

Empowering our patient representatives/ partners

27th November 2018
Network Board
Coldra Court

Purpose of session

- Standards
- Background and context to the role of the patient representative
- Progress to date Stakeholder day/Challenges
- Hearing from patient representatives, flip charts feedback
- Group work - Top priorities for next twelve months
-
- Feedback

Background

Classification: Official

Level 1 – Specialist ACHD Surgical Centres. Section A – The Network Approach

Standard	Adult	Implementation timeline
A21(L1)	Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months. Network patient representatives will be invited to participate in these meetings.	Immediate
F3(L1)	<p>All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:</p> <ul style="list-style-type: none">a. regular continuous network clinical audit and quality improvement;b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance;c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year


What is patient engagement?

- Patient engagement is increasingly recognized as an integral part of health care and a critical component of safe people-centred services.
- Engaged patients are better able to make informed decisions about their care options.
- In addition, resources may be better used if they are aligned with patients' priorities and this is critical for the sustainability of health systems worldwide.
- Mutual accountability, “You said, we did” work.


National documents



Involving people in their own health and care:
Statutory guidance for clinical commissioning groups and NHS England



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Working with
lay members
and patient
representatives

{Smart Guides}
toENGAGEMENT

For better commissioning

Equity
of access

Seamless
care

Meeting
national
standards

Continual
improvement

Patient
voice

Stakeholder Day July 2018

- Patient representative feedback in July
- *An accessible, personable and trusted relationship with a **higher profile***
- *A process that gathers feedback from a **wider patient** cohort reaching different cultures across the Network*
- *A process that is defined by collaboration where there is **clear evidence of impact***
- *A common language and understanding of the patient partners relationship*

Workshop feedback Tony Watkin

One thing I wish to see Stakeholder day

- We want to work together as *partners* in the network
- An investment in patients as *leaders*
- A good governance process to recruit, support and grow *patient partners at board level*
- Develop the use of *social media* as a tool for involvement without losing the emotional connect of face to face work
- Disseminate knowledge, debate and discuss
- Be *engaged* in the conversation
- Get the simple things right and be aware that *patient partners have other lives*
- Be able to say – *‘this wouldn’t have happened if it were not for patient partners’*

Workshop feedback Tony Watkin

Successful patient engagement

- Clear Trust process, recruitment
- Trust governance
- Board participation
- Communication
- A balanced group, young people, male, female



Challenges

- Meaningful engagement eg Board representation
- Duration of involvement
- Unclear remit
- Other commitments



Welcome Frankie and Becky

Introductions

November 1st

Thursday 1st November 2018

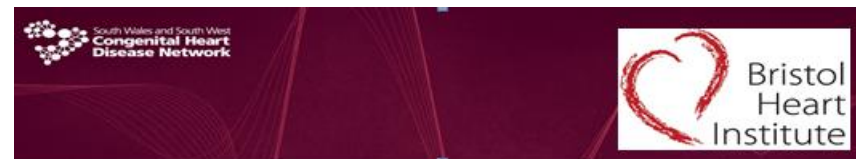
14.00 – 17.00

Lecture Theatre 1, Education Centre BS2 8AE

Patient representative

Final program

13.45	Registration	Lecture Th 1
14.00-14.30	Introducing the CHD Network and website	Sheena Vernon Lead Nurse
14.30-15.00	Review terms of reference for the Patient representative	All
15.00-15.30	The role of the Patient representative	Sheena Vernon
15.30 15.40	<i>Coffee</i>	
15.40-16.00	How to raise the Patient Representative profile in the Network What skills do we all have? Twitter?	All
16.00-16.30	Drafting the job description	All
16.30-17.00	Support required in the role eg before meetings	All
17.00	End Evaluation	



Save the date!

Patient Representative meeting



Thursday 1st November
2018

2pm-5pm

Lecture Theatre 1 Education Centre
University Hospitals Bristol, BS2 8AE

For further information please contact:
Sheena.Vernon@uhbristol.nhs.uk

Equity
of access

Seamless
care

Meeting
national
standards

Continual
improvement

Patient
voice

Themes

1. Communication
2. Use of Social media
3. Support attending Board meetings
4. Support for patients reps
5. How many patient reps

Role of patient representative patient rep day November 1st

1 Communicate

Support – link

Give feedback to Board and patients

Visibility across network

What

Outpatients and In-patients

CNS to refer to appropriate to patient rep

Suggest improvements to board (made by patients)

Teenager on board

Identify common themes from patients

What went well? Good news

Parent rep in Facebook page to feedback to board

How?

Social media, Facebook and Twitter



2 Use social media to communicate with wider CHD network

Facebook

Follow charity Facebook and Trust Facebook

All trusts Facebook page – UHB, Children's, Cardiff comms, Taunton,

Twice a month posts on social media

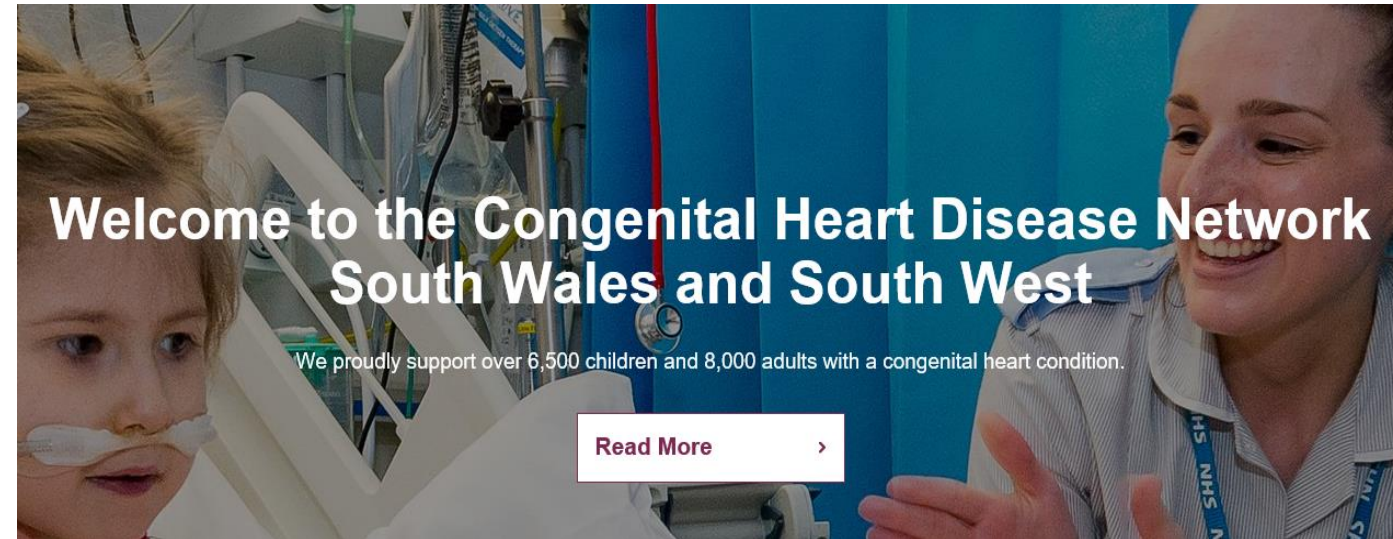
Introducing Pathways etc

Have you seen – 'video', training days etc

Twitter (lesson)

Website posting

Posters + link to website



3 Support in attending Board meetings

Attending OK

Would value specific tasks

How to get a voice on board?

Article newsletter

Feedback poster

Comment on patient information

Individual approach to requests:

Eg. Invite to M&Ms,

Eg. Explanations – ‘end of life document’

Eg. Housekeeping – ‘Permission to leave’ if sensitive topic – support if sensitive topic

‘Appropriate engagement’

Pre-board meeting/phone call – patient reps to call



4 Support for patient reps

Meeting twice a year (1st May, between board)

WhatsApp

Psychologist support

Supervision meeting – for personal support

Training from Trust

How to present at the board

Supporting carers



5 How many patient reps?

8-10?

How many to attend the board?

Check with neonatal reps

Get level 3 reps

More men

Teenager/ young people

Advertise on social media

Introduce to existing rep to discuss role

Time – 2 years?



Group work

Group work 10 mins 2 groups

- Top 3 priorities for patient for the next 12 months
- How could this work ?
- How can we recruit more patient representatives?
- What is successful patient engagement in the CHD Network?
- Comments on the job description, circulated

Group work

Feedback from group work

Actions

Role and Person specification

Group 1

Review and feedback

2 groups



Patient and Public Voice (PPV) Partners involvement in the Congenital heart Disease Network (SWSWCHD Network)

ROLE AND PERSON SPECIFICATION

1. Background

The South Wales and South West Congenital Heart Disease Network (SWSWCHD Network) was formed in 2016 in response to the NHS England “Congenital Heart Disease Standards and Specifications”. The report set out adult and paediatric standards and service specifications for congenital heart disease services in England agreed by the NHS England Board in 23rd July 2015 and effective from 1 April 2016.

The standards cover adult and paediatric care in the Level 1 specialist surgical centre, the Level 2 specialist cardiology centre and the Level 3 local cardiology centres.

The Standards of Care are based on the principle of a Network Model. Fetal, Paediatric and Adult services will work together in Congenital Heart Networks to deliver care through three “Levels” of provider as described in the Standards of Care.

Each standard has a timescale for achievement ranging from those that must be achieved immediately to those which must be achieved within 5 years. The timescales are provided in the standards document.

1.2 Standards have been set for the following:

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

2. SWSWCHD Network Mission Statement

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)

SWSWCHD Network Standards of Care, Version 1.0, 1st April 2016

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Thank you