

# CHD Network South Wales and South West Stakeholder Day

10<sup>th</sup> July 2018  
Bristol

# Welcome!

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- Welcome from the Clinical Director
- Update from the network team
  - Background to the CHD Networks
  - What is a network?
  - Our launch event 2016
  - Progress since then
  - Key risks and challenges
  - Moving forward
  - The structure of today



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



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# Background



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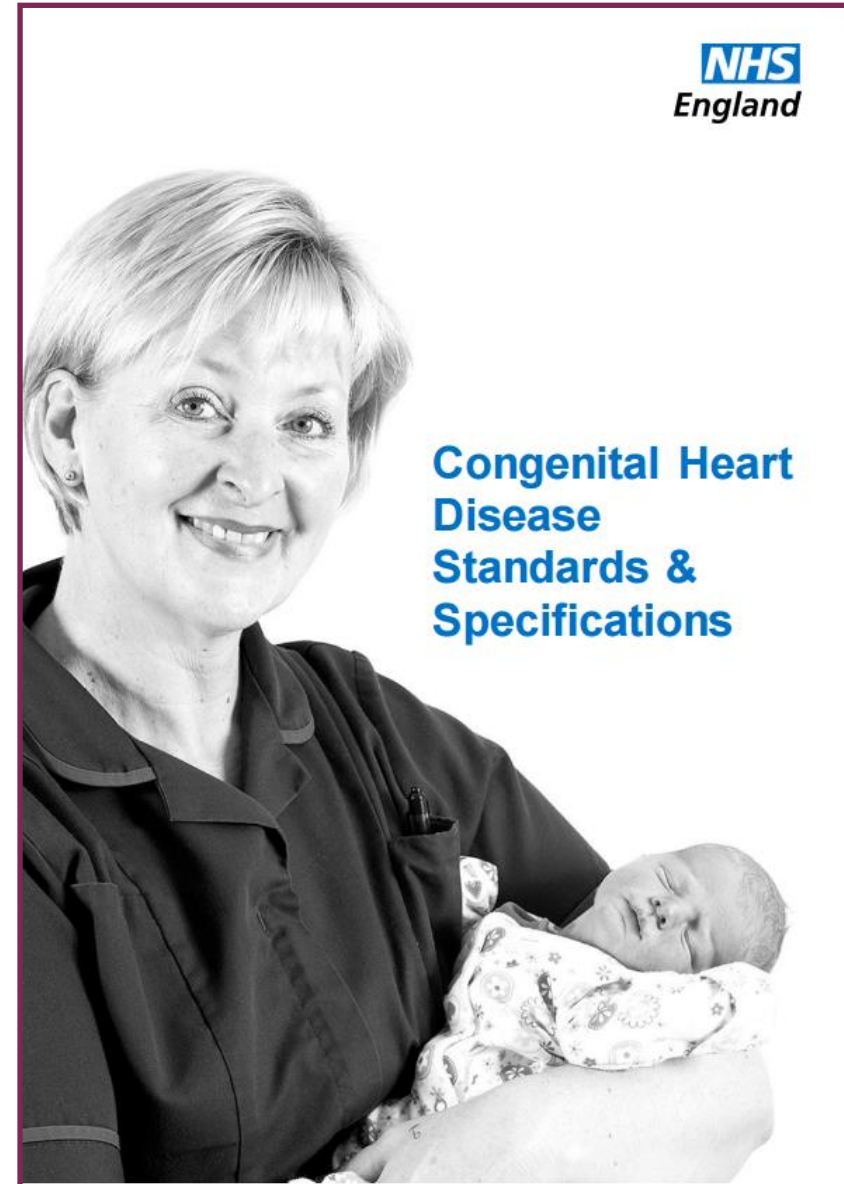
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- Safe and sustainable, 2008
- Review of the provision of paediatric cardiac surgery services, consolidate practice
- 2012 new standards for children and adults
- Congenital Heart Disease Standards and Specifications NHS England completed and launched 2016



# 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](#)





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# What is a Network?



# Is it the core team?

- Recruitment to core team and chair roles:
  - Manager 0.7 WTE\*
  - Clinical Director 2.0 PAs
  - Administrator 0.5 WTE
  - Lead Nurse 0.7 WTE\*
  - Lead Psychologist 0.2 WTE\*\*
- Chairperson (Unfunded)

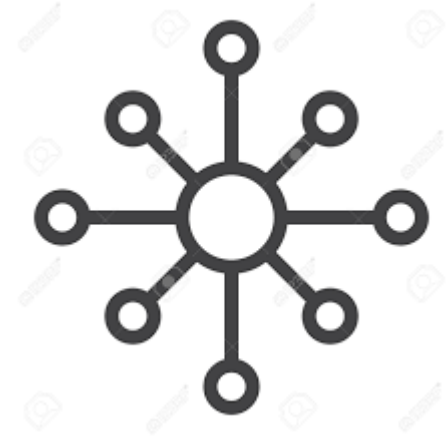


\* Part-time working leaves 0.4 WTE 8B to be reinvested this year

\*\* Funded by the BRHC

# Is it a hub and spoke Clinical Network?

- **Level 1 Centre** – UH Bristol for Paeds and Adults
- **Level 2 Centre** – UH of Wales (Cardiff) – interventional cardiology for paeds and adults



- **Level 3 Centres**

**South West:** Royal Cornwall – Truro, Musgrove Park – Taunton, N Devon – Barnstable, S Devon – Torbay, Royal Devon & Exeter, Cheltenham & Gloucester

**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.



# Our Network in Numbers:

- over 50 clinics per week, seeing more than **23,000** outpatient attendances per year
- over **20,000** patients with congenital heart conditions
- over **450** heart operations and **650** cardiac catheters

**17 ADULT AND 19 PAEDIATRIC CENTRES**  
 covering level 1 (specialist surgical), 2 (specialist medical) and 3 (local centre) services

Adult Clinics Child Clinics Fetal Clinics

**CONSULTANTS INCLUDING:**  
 3 cardiac surgeons  
 14 paediatric cardiologists  
 6 consultants in adult congenital heart disease  
 32 paediatricians with expertise in cardiology  
 19 adult cardiologists with specialist congenital interest

**1022** psychology contacts undertaken (2017/18) | **4 SPECIALIST** CHD clinical psychologists

**A CORE NETWORK TEAM OF 5**

**NURSING STAFF INCLUDING:**  
 33 link nurses and 18 clinical nurse specialists

- 1 NETWORK BOARD**
- 9 PATIENT PATHWAYS** and 32 patient toolkits
- 1 NEW NETWORK WEBSITE** [www.sswchd.co.uk](http://www.sswchd.co.uk)
- 1 TWITTER ACCOUNT** @CHDNetworkSWSW

# Discussion session

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- What does the network mean to me?
- How has the network impacted on me?
- What is my role within the network?
- What can I do to improve the function of the network?

*Discuss in small groups (5 minutes) and feed back in plenary*



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# Our Launch Event



# Setting up the formal network

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## Our network launch event:

- Took place in Bristol in June 2016
- Around 50 attendees
- Good range of stakeholders and geography
- Topic based workshop approach AM
  - Core Network Business
  - Patient experience and engagement
  - Network governance
  - Clinical issues
- CPD sessions PM



# Setting up the formal network



Equity of access

Seamless care

Meeting national standards

Continual improvement

Patient voice

# What came out of the launch event?

Our vision and objectives

To engage and learn from patient experience

An approach to training and education

A plan on what data we would ask for

Identified need for a single point of resources/information

A plan for how we would approach network governance

A plan for how to set-up our board

An approach to clinical pathways/protocols

An approach to self-assessment and the standards

# Network Vision

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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





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# Progress since then

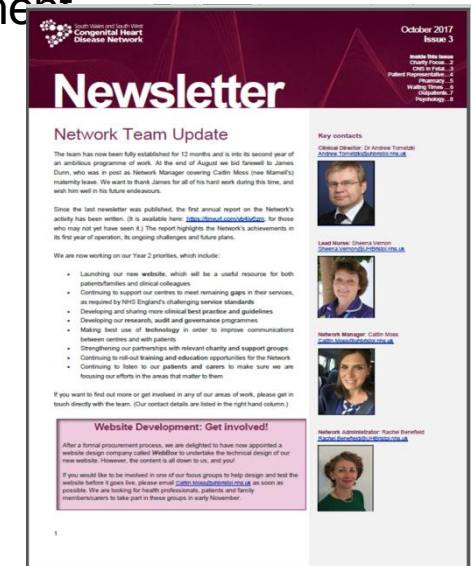




# Year 1 Achievements (16/17)

Starting from a blank page...

- **Team recruitment**
- **Launch event** June 2016
- **Stakeholder mapping** and set up database of all centres & contacts
- **Self assessment** process – visited 12 adult and 12 paediatric Level 3 centres
- Network **risks and incidents** processes defined and begun
- **Patient/family engagement work:** visits/questionnaires across L3 centres, engagement event Exeter
- **Comms & engagement strategy:** newsletters, getting out there presenting etc.
- Procured **website developers**
- Network performance **dashboard** designed and implemented
- Began developing network **clinical protocols**
- Building on existing **training and education days**



# Year 2 achievements (17/18)

Key objective	Achievements
Strategic direction for the Network	<ul style="list-style-type: none"> <li>• Influenced positive change in <b>Taunton</b></li> <li>• <b>Strategic engagement</b> with other Networks, CRG, NHS England (regional and national teams), WHSSC.</li> <li>• <b>Assurance</b> function around <b>Independent Review</b></li> </ul>
Monitor and drive improvement in quality of care	<ul style="list-style-type: none"> <li>• Tackling key gaps in <b>standards</b></li> <li>• Clinical <b>protocols</b></li> <li>• <b>Governance</b> – inaugural M&amp;M, incident reporting, risk management</li> <li>• <b>Audit programme</b> initiated</li> </ul>
Equitable access for patients	<ul style="list-style-type: none"> <li>• <b>Fetal audit</b> initiated</li> <li>• Regional <b>psychology service</b> including ACHD</li> <li>• <b>Transition</b> at BRHC</li> <li>• <b>Palliative care toolkit</b></li> <li>• <b>Performance dashboard</b></li> </ul>
Patient experience	<ul style="list-style-type: none"> <li>• Partnership working with <b>charities and support groups</b>, especially: HFSW, A&amp;B, Youth@Heart</li> <li>• <b>Website</b> development and launch</li> <li>• <b>Patient engagement events</b>, UHW, Gloucester and Exeter</li> </ul>

# Year 2 achievements (17/18) cont..

Key objective	Achievements
Workforce training and development	<ul style="list-style-type: none"><li>• <b>Training and education events</b> including PEC day</li><li>• <b>Medical workforce</b> review, risk management and engagement with national bodies (HEE, SACs)</li><li>• <b>Nursing strategy</b> and delivery of nursing day for Level 1 and 2, BRHC CHD link nurse group.</li><li>• <b>Education strategy</b></li></ul>
Information and communication	<ul style="list-style-type: none"><li>• Development and launch of <b>website</b></li><li>• <b>Newsletters</b></li><li>• <b>Stakeholder engagement and communication</b></li></ul>
Demonstrating value of Network activities	<ul style="list-style-type: none"><li>• <b>Annual report</b></li><li>• Seeking <b>funding opportunities</b> e.g. BHF fund, A&amp;B partnership, the Grand Appeal</li><li>• <b>Escalation of issues</b> as appropriate (national bodies, NHSE, UHB etc.)</li></ul>

# Network Website



Patients & Families ▾

Professionals ▾

About ▾

Hospitals

Patient Pathways ▾

Research ▾

Contact Us

Donate

[www.swswchd.co.uk](http://www.swswchd.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

# Key Risks and Challenges

# Key risks

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- Medical workforce **recruitment gaps** in certain centres
- Long term **sustainability of medical workforce** in Level 3 centres
- **Cancelled operations** at BRHC due to PICU capacity pressures
- Risk that Level 3 centres unable to fund/support the **role of the link nurse**
- Risk around delays of **Phase II investment** in some parts of **South Wales**
- Clinical risk around **image sharing**



# Key challenges

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- Working across **commissioning boundaries**
- **Engagement** in some centres/ individuals' competing demands/lack of dedicated time
- **Creating a culture** - geography, face to face interaction and relationships
- Limited formal **levers**
- **Financial environment** constraining service development
- Pockets of clinical risk due to **long waiting times for patients**
- **Small core team** (2.5 WTE)





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# Moving forward





# At present...

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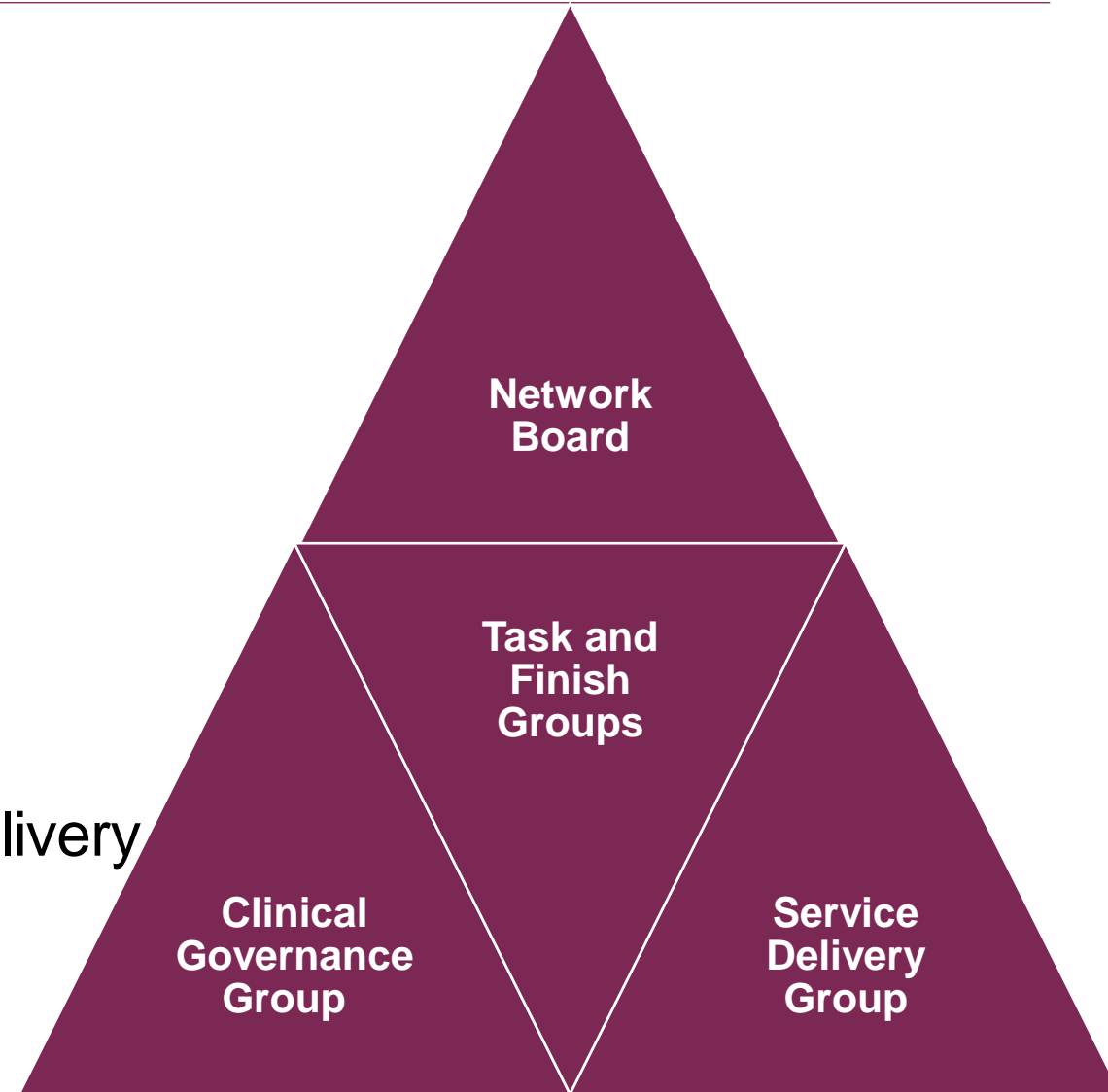
- Feel we are **delivering improvements** for patients
- **Recognised nationally** for being ahead of the game  
(Led national 'get together' of UK CHD Networks)
- Some absolute **clinical champions** across the network
- **Bottom up approach** as well as being driven by
- Still very **young!**
- Our approach is **evolving** as we learn
- **Opportunity** for a new approach.....



# 2017/18 Plans

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- New ambitious work plan
- New board and sub-group structure
  - Membership
  - Meeting frequency
  - Focus on doing
- New focus on patient representatives and charity partners
- Seeking to co-create a new approach to delivery
- Preparation for peer review



# Key new opportunities (Year 3)

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*In addition to ongoing areas of work..*

- Paediatric protocols and pathways
- Improving discharge communications project
- Develop role of patient/charity representatives
- Delivering exciting M&M
- Transfer and repat policy
- Lost to follow-up work
- Learning from PREMs survey in Level 1 - [chdpatientsurvey.co.uk](http://chdpatientsurvey.co.uk)
- Working with primary care
- Working with dental specialists
- Building our training and education programme





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# Structure of today



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- Update from us – done
- Now time to discuss what you think
- After break, split into two groups for in-depth discussion
  - Managers and clinicians
  - Patient reps and charity partners
- Lunch at 1pm
- Afternoon of CPD for clinicians
- Evaluation forms
- Get or stay involved this year!
- Dinner/drinks tonight.....NB Change of venue:

<https://westburyparkpub.co.uk/>



## Dates for your diary

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- Network M&M – September 11<sup>th</sup>
- ACHD training day – October 2<sup>nd</sup>
- PEC day – November 1<sup>st</sup>