



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

Network Board – March 2018

Psychology Team Update – Dr Vanessa Garratt, Paediatric and ACHD Cardiology Psychology Lead

Dr Michelle O'keeffe , Specialist Clinical Psychologist

Dr Joanna Latham, Clinical Psychologist

Dr Nell Ellison, Clinical Psychologist



The Service

2017 onwards

3.4 wte in Bristol

Covering the following pathways for all families in the network:

- Fetal
- Catheter
- Surgical
- ACHD
- General outpatients



The proposed approach (July 2017)

Establishing a tiered approach to psychological support

- Patients to find the support they need when they have questions or concerns
- Clinicians to direct patients to appropriate care and support when needed
- Equitable access to specialist care across the network to those in greatest need

Developing the model

Resources for all clinicians and families (32 toolkits, support digibook, 9 visual pathways)

Embedding psychology in existing clinics, teaching training and consultation

Targeted
1:1
Support

Resources available to all clinicians and families (32 toolkits, support digibook, visual pathways)

South Wales and South West Congenital Heart Disease Network

University Hospitals Bristol NHS Foundation Trust

Getting the support you need

When you, your baby or child is diagnosed with a congenital heart condition you will be looked after by a network of clinicians who work together to form the South West and South Wales congenital heart disease service. This means that you or your child will be looked after by the local hospital team but may also meet specialist clinicians at our specialist cardiac centre in Cardiff (Welsh patients only) and/or the specialist surgical centre for the network in Bristol.

A congenital heart condition is a life long journey of care, and it is important to know where you can get support at the times you need it. This leaflet contains information about the support that is available to you and your family, and how to access it.

You can find out more about the South Wales and South West CHD network and the range of support available to you on the South West and South Wales congenital heart disease (SWSWCHD) website: swwchd.co.uk

What will my or my child's pathway of treatment and care look like?
On the website, you will find our visual pathways for different groups: babies and children, young people, parents and adults. These pathway documents explain the things that are likely to happen when you need outpatient or inpatient care, or if your child requires cardiac surgery or a cardiac catheter.

The documents have interactive links that give you more information about particular steps in the pathway.

For example, what will happen before and after an admission for surgery, and what type of health professionals you are likely to meet along the way.

How do I find out more about support?
You and/or your child may have a number of emotional needs due to having a congenital heart condition or because of an event occurring, such as needing to have surgery. We recognise that these things can be worrying, and that it is helpful to be able to find trusted information, to know where to turn to in times of need, or to know how to find others who have been through similar experiences. In order to help you navigate your journey, we have put together a range of support 'digibooks', which are tailored for children, young people, parents and adults. In these interactive 'digibooks' you will find information about the areas our patients and families have told us are the most challenging to manage. These include things like: coping with a diagnosis, being prepared for surgery, how to manage school or work when you have a congenital heart condition.

If the support you need is not within our specialist expertise, the information in the 'digibooks' will point you in the direction of local or national resources that might better suit your needs. We have included different types of support including online information, specialist clinical teams and specialist non-clinical support (e.g. marriage support). These can be found on the SWSWCHD website, under the 'Getting Support' section: swwchd.co.uk/en/page/getting-support



Respecting everyone
Embracing change
Improving services
Our hospitals.

GRAND APPEAL

South Wales and South West Congenital Heart Disease Network

University Hospitals Bristol NHS Foundation Trust

There are three levels of support detailed on the website:

Level one: If you want to find out more. You will find information here about many online resources that you can access, whenever and wherever you need to.


Level two support: if you need to talk to someone. The 'digibooks' direct you to a range of local support groups and organisations that you can approach if you feel you would like to speak to someone about your worries or concerns, either in person or by telephone.

Level three support: specialist clinical support. You can find out more about how you can access specialist support through our clinical teams. This may be through your consultant or cardiac nurse specialist, who may be able to answer your questions or refer you on to our specialist psychology team.

Toolkits to help you cope with some key issues:
We also have a number of toolkits that describe a range of tools and techniques you can use to help you with issues that we are often asked about. For example, what to do if you or your child is feeling low, or how to prepare for coming into hospital. Our toolkits contain information, ideas and strategies to help with questions and worries you may have.

Your clinical teams are also available to talk to you about your pathways of care and support. Please talk to our clinical nurse specialist teams about questions that you have on:

Bristol paediatric team 0117 3428286
Cardiff paediatric team 07813922441 / 07811197136
Bristol adult team 0117 342 6599
Cardiff adult team 029 2074 4580



For access to other patient leaflets and information please go to the following address:
www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients
Hospital switchboard: 0117 934 9869 | Minicom: 0117 934 9869 | www.uhbristol.nhs.uk
© University Hospitals Bristol
Published: 27/03/19 | Expires: 31/03/22 | DOTS/TS/PH/SGT/SYN/MAR19

Respecting everyone
Embracing change
Improving services
Our hospitals.

GRAND APPEAL

Equity of access

Seamless care

Meeting national standards

Continual improvement

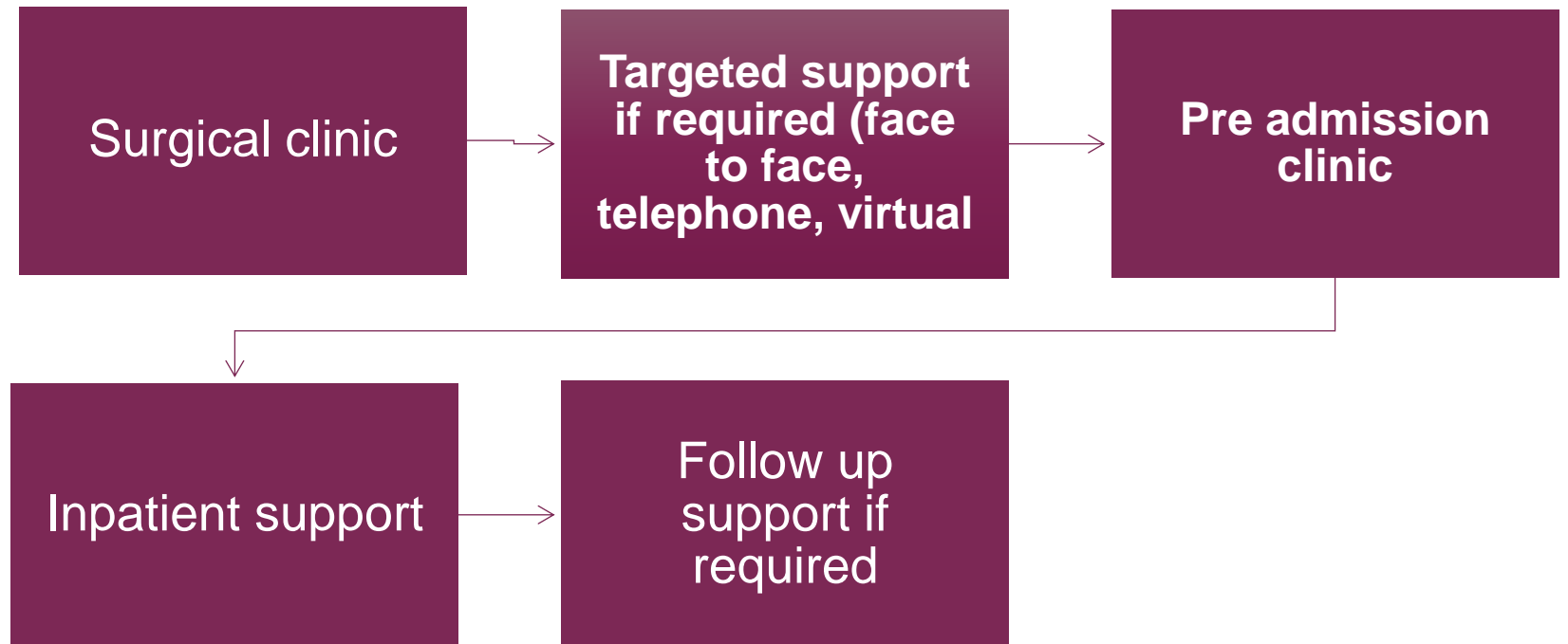
Patient voice

Pathway support

Embedding psychology
in existing clinics,
teaching training and
consultation

Putting psychologists into existing clinics

- Medical and psychological **collaboration**
- More families seen
- Time effective
- **Preventative**
- Reduces referral time
- Reduces travel time



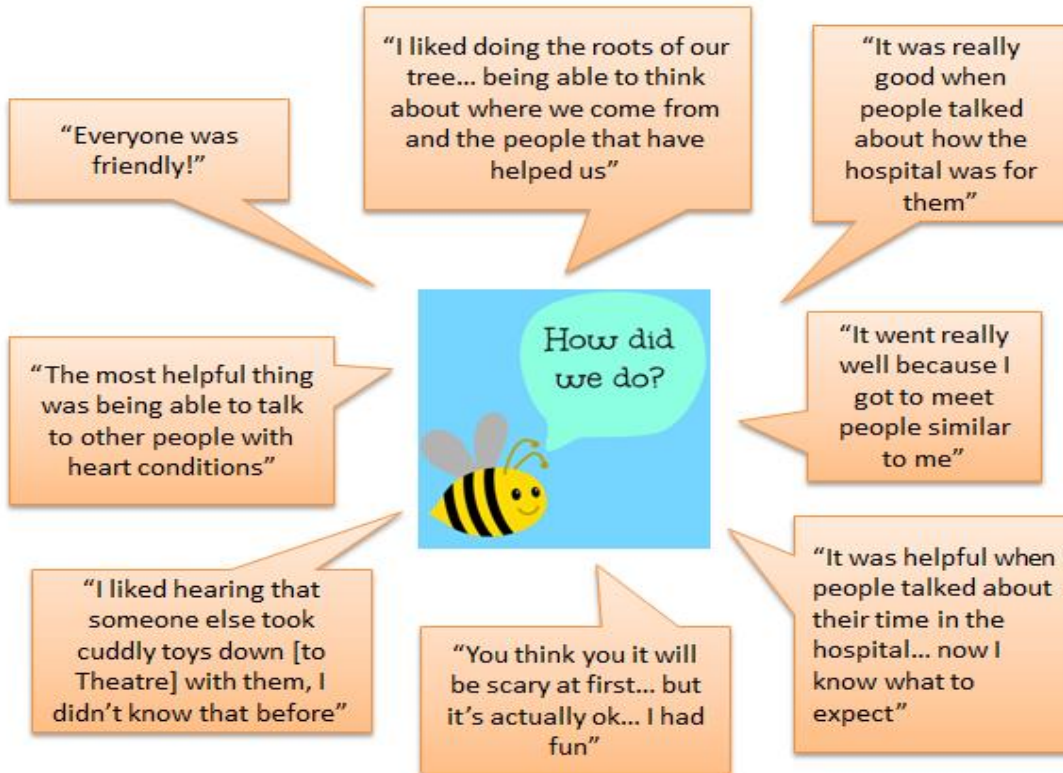
Offering groups

Embedding psychology in existing clinics, teaching training and consultation



Tree of Life groups Organised & facilitated by Dr Jo Latham April 2018 – March 2019

Number of groups ran:	3
Number of participants accepted invitation:	28



What do we offer in 2019

Targeted
1:1
Support

Face to face

Telephone

Virtual

- 10 outpatient clinics offered a week with 28 appointment slots in total (1176 annually)
- 8 inpatient clinics with 12 appointment slots in total (504 annually)

Pathway	Outpatient Face to Face	Outpatient Telephone/Virtual	Inpatient
Fetal	1 clinic (3 slots)	1 clinic (3 slots)	1 clinic (2 slots)
Catheter	1 clinic (3 slots)	1 clinic (3 slots)	1 clinic (2 slots)
Surgical	1 clinic (3 slots)	1 clinic (2 slots)	2 clinics (4 slots)
ACHD	3 clinics (11 slots)	2 clinics (4 slots)	4 slots

Referral Criteria

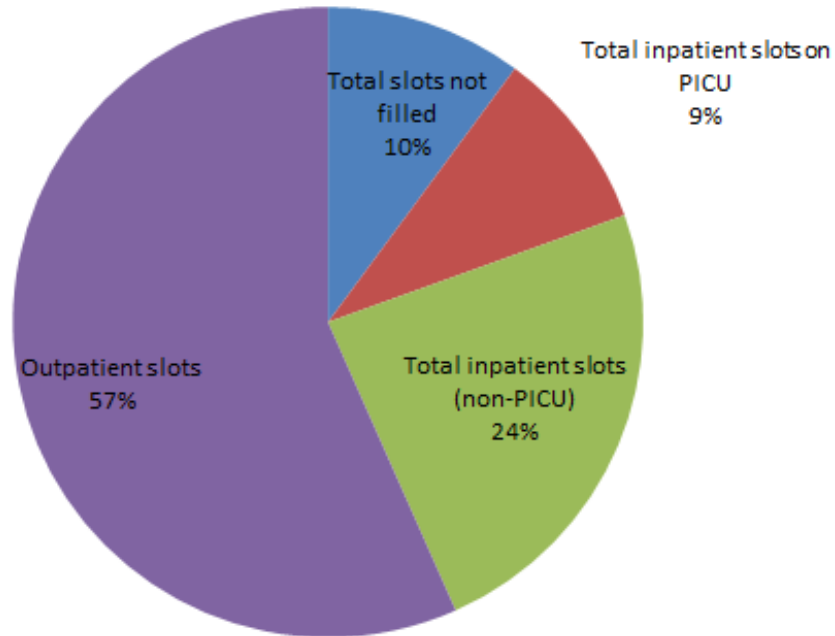


Targeted
1:1
Support

- Difficulty in coping with or adjusting to health condition/status e.g. further cardiac surgery required, poor prognosis, long hospital admission life limiting illness, significant impact on day to day functioning
- Distress related to a long hospital admission for their cardiac condition
- Distress associated with physical issues such as scars and symptoms such as pain, cyanosis, breathlessness, and tiredness.
- Trauma associated with past medical interventions(e.g. MRI, CT scan, ICD implantation, Catheter implantation, Cardiac surgery) and hospital and needle phobia.
- Anxiety related to a high risk pregnancy
- Anxiety related to upcoming medical procedures
- Additional needs (including learning disabilities) requiring additional support when accessing treatment

1:1 support – cath/fetal post

One-to-one clinical work - Jo (inpatient, outpatient)



Total slots offered (taking into account annual/study/sick leave etc):	821
Total slots filled:	738
Total slots not filled:	83 (10.1%)

MDT Work

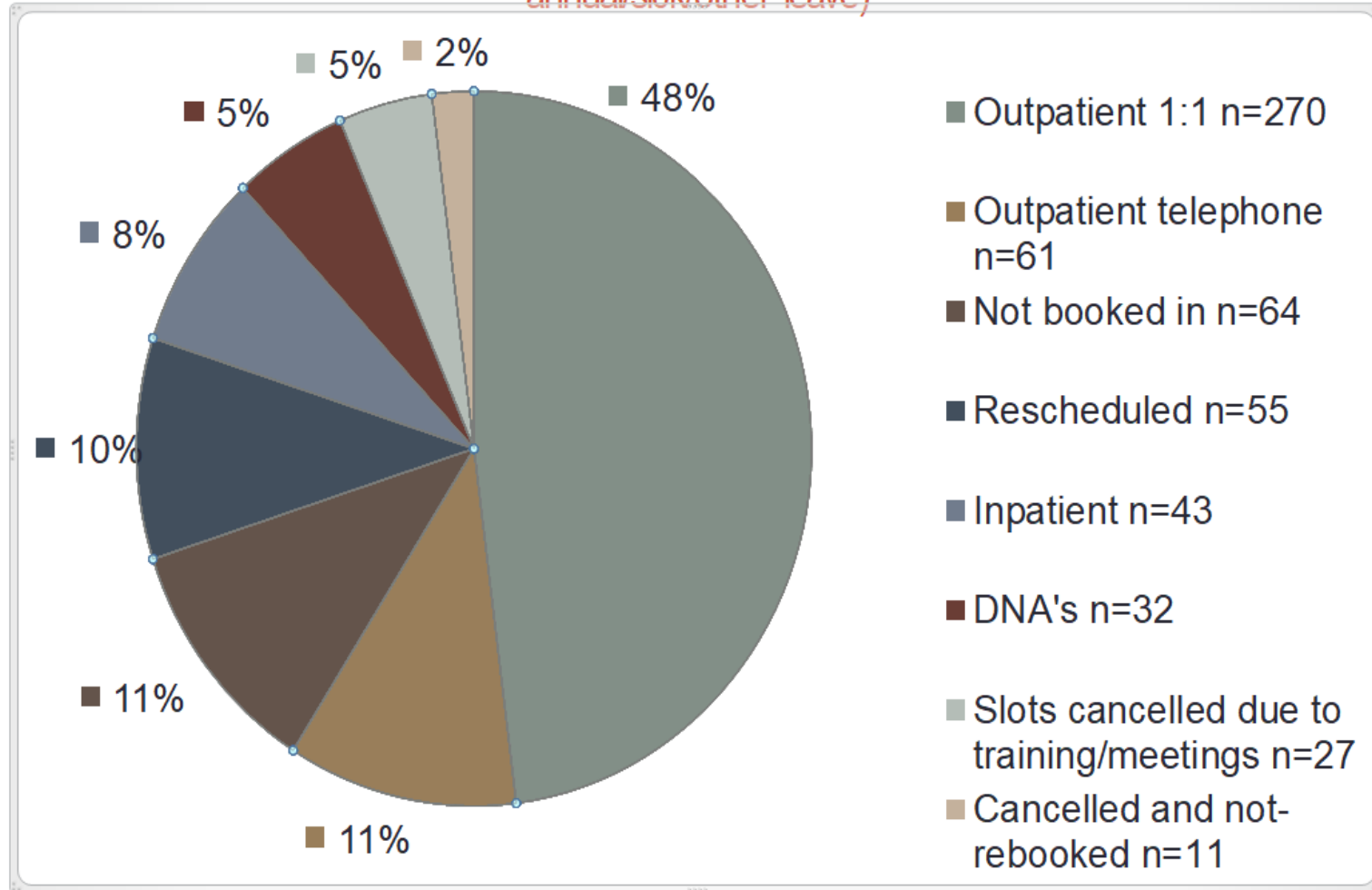
Total number of MDT sessions attended:	60
Total number of patients seen:	227

Input into PICU

Total number of inpatient slots filled:	273
Inpatient slots which were filled on PICU:	77
Percentage of our total inpatient slots which were offered on PICU:	28%

ACHD data

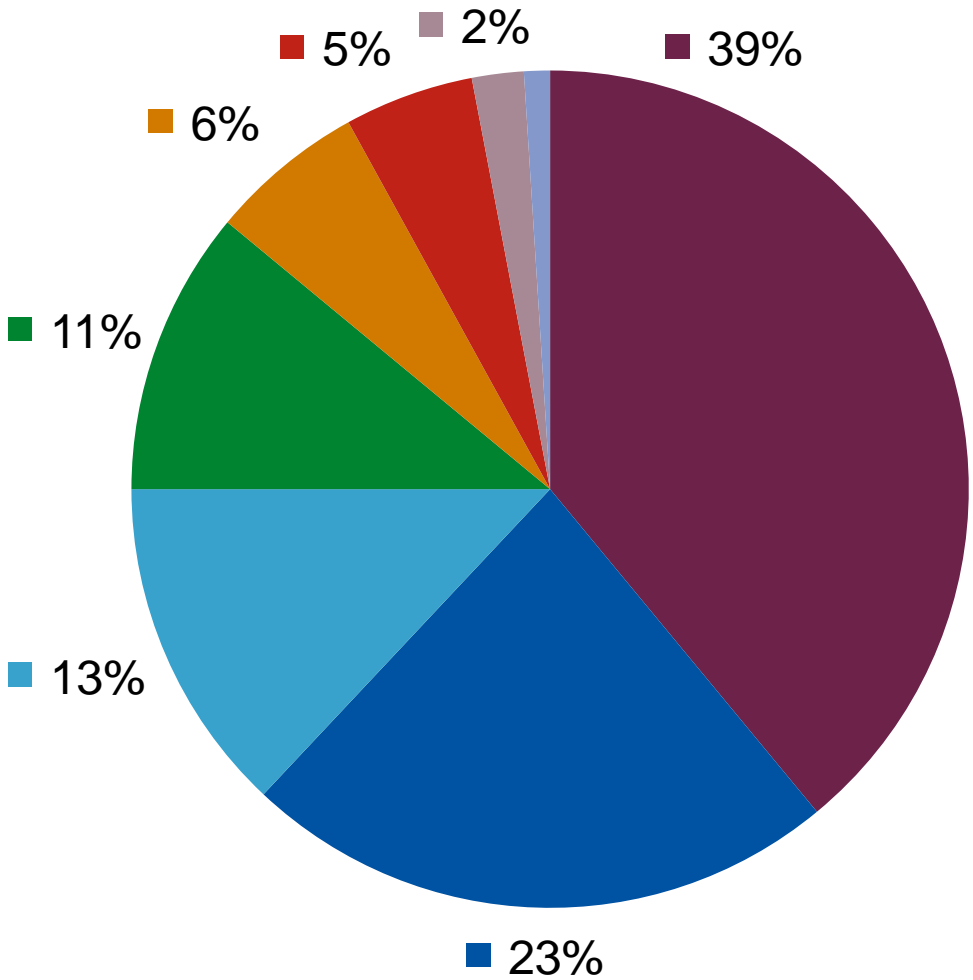
557 inpatient (n=43) and outpatient (n=514) slots offered (taking into consideration annual/sick/other leave)



Paeds data

<u>Type of referral</u>	<u>Number of referrals</u>			
	Jo (from Apr 18 – Mar 19)	Nell (from Jan 19 – Mar 19)	Nina (from Apr 18 - Dec 19)	Combined
Surgical	46	56	165	267
Fetal	31	0	1	32
Catheter	208	0	4	212
General Outpatient	37	13	6	56
Medical	12	2	2	16
Total number of referrals	334	71	178	583

Achd data



- Health Anxiety (n=41)
- Pre-surgical/procedure anxiety (n=24)
- Phobias (n=14)
- Depression (11)
- Post Traumatic Stress (n=6)
- Long hospital admission (n=5)
- Adjustment to new diagnosis (n=2)
- Transition Support (n=1)

Next Steps – Network Links

Developing specialist cardiac psychology services across the network

Developing links with local psychologists

Offering a link psychology CPD day annually

Bristol
Lifespan 3.4
wte

Taunton
paeds 0.2
wte

Cardiff paeds
0.6 wte and
adult



Next Steps - raising Awareness #myquestion

- 6 months, one question a month
- Aim to help direct families to the website and finding the help and support they need
- Consulting with patient reps and support groups to design the posts and agree the questions



Heart Families South West...

heart children
gloucestershire



Next Steps – 2019

- All level three/ two centres to receive support group leaflet and awareness letter
- Database to be created for all cardiac specialist, link and local psychologists
- Invite to annual link psychology CPD event
- Redesign support and psychology sections on the website
- Parent reps and support groups input to co design myquestion campaign
- Design and trial metrics to measure impact of the campaign and Bristol and specialist link psychology services.

Paediatric Service Development at Musgrove Park Hospital, Taunton

- New: 0.2 wte cardiac psychology provision
- Referral for psychology support either through Taunton cardiac specialists or Bristol cardiac psychology team
- 1 outpatient clinic a week (3 out of 4 weeks of the month) with 2 appointments

Face to face

Telephone

Virtual

The link between Bristol and Taunton

- Specialist cardiac psychology supervision offered by the Bristol lead cardiac psychologist, Vanessa Garratt
- Direct liaison between psychology services in Bristol & Taunton to ease transitions
- Access to resources, database and communication through an honorary contract with UHB
- Children and parents seen on any cardiac pathway in other tertiary centers won't be seen for psychology support in Taunton, as psychology support provided on those pathways
- Option to join weekly cardiac psychology meeting in Bristol
- Shared cardiac CPD events

