



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

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Psychology Update

Drivers to focusing on psychological support:

1. The evidence (23% increase in PTSD symptoms for young people and families post cardiac surgery)
2. Family feedback at our consultations *“It feels like no mans land after you leave hospital”*
3. The Independent Review *“The need for psychological support is crucial, it is under resourced and unable to meet the needs of those who could benefit from it”*
4. The Standards

The Standards

Paediatric Cardiology		
Staffing and Skills		
B31 (L1)	Each Specialist Children's Surgical Centre must employ a minimum of 1wte practitioner psychologist (with experience of working with CHD) per 400 patients undergoing cardiac surgery each year. In addition, each Congenital Heart Network must have 1 <u>wte</u> practitioner psychologist, employed by the specialist ACHD Surgical Centre, per 5,000 patients with CHD The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network	Within 1 year
B14 (L2)	Each Specialist Children's Surgical Centre must have access to a clinical psychology service that is integrated with the cardiology team	Immediate
Interdependencies		
D34 (L1)	The following specialties (psychology) must be able to provide advice and consultation at least by the following working day. 1. Psychology, with dedicated sessions for CHD	Immediate
Organisation, Governance and Audit		
F23 (L1)	Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. <u>by</u> the next working day for inpatients in acute distress; b. <u>within</u> 10 working days for adjustment, adherence or decision making difficulties that interfere with medical care; or c. <u>within</u> six working weeks for all other referrals.	Immediate
F24 (L1) & (L2)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patients home or other agencies.	Immediate

The Standards

Communication with patients		
H27 (L1), H23 (L2) & (L3)	A practitioner psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision making around care lifecycle transitions, including transition to adult care.	Within 6 months (L1 & L2) Within 1 year (L3)
Transition		
I12 (L1), (L2) & (L3)	Young People must have the opportunity to be seen by a practitioner psychologist on their own. Psychological support must also be offered to partners/family or carer When this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.	Immediate (L1 & L2) Within 1 year (L3)
Family Planning Advice		
J5 (L1) (L2) & (L3)	Patients must be offered access to a practitioner psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or their patient and partner are concerned about attachment	Within 1 year (L1) Immediate (L2 & L3)
Palliative Care		
L24 (L1)	Staff involved at the time of a death will have an opportunity to talk through their experiences either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate

The Service

0.4 wte 2005 – 2015



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

Family and young people perspective – “Help us manage the long term psychological affects”

Exeter and Gloucester listening events and Facebook survey

We want help around :

- Helping children and young people cope at school
- Marital and relationship support
- Trauma symptoms and memories from hospital admissions
- Helping our child and us cope with hospital admissions
- Access to psychology locally - not just in Bristol
- Access to support whilst waiting for a diagnosis

The people we ask for help are:

- The support groups
- CNS team
- GP

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The image shows the cover of a report titled "Cardiac Services Listening Event March 2017". At the top left is the logo for Bristol Royal Hospital For Children. The title is in large, bold black text. Below the title, it says "Working with" followed by the logos for "heart children" and "gloucestershire", which are stylized with heart shapes. On the left side, there is a vertical sidebar with a "Contents" section listing: Introduction (1), What happened? (1), What we learned (4), Inside Story (5), and Last Story (6). Below the contents is a small photo of a man in a suit speaking. The main body of the report starts with an "Introduction" section, followed by "What happened?" and "Session 1 - Feedback from previous events".

**Cardiac Services Listening Event
March 2017**

Working with

heart children
gloucestershire

Introduction

Thank you for attending our Listening Event. It was wonderful to see so many of you and we really hope you found the event useful.

We wanted to share a brief report with you about what we've learned and what we are planning to do as a result of the event, but also summarise the event to share with families who weren't able to attend.

What happened?

Session 1 - Feedback from previous events

Mr Parry, Paediatric cardiac surgeon, explained the background to the Listening Events and why we had decided to change the format. He highlighted the key work from previous events:

Clinician view (15 responses 60% adult 40% paed)

What do you do currently?

- Refer to nurse led support
- Do it myself
- Refer to CAMHS but long waiting lists

3 most common areas for support?

- Parental anxiety
- Coping with procedures
- Telling my child about surgery

Are there areas that psychological support would benefit you and or your team?

- Debrief
- Supervision
- Talking to young people about end of life and bereavement

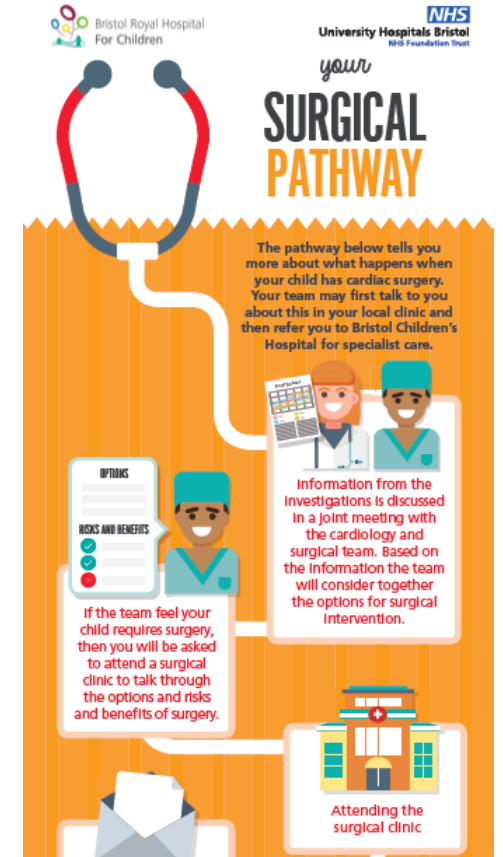
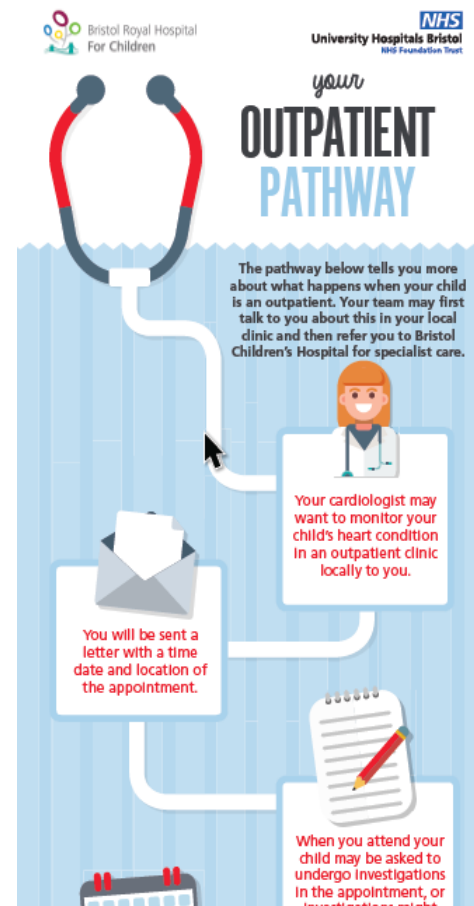
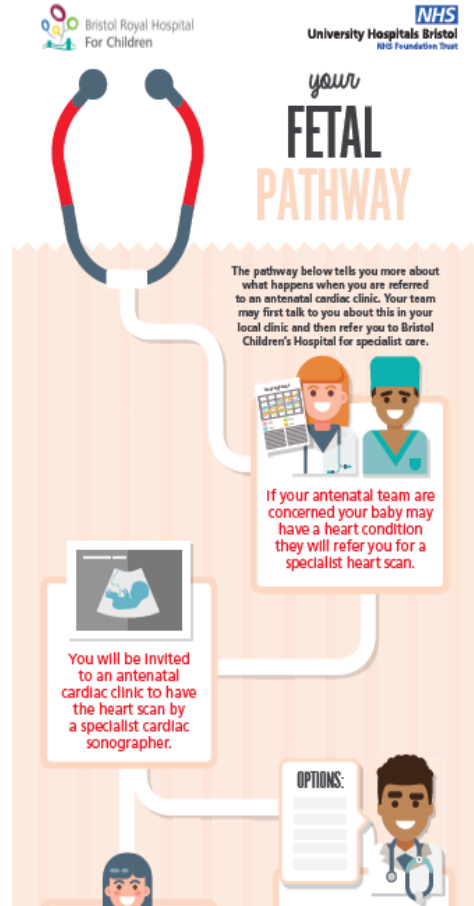
Developing the model

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)



Equity of access

Seamless care

Meeting national standards

Continual improvement

Patient voice

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

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How do I cope when my CHILD IS IN HOSPITAL?

When you first find out your child is ill, you are likely to feel worried about many things. How will your child be affected? What sort of future will they have? How will your life change? What should you tell friends and relatives? Some parents also feel angry, lonely, depressed and unable to cope.

Remember, it is natural to have these feelings. It may help to think about how you have come through difficult situations in the past. What are the strategies that you have used before when you have been worried? Which of these could you use now?

This toolkit is designed to help you cope with these difficult feelings that may arise and help you realise the importance of looking after yourself as well as your child.

Respecting everyone
Embracing change
Recognising success
Working together
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Bristol Royal Hospital
For Children

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How can I manage ANXIETY & WORRY?

Why is feeling anxious or worried important to talk about?
Anxiety is an emotion which we can all experience at one time or another, for a variety of reasons. We know that being diagnosed with and managing a health condition, having life changes and/or difficult medical decisions (e.g. consent), or dealing with traumatic physical events or unexpected medical interventions can be a source of anxiety for patients and their loved ones. One common feature of anxiety is to worry, which is thinking about negative events happening in the future, often characterised by negative 'what if?' scenarios. We know that when faced with uncertainty (e.g. awaiting the outcome of a test result, we tend to feel anxious as a result of overestimating the likelihood of a very negative, or catastrophic outcome and underestimating our ability to cope with it.

What is the impact of reducing my anxiety and worry?
We know that when someone is anxious about a certain situation or event, people may manage their anxiety by avoiding that situation. This can help in the immediate term as anxiety is reduced, however avoiding a test or procedure for their condition for instance may negatively impact their physical health in the longer term. Reducing your anxiety and worry can help you to improve your mood overall and better connect with what's important to you.

How can you use this toolkit?
This toolkit is designed to provide you with information about some of the symptoms of anxiety and worry and also provides some techniques that you can use to help you reduce these symptoms. At the end of the toolkit there are also links to further information and support if you wish to explore this area in more detail.

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GRAND APPEAL
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Improving services
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How do I bond with my baby IN INTENSIVE CARE?

When a newborn baby needs intensive care many parents can worry that they are missing out on early bonding experiences. The birth experience and/or condition of the baby at birth may mean that you haven't been able to have skin-to-skin contact or to share the first feed you had been hoping for.

will reassure you that, although it might look a bit different to how you imagined, bonding continues throughout your baby's stay in intensive care.

By using this toolkit to develop your confidence, we hope you will feel less worried about bonding and will be able to enjoy the interactions that you can have with your baby.

This toolkit is designed to give you some information about bonding and help you to develop your confidence in bonding with your baby while they are in intensive care. We hope it

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CHILD SUPPORT AREAS

- LIVING WITH A HEART CONDITION
- HOW YOU'RE FEELING
- FRIENDSHIPS AND FAMILIES
- LIFESTYLE
- SCHOOL

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PARENT SUPPORT AREAS

- ADMISSIONS
- POST-DISCHARGE & AT HOME
- LOOKING AFTER YOURSELF
- SIBLING SUPPORT
- MARRIAGE/PARTNER SUPPORT

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YOUNG PEOPLE SUPPORT AREAS

- HOSPITAL ADMISSIONS AND MANAGING A HEALTH CONDITION
- EMOTIONAL HEALTH
- FAMILY RELATIONSHIPS & FRIENDSHIPS
- LIFESTYLE
- WORK AND EDUCATION

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ADULT SUPPORT AREAS

- MANAGING A HEALTH CONDITION
- EMOTIONAL HEALTH
- FAMILIES AND RELATIONSHIPS
- LIFESTYLE
- WORK AND EDUCATION

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Welcome to your



HOSPITAL ADMISSIONS AND MANAGING A HEALTH CONDITION

Having a cardiac condition can often mean dealing with uncertainty, going to hospital appointments and admissions, and symptom management. These things can bring up different feelings for different people. There's lots of support out there to help you manage your health condition; whether that be advice on how to help manage your symptoms, manage day to day activities, the practicalities of hospital appointments and stays, and knowing the different treatments and procedures you might undergo.

LEVEL ONE SUPPORT
If you would like to find out more

LEVEL TWO SUPPORT
If you would like to talk to someone

LEVEL THREE SUPPORT
If you would like specialist support

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Empowering change
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LEVEL 1 SUPPORT

If you would like to find out more about being admitted and managing a health condition:

- **British Heart Foundation** site for young people has lots of helpful information about hospital admissions and managing your health condition - www.yheart.net [They provide information on:
 - Preparing for surgery - <https://www.bhf.org.uk/heart-health/children-and-young-people/heart-conditions-in-young-people/preparing-for-surgery>
 - Transitioning from children's to adults services - <https://www.bhf.org.uk/heart-health/children-and-young-people/heart-conditions-in-young-people/the-journey-from-child-to-adult-care>
 - Understanding your heart condition - <https://www.bhf.org.uk/heart-health/children-and-young-people/heart-conditions-in-young-people>
- You can **visit your local hospital's website**, so you know where you are going and what it is like:
 - Bristol Heart Institute - <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-heart-institute-clinical-services/>
 - The Heath in Cardiff - <http://www.cardiffandvaleuhb.wales.nhs.uk/our-hospitals>
 - Royal Cornwall Hospitals in Truro - <https://www.royalcornwall.nhs.uk/>
 - Royal Devon and Exeter trust - <http://www.rdehospital.nhs.uk/>
 - Musgrove Park Hospital in Taunton - <http://www.tsft.nhs.uk/>
 - Great Western Hospital in Swindon - <http://www.gwh.nhs.uk/>
 - Gloucestershire Royal Hospital - <http://www.gloshospitals.nhs.uk/>
 - Torbay and South Devon Trust - <https://www.torbayandsouthdevon.nhs.uk/>
- **The hospital online toolkits** aim to answer common questions that you might have about managing a health condition and hospital admissions. They outline different topics and provide helpful ideas, top tips, and strategies for how to cope.
 - I'm transitioning to adult services and don't know what will happen
 - **Cardiomyopathy Association**– Provide information and support for people with cardiomyopathy. You can visit their website for:
 - Useful information regarding cardiomyopathy - <http://www.cardiomyopathy.org/cardiomyopathy-information/cardiomyopathy-information>
 - Contacting young peer support volunteers and finding out how to join their online Facebook group - <http://www.cardiomyopathy.org/young-people/young-peer-support-volunteers->
 - Going to support Groups and speaking to other young people who have had similar experiences can be helpful. Some websites where you can find more information on support groups include:
 - **The Somerville Foundation** - who have information on being young with a cardiac condition and they also have an active support group - <http://www.thesf.org.uk/16-24/>
 - They also provide comic books that you can read about growing up with a heart condition - <http://www.thesf.org.uk/16-24/comic-books.aspx>
 - They also run events for people with a congenital heart disease who are ages 16-24. It's a great opportunity to meet other people, share experiences and get support - <http://www.thesf.org.uk/16-24/>
 - **Meet@teenheart** – You can sign up to meet@teenheart if you want to meet other young people (13-19 year olds) with a heart condition. By signing up you can also participate in events to help you build your confidence, communication and leadership skills. - <https://www.bhf.org.uk/heart-health/children-and-young-people/heart-conditions-in-young-people/meet-at-teen-heart>

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Services available across Wiltshire:

Service	Location (town/city)	Geographical boundaries	Referral criteria	See adults/children with health conditions?	Local recommended services for emotional health	Information about service/contact details:
Marlborough community CAMHS and Marlborough house inpatient unit *	Marlborough	covers North and East Wiltshire excluding Swindon - part of a group of CAMHS covering Swindon, Wiltshire, Bath and North East Somerset	https://www.oxfordhealth.nhs.uk/children-and-young-people/south-west/child-and-adolescent-mental-health-services-camhs-tier-2-3/referrals-criteria/	We see any children with significant mental health difficulties and this can include co-morbid physical health conditions, however we would not see them for the psychological aspects of the physical health condition if they did not have symptoms of a significant mental health difficulty	Locally we have Relate, school counselling, NSPCC and a variety of private practitioners	<ul style="list-style-type: none"> 01865 904666 obmh.marlboroughcamhs@nhs.net https://www.oxfordhealth.nhs.uk/children-and-young-people/young-people/south-west/wiltshire/marlborough-camhs/
Melksham community CAMHS *	Melksham					<ul style="list-style-type: none"> 01865 903777 obmh.MelkshamCAMHS@nhs.net https://www.oxfordhealth.nhs.uk/children-and-young-people/young-people/south-west/wiltshire/melksham-camhs/
Salisbury community CAMHS *	Salisbury					<ul style="list-style-type: none"> 01722 336262 ext 2779 obmh.salisburycamhs@nhs.net https://www.oxfordhealth.nhs.uk/children-and-young-people/young-people/south-west/wiltshire/salisbury-camhs/
Swindon Community CAMHS, outreach service and	Swindon	We cover the town of Swindon only and	We see adults (over age 16) registered with a GP practice in	We see adults with health conditions and are currently offering an expansion project with	Some services that we commonly signpost to include: MIND Swindon, CRUSE	<ul style="list-style-type: none"> 01865 903422 camhs.swindon-admin@oxfordhealth.nhs.uk https://www.oxfordhealth.nhs.uk/children-and-young-people/young-people/south-west/wiltshire/swindon-camhs/

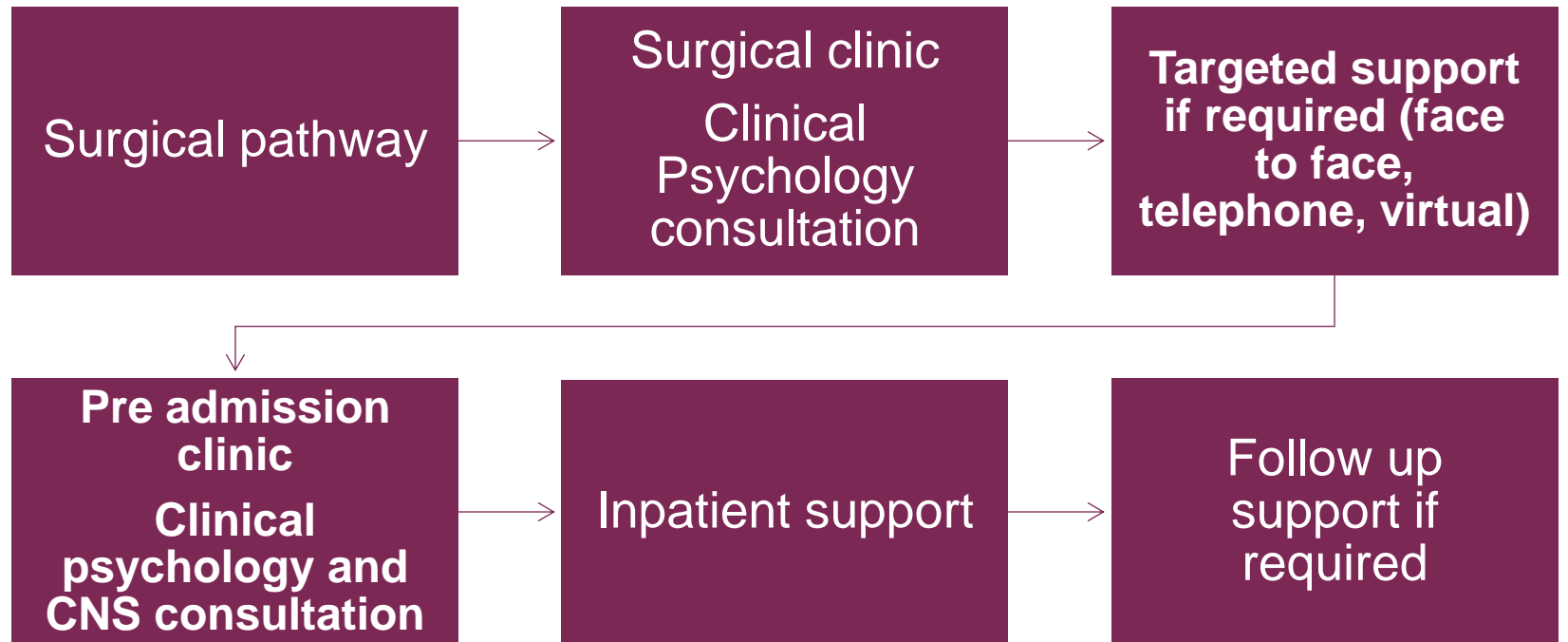
Surgical pathway

Embedding psychology
in existing clinics,
teaching training and
consultation

Putting psychologists into existing clinics, is this a better model?

■ Medical and psychological **collaboration**

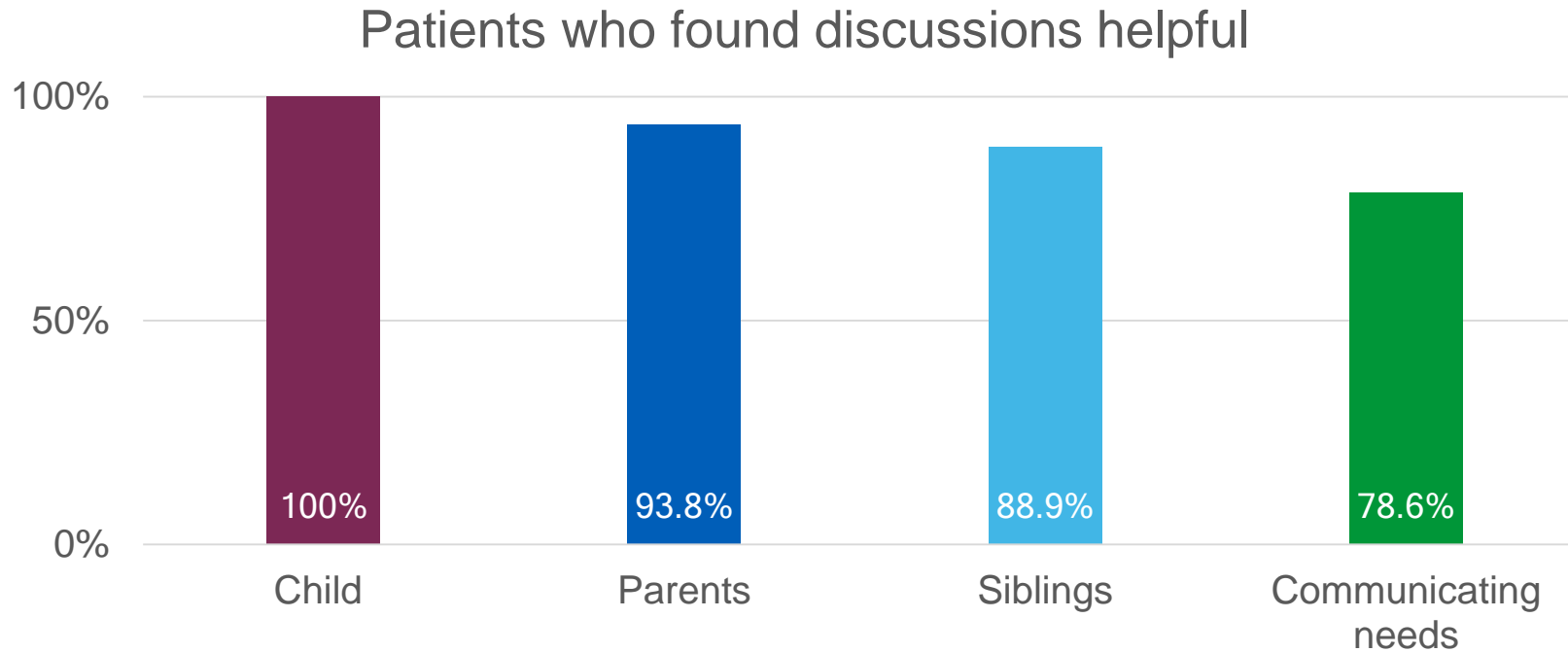
- More families seen
- Time effective
- **Preventative**
- Reduces referral time
- Reduces travel time



From surgical clinic

Embedding psychology
in existing clinics,
teaching training and
consultation

“Lots of ideas and suggestions...Lots of support and info for parents. Has made a massive difference to us, it’s brilliant.”

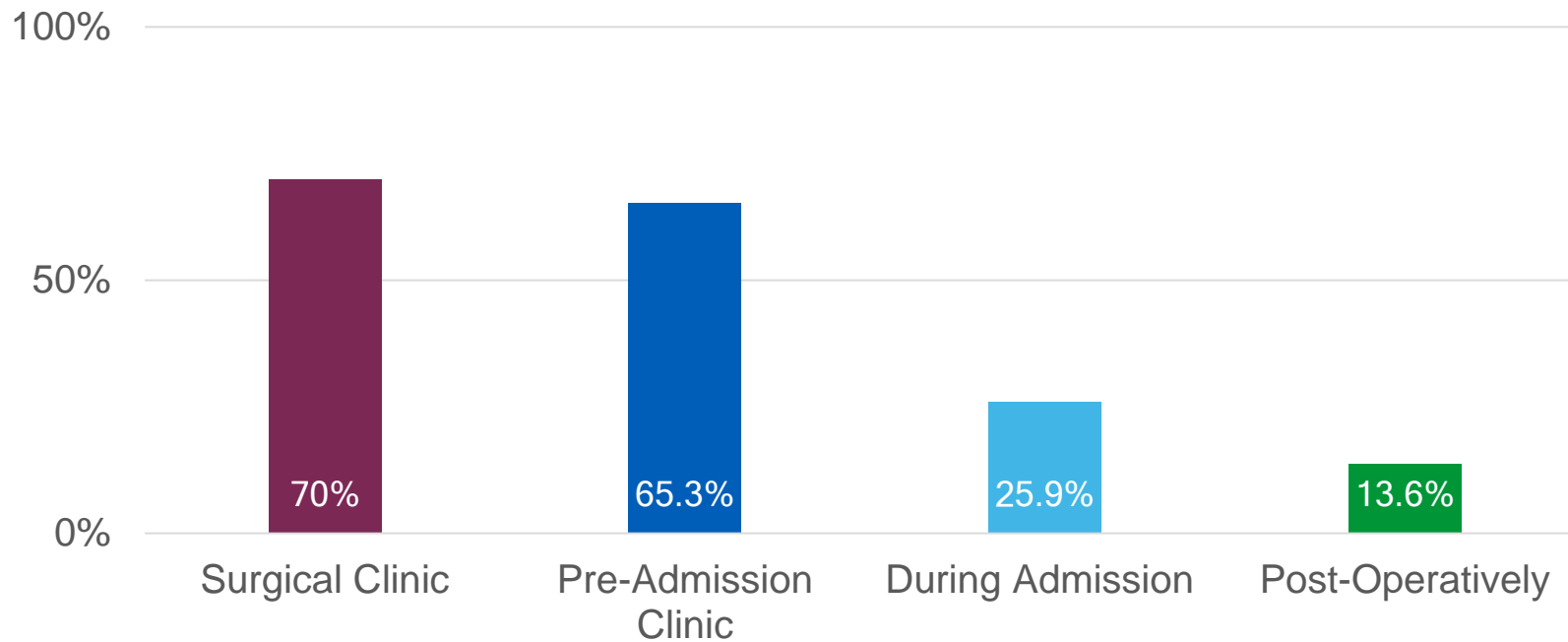


Preventative maybe?

Embedding psychology
in existing clinics,
teaching training and
consultation

“very informative, exceeded my expectations”

Patients who saw a clinical psychologist



The balance of referral and treat vs integrated models

- Lose 6/8 one-hour outpatient appointments
- Lose capacity to offer more in-depth sessions
- Gain seeing 10-12 patients routinely
- Psychology becomes normal component of surgical journey

What do we offer in 2018?

Targeted
1:1
Support

Face to face

Telephone

Virtual clinic

- 11 outpatient clinics offered a week with 28 appointment slots in total
- 8 inpatient clinics with 12 appointment slots in total

Pathway	Outpatient Face to Face	Outpatient Telephone	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

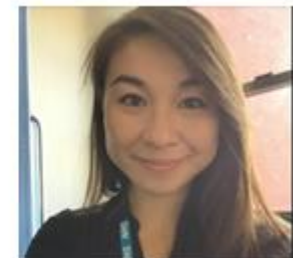
How to refer?

Targeted
1:1
Support

Year One

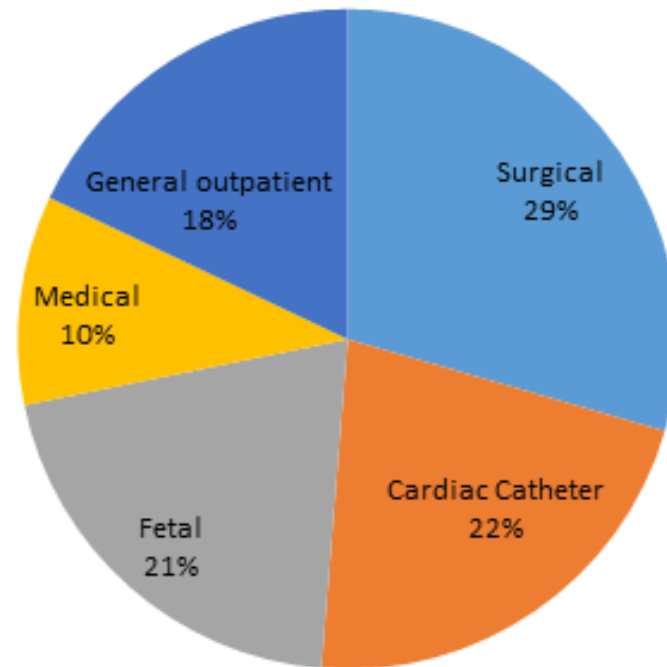
- Via cardiac nurse specialist teams
- Level one centre cardiologist
- Via electronic referral system

Year Two – review



1:1 support – Paeds data

Referrals via Service Order October 2017 - March 2018



Pathway	No of referrals
Surgical	23
Catheter	17
Fetal	16
Medical	8
General outpatient	14
Total	78

Reasons for referral to Psychology

- Parents were very anxious about their unborn baby's heart condition (information from HeartSuite: multiple VSDs, DORV mitral aortic discontinuity, LSVC to CS, TAPVD? stenosed PVs? Lymphangectasia)
- Parents live in Barnstaple, opted for telephone appointments rather than coming to Bristol for face-to-face appointments

Type of input

- Telephone appointments offered to parents prior to induction of labour
- Sadly the baby died a few hours after birth; parents returned home the same weekend
- Telephone appointments continued weekly to support parents processing the loss

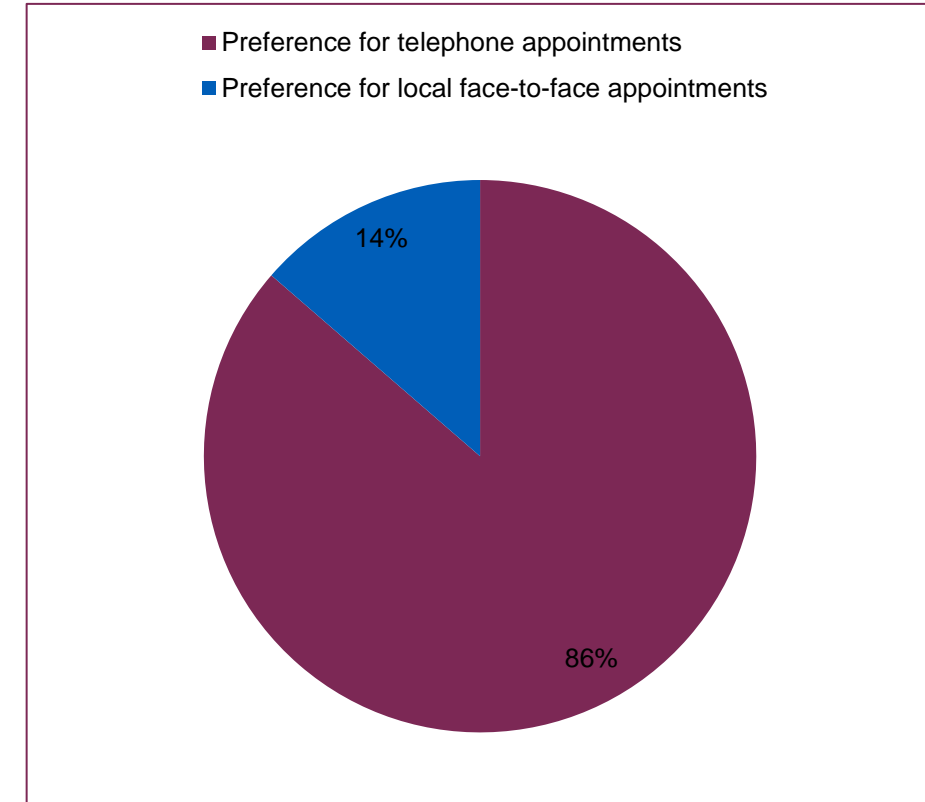
Offering telephone clinics

Summary telephone appointments (6 MONTHS)

- 68 people referred ($\frac{1}{3}$ inpatients, $\frac{1}{3}$ outpatients face-to-face, $\frac{1}{3}$ outpatients telephone)
- Outpatients who live outside of Bristol
 - 86% preferred telephone appointments
 - 14% declined telephone appointments, opting for local face-to-face support

General feedback around telephone appointments

- Parents feedback that whilst they would have preferred to see a cardiac clinical psychologist, they opted to see a general clinical psychologist as they can be seen face-to-face
- Many parents said they are glad that Psychology can be offered via telephone so that they do not have to travel to Bristol to speak with a clinical psychologist



Thank you for everything and
thank you for being you.
So wonderful and caring. ♥

Lots of love,

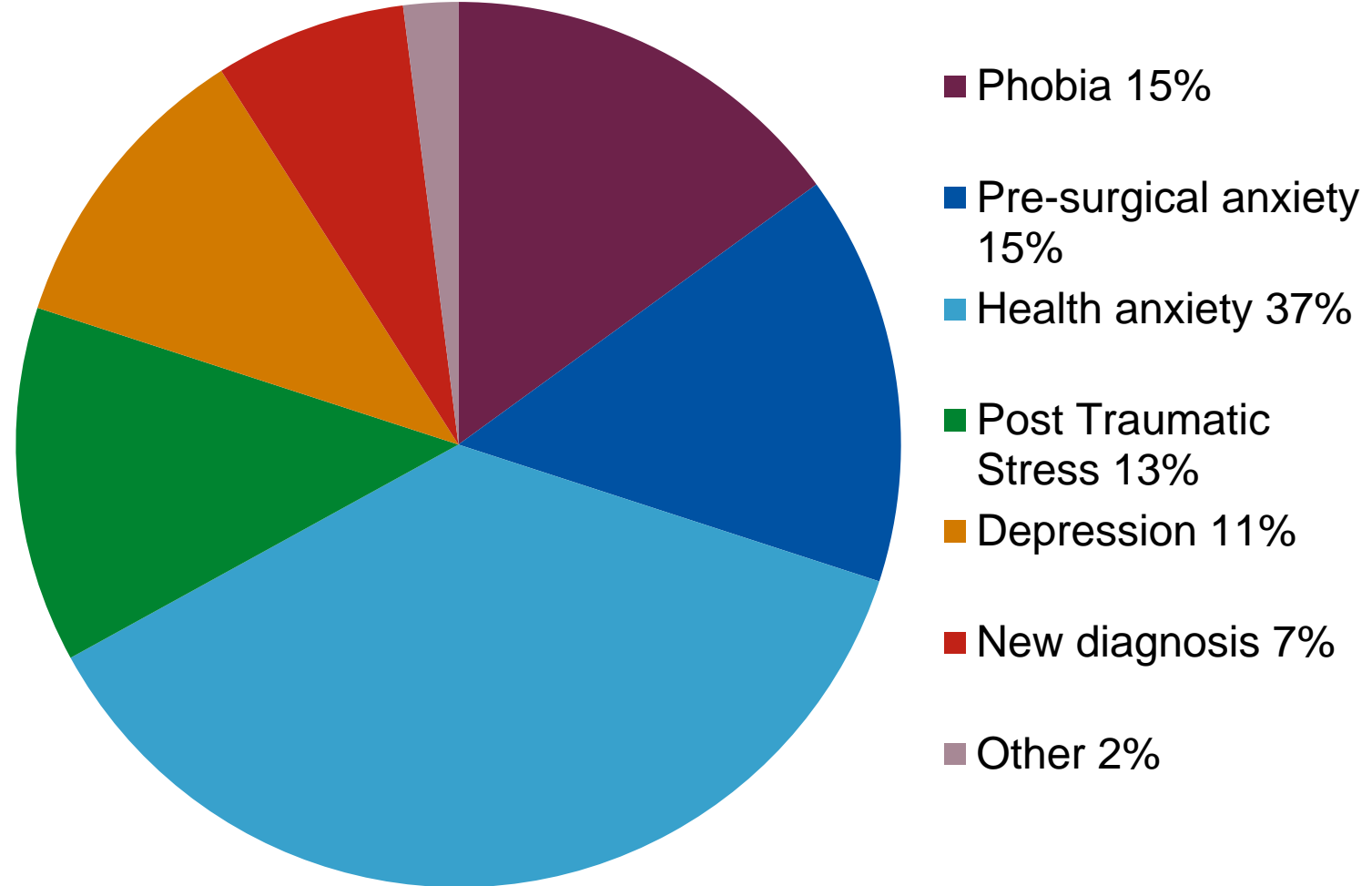
Megan.
X.

JO,

Thank you for being there
to support me at the most
difficult point in my life.
Normally, I'd really try to bottle
things up and ignore how I
feel, but I'm so glad you
called me and I'm so glad I
answered the phone and chatted
to you. Just being there to talk
to me has meant so much and
also just taking the time to come
and find me wherever I was in
the hospital. Thank you!
I think parents really do tend to
forget about themselves at times
like this and it's so nice to have
such lovely people like yourself
there for us.

1:1 support – ACHD

- 69 referrals since Sept 2017
- 73% opted in for treatment
- 89% outpatients -11% inpatients
- 63% female
- On average 6 sessions



Feedback– ACHD

Snapshot - 8 patients asked to complete the Experience of Service Questionnaire (ESQ+)

- 100% reported finding the help they received good
- 100% reported finding the sessions helpful

Comments included:

- “Michelle is very good at explaining the impact of all 'things' that affect mental health”.
- “The problems I worried about were treated very seriously”.
- “Was helpful and helped me through my surgery”.
- “They listened to me with care and did not judge”.
- “It is a relief to know this service is now available for CHD patients”.

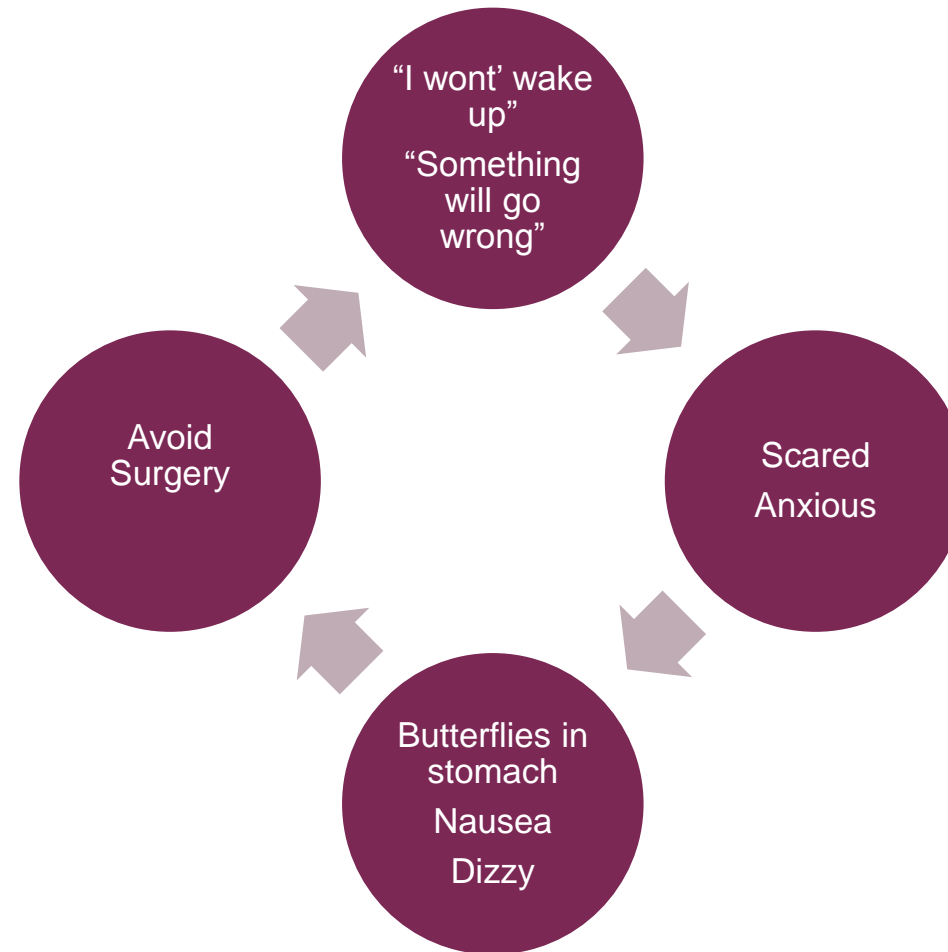
Case Study – ACHD

- 26 year old male, Tetralogy of Fallot
- Referred by CNS- Pre-surgical anxiety
- Precipitating factors- Recommended to have surgery two years prior- anxiety building over this period of time. Rescheduled 2 previous surgeries.
- Predisposing factors – Bristol Heart Scandal, court case, poor trust in medical professions, trauma from previous hospital admissions
- Previous psychological treatment- PTSD, hospital phobia

Case Study – ACHD

- 12 CBT sessions
- Initial work: Two sessions exploring pros and cons of surgery and motivation. “Feeling calm”
- Open heart surgery – changed to percutaneous pulmonary valve replacement the day before surgery.
- Day of surgery: declined – initial support plan developed and progress reviewed

Cycle of Anxiety



	Exposure Task	Anxiety rating (0-100)
1	Smell of ward	10
2	Low lights in holding area	10
3	Seeing people being wheeled to their operation	20
4	Standing outside procedure room	30
5	Looking at picture of procedure room	40
6	Listening to heart monitor –regular rhythm	40
7	Moving arm forward knowing someone will touch it	40
8	Video of the room	60
9	Listening to heart monitor-irregular rhythm	60
10	Seeing cannula equipment	60
11	Someone picking up a cannula	70
12	Someone putting in the cannula	70
13	Standing in doorway of procedure room	80
14	Something being put in cannula	80
15	Standing in the procedure room	100

ACHD- Case Study

Things I can do to manage my anxiety

My anxiety may increase but that it will eventually come down again on its own.

Slow deep breathing

Stroking arm

Coping statement **“Its common and safe, lots of people have done it, there is very low risk”**.

If I have a flashback I can ground myself to the present moment:

- 1 thing I can see
- 1 thing I can hear
- 1 thing I can taste
- 1 thing I can touch
- 1 thing I can smell

Case Study- ACHD

Patient successfully had a percutaneous pulmonary valve replacement on the 13th December 2017.

Follow up session – Patient feeling physically and emotionally well.

Hospital Anxiety and Depression Scale (HADS)	At assessment	At discharge
Anxiety	13=moderate range	7= normal range
Depression	4=normal range.	3= normal range

Our Dilemmas

- How to raise awareness of the resources so families, adults and clinicians can access initial information and signposting?
- How to ensure we continue to monitor and review when we integrate psychologists into clinics and when we offer
- How to assess whether offering telephone and virtual clinics is a 'good enough' service to the network?



