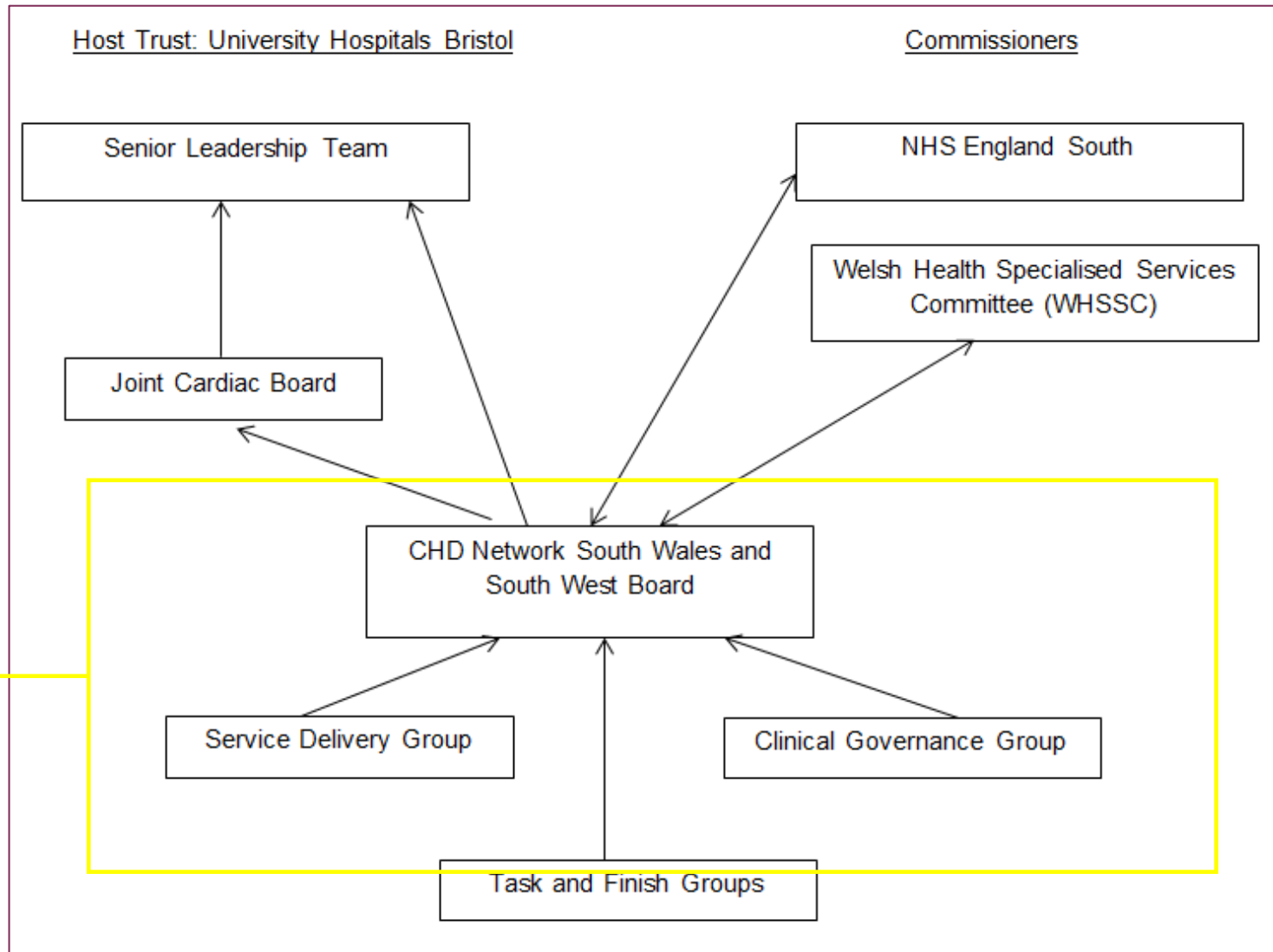
South Wales: ABMU Health Board (HB) – Singleton, Morriston, Princess of Wales; Aneurin Bevan HB – Royal Gwent, Nevill Hall; Cwm Taf HB – Royal Glamorgan, Prince Charles; Hywel Da HB – Glangwili, Withybush.

CHD SWSW network team



Name	Role	WTE	Email	Twitter & Website
Dr Andy Tometzki	Clinical Director	2 PAs per wk/0.2WTE	Andrew.Tometzki@UH Bristol.nhs.uk	@CHDNetworkSWSW www.swschd.co.uk
Sheena Vernon	Clinical Lead Nurse	0.7WTE	Sheena.vernon@UH Bristol.nhs.uk	
Cat McElvaney	Network Manager	0.8 WTE	Cat.mcelvaney@UH Bristol.nhs.uk	
Rachel Burrows	Network Support Manager	1.0 WTE	Rachel.burrows2@UH Bristol.nhs.uk	

Existing Governance Structure



Member organisations represented by clinician's and managers

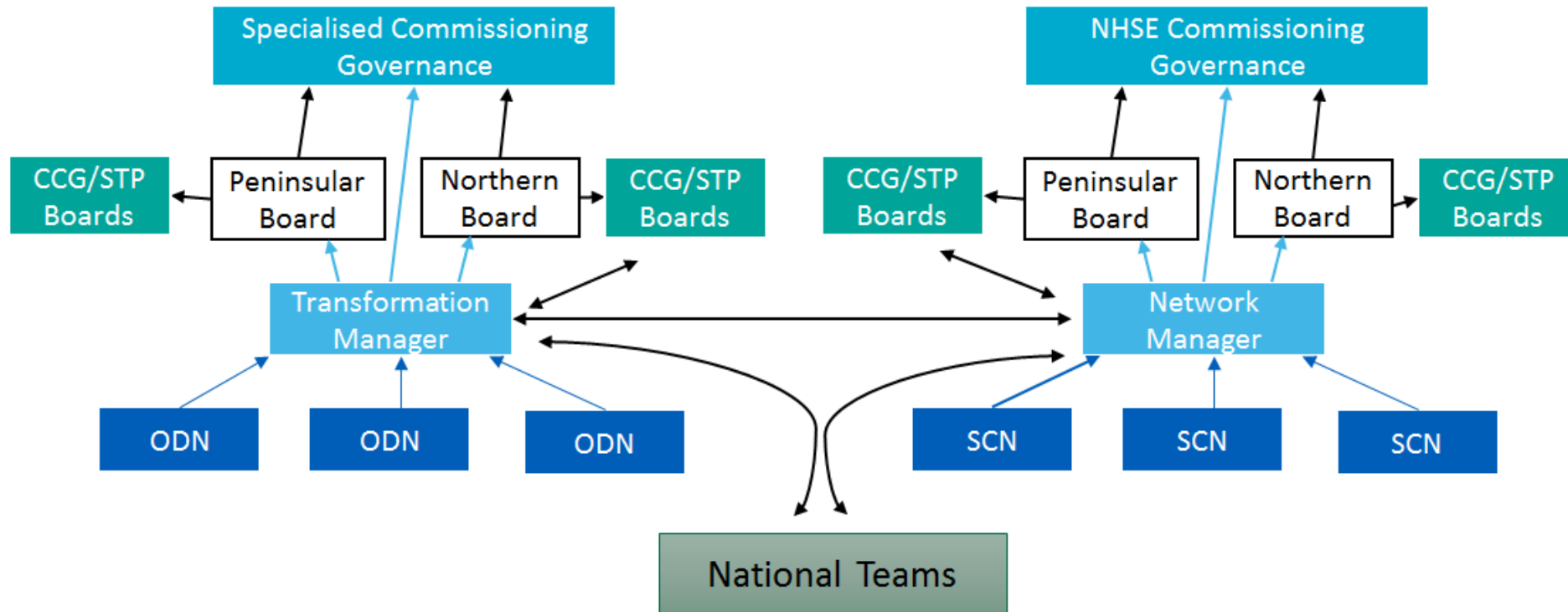
Table 4. Division of responsibilities for CHD SWSW Network Groups

Network Board	Network Clinical Governance Group	Network Service Delivery Group	Task & Finish Groups
Overall responsibility	Education and training programme	Standards & self-assessments	Specific tasks or projects
Escalation of concerns	Incident management and learning	Performance and capacity	Defined lifespan
Risk Management	Annual Mortality & Morbidity	Workforce issues	For example:
Strategic direction	Audit programme	The website and other technology projects	Paediatric protocols group
Performance assurance	Clinical pathways, protocols, guidance	Patient engagement and support groups	Discharge communications reference group
Centres', commissioners, charity etc. updates	Patient leaflets and pathways	Finance/Tariffs etc	

A New Governance Structure

- ODNs

- SCNs



Network Vision

Our vision is to be a Network whereby:

- Patients have **equitable access**
- **Care is provided seamlessly**
- **High quality care**
- **High quality information** for patients,
- There is a strong and **collective voice** for Network stakeholders
- There is a strong culture of collaboration and action to **continually improve** services



Key risks & issues

Risks

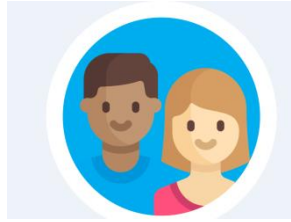
- Medical workforce recruitment gaps in certain centres Long term sustainability of medical workforce in Level 3 centres
- Risk that Level 3 centres unable to fund/support the role of the link nurse
- Risk around delays of Phase 2 investment in some South Wales services
- Risk that clinical care is being delayed due to long follow up backlogs

Issues

- Image Sharing!



Comms & Engagement



Patient Representatives

- 14 Patient Representatives- 6 active
- Attendance and input to Network Board – slot on agenda, pre-board briefing phonecalls
- Role & responsibilities description
- Ongoing recruitment

Charities/Voluntary 3rd Sector

- 6 monthly mtgs with all charities together for sharing updates and to facilitate collaborative working
- Webpage for charities on CHD website
- Support Youth Worker at BHI (16-25 yr olds)

Network Events

- 4 x network meetings (Board, & subgroups)
- Stakeholder day
- Annual Mortality & Morbidity session
- Training & Education – signposting
- Audit sessions



Communications- Twitter & Bi- annual newsletter



News from the network team

Welcome to our Autumn Newsletter!

Reading through the many articles has provided us, and we hope you the reader, with a real sense of pride. This edition champions just a small selection of the recent progress we have experienced across our network, and includes a number of interesting articles and updates for our network staff, patients and families alike. With a particular focus on young people, we have lovely story from Evie talking about her journey from children's to adult's services, and signposts to the support and help available for young people with congenital heart disease (CHD).

There have also been a significant number of personnel changes across the whole network, not least the permanent appointment of Cat McElvaney who has been covering the role substantively since last October. We are also delighted to welcome Xander Cook, the new youth worker in the adult congenital heart service, to the network. We are already enjoying reading his often witty tweets and his informative Facebook updates. Xander will certainly be a great support and help for our young patients with CHD in the network.

In early summer, we were peer reviewed, as were all congenital heart services across the UK, by NHS England's quality surveillance team. The results of these reviews have been published and we are proud to report that the feedback was very positive for the network with a number of significant achievements identified. We have found it a useful exercise to enhance our work plan moving forward.

It is with great sadness that we end the introduction with a reflective note on the sad loss of our dear colleague Cathy Harrington around Easter of this year. Many of us were overwhelmed by the support shown by colleagues, patients & their families at her funeral. We are sure this helped her family come to terms with their grief. It was a beautiful day, the sun shone in the same way as she always did. May she forever rest in peace.

We would like to commend the efforts many members of the team who undertook a Mighty Hike in the Lake District for Macmillan in memory of Cathy and regret not being available to join them.

As ever we would like to thank all those who continue to collaborate, support and progress the work of the network to make it a success. We always welcome your input to the network, however small the contribution to improve the experience for patients and staff alike.

Meet Cat, our network manager



We are delighted to welcome Cat McElvaney to the team as the permanent CHD network manager for South Wales and the South West. Passionate about improving healthcare for patients and families, Cat joins the team with over 15 years' experience of improvement, change and programme management within the NHS. To find out more check out Cat's profile on our website: (www.sswchd.co.uk)

Key contacts

Clinical Director: Dr Andrew Tomeski

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Lead Nurse: Sheena Vernon

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Network Manager: Cat McElvaney

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Lead Psychologist: Ness Gerrit

Vivian.Gerrit@uhbristol.nhs.uk

Support Manager: Morwenna Bugg

Morwenna.Bugg@uhbristol.nhs.uk

- ✓ Next one- Spring 2020
- ✓ Email notification to clinicians and managers
- ✓ Distributed to clinical areas
- ✓ For staff & patients



Follow @CHDNetworkSWSW

Equity of access

Seamless care

Meeting national standards

Continual improvement

Patient voice



Annual Report

2018/19



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<http://chdn.webboxdemo.co.uk/>

Welcome to the Congenital Heart Disease Network South Wales and South West

We proudly support over 6,500 children and 8,000 adults with a congenital heart condition.

[Read More](#) >

Babies and Children

When your baby or child is diagnosed with a cardiac condition you may not know what to

Teenagers/Young People

When you are diagnosed with a cardiac

Adults

When you are diagnosed with a cardiac condition you may not know what to expect.

Equity
of access

Seamless
care

Meeting
national
standards

Continual
improvement

Patient
voice



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

Cardiff, University Hospital of Wales

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SERVICE NUMBERS



THE TEAM



HOSPITAL SERVICES



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Having a congenital heart condition can often mean dealing with uncertainty, managing symptoms, having to go to hospital a lot and bringing up different feelings, concerns or worries at different times. It can affect your family, friendships and relationships. It is especially important for you or your loved one to lead a healthy lifestyle, and your health condition can impact on your ability to function at school or at work.

Supporting our patients and their loved ones through their congenital heart condition and journey is very important to the Network. On this page you will find information on the range of support available to you. There are a number of types of support available and different services you can access, depending on how much support you need at a given time.

Click here to view a leaflet explaining the range of support available on the website.



On these pages, you will find our online 'digibooks'. These are interactive

Training & Education

[Home](#) | [Professionals](#) | [Training & Education](#)

Welcome to our training and education page. Here you will find information about forthcoming training events run by the network or hospitals within the network, as well as events run by other organisations that may be of interest.

Our **training and education strategy** is available here.

2020 NETWORK EVENTS

- Paediatric and Adult Nurses (Level 1 & 2) Away Day, Bristol, 4th February 2020. For more information, [click here](#).
- Psychology Network Event, Bristol, 11th February 2020. For more information, [click here](#).
- Inherited Cardiac Conditions Conference, Bristol, 14th February 2020. For more information, [click here](#).
- Paediatricians with Expertise in Cardiology Training Day, Exeter, 10th March 2020. More information to follow.
- Fetal Cardiology Course, Bristol, 20th March 2020. For more information, [click here](#).
- Welsh Paediatric Cardiovascular Network Spring Meeting, Cardiff, 2nd April 2020. For more information, [click here](#).
- Intermediate Adult Congenital Heart Disease Training Day, Bristol, 6th April 2020. For more information, [click here](#).
- 18th Adult Congenital Heart Disease Study Day, Bristol, 14th October 2020.

2020 OTHER EVENTS

- Clinical Cardiovascular Research Event, Bristol, 5th February 2020. For more information, [click here](#).
- RV Masterclass 'PH and the Right Heart: An Update' Meeting, Glasgow, 28th February 2020. For more information, [click here](#).

Network Headline Progress to date

2016/17

- Network Launch, core team recruited
- Network governance established
- Self assessment visits –baseline against standards
- Risks & Incidents process
- Pt Engagement events

2017/19

- Comm& Engagment; Website, newsletters, annual report, Pt reps
- Nursing Strategy; link nurse, Nurse days level 1, 2
- Training & Education; study days, PEC day, nurse network days
- Transition clinics @ BRHC
- Palliative Care Toolkit (commended peer review)
- Regional psychology serice
- Linking with other CHD and Bristol based networks

Network Headline Progress to date cont'd

2018/19

- Highly commended in CHD National Peer Review
- CHD adult and paediatric protocols inc. drug and dental
- Network link nurse resource folder
- 6 mthly charity partnership meetings
- Network Training and Education Strategy
- BHI Youth worker role
- Research strategy

2019/20

- Network audit lead and audit programme established
- Positively evaluated Mortality and Morbidity annual event
- ACHD and PEC study days
- Patient rep role – job description & contract
- Transition evenings
- Enhancing performance dashboard
- Lesion of the month board!

Network Priorities 2020/21

- Engagement & **self assessment visits**- all level 3 centres
- **5 year plan**
- Enhance existing **performance dashboard** and process
- Finalise **#myquestion** campaign-Jan launch
- Top 3/5 standards focus
- Joint working with IM&T on image sharing – virtual clinics
- Follow up backlogs- virtual clinics
- Image sharing
- Network **wide psychology training event** in spring
- **Nurse competencies** for CHD
- **Link Nurses**
- **2 x PEC study day** in Spring, Adult study Days, AHPs?
- **Lesion of month** & clinical updates
- **Pathways & protocols**- fetal, pregnancy & dental



2020 and beyond- 5 year plan for CHD in South Wales & South West

Our objectives



For our patient groups;

- Fetal
- Neonates
- Children with CHD
- Adults with CHD

Within these areas;

- How can we enhance/improve over the next 5 years?
- What should be the network priorities 12/18 months?
- Are there ways in which we could work smarter/more efficiently?
- What should we measure to show we have made a difference?



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

Thank you & Questions

