

Newsletter

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Welcome

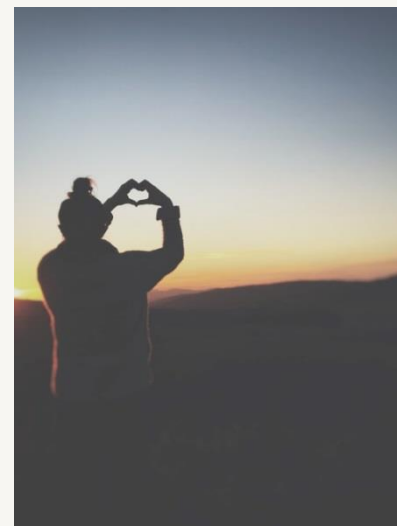
Welcome to the second issue of the Congenital Heart Disease Network Newsletter. We have been busy since our last edition getting out around the region meeting with clinical teams and patients, seeing the excellent work that is already under way and supporting improvements where needed. We have only been able to cover a small amount of the progress here but our new website, due to launch in July, will have much more information. We would love to have input from patients, parents and clinicians into the design of the website and will be running some workshops over the next few months. Please [get in touch](#) if you want to input to one of these.

Network Board Update

We held our third Network Board meeting in Taunton in March. You can read the minutes of the meeting [here](#). The key developments are:

- We have visited 14 of the network's hospitals and have another 5 visits in the diary. We are helping to understand local issues and to prioritise network-wide solutions where these are required
- We have heard from 100s of patients in clinics, listening events and online, allowing us to focus on their priorities, such as access to information and support
- We have started a dashboard of key data, including waiting times. There is some variation across the region. Those centres with the longest waits have actions under way to reduce wait times, which the Board will continue to monitor
- There is a new process (click to open) for reporting network [risks](#) and [incidents](#) to the Board. Please can all clinicians ensure they report relevant risks & incidents
- A three-year network nursing and education plan is being developed
- The patient support groups continue to grow in popularity and provide valuable input to the Board decision making. See p.5 for next events
- NHS England are proceeding with the consultation on proposed changes in which they are minded to cease commissioning surgery at several units nationally. There is little impact from this on the South Wales & South West network and Bristol will continue to provide surgery and all other CHD services.
- The network is setting up with [Above & Beyond](#) as a formal charity partner. The plan is to launch this in July when we launch the network website
- Network guidance on managing pregnancy in CHD patients will be shared with all clinicians. Training days will also be available.
- Regional training days for PECs are being developed. There will be a survey to assess their CPD / training needs. ACHD training days already take place yearly.
- The focus for future working groups will be: network psychology support, transition and learning disabilities, research and education

If you would like to find out more about any of our work areas please get in touch - James.Dunn2@UHBristol.nhs.uk



About us:

The South Wales and South West Congenital Heart Disease Network was formed in April 2016 in order to coordinate delivery of NHS England's new Congenital Heart Disease Standards. It brings together all of the hospitals, clinicians, commissioners and patients involved with congenital heart disease services in the region in order to deliver the best possible service. There is a dedicated network team, with a lead nurse, clinical director, manager and administrator.

Network vision

<i>Equity of access</i>	<i>Seamless care</i>
<i>Continual improvement</i>	<i>Patient voice</i>
<i>Meeting national standards</i>	

Key contacts

Clinical Director: Dr Andrew Tometzki Andrew.
Tometzki@uhbristol.nhs.uk

Lead Nurse: Sheena Vernon
Sheena.Vernon@UHBristol.nhs.uk

Network Manager: James Dunn
James.Dunn2@UHBristol.nhs.uk

Network Administrator: Rachel Benefield
Rachel.Benefield@UHBristol.nhs.uk

Access This Newsletter Online:

<https://tinyurl.com/CHDNews>



Support group focus: Heart Children Gloucestershire

Who would have thought that a chance meeting in a swimming pool would have led to a new support group for parents of children with Heart conditions? Well that's exactly what happened in the case of Ruth and Lucy meeting for the first time a year or so ago before starting Heart Children Gloucestershire. Both had taken their children, Maggie and Oz swimming at a different pool to normal when their paths crossed. "Excuse me, do you mind me asking if your little one's had heart surgery" was the first thing I remember Ruth saying to me, says Lucy. "As usual, I'd left Oz's scar proudly on show and Ruth had noticed it and came over. We quickly discovered that our children both had the same heart condition". "We just hit it off immediately" adds Ruth. Not only did we discover that Maggie and Oz both have Tetralogy of Fallot but we also found out that they are the same age, had heart surgery a month apart from each other, share the same cardiologist AND paediatrician who we were both actually seeing on the same day that week". They have been firm friends ever since and following a bit of support and encouragement from their Cardiologist Professor Tulloh, they decided to start Heart Children Gloucestershire to support other parents in the area. Both mums want to help others in a similar position. "There's nothing quite like having someone to talk to who has been through what you've been through. I'm so grateful to have Ruth, I say things to her about Oz or our journey and she just gets it and that's the kind of thing we wanted to replicate for others" says Lucy. Before the group started, there wasn't really much available for parents but now the group offers support, coffee mornings, a Facebook group and has just produced a new leaflet which helps parents at the point of diagnosis. If you want to contact the group you can find them at facebook.com/groups/heartchildrenglos



"There's nothing quite like having someone to talk to who has been through what you've been through".

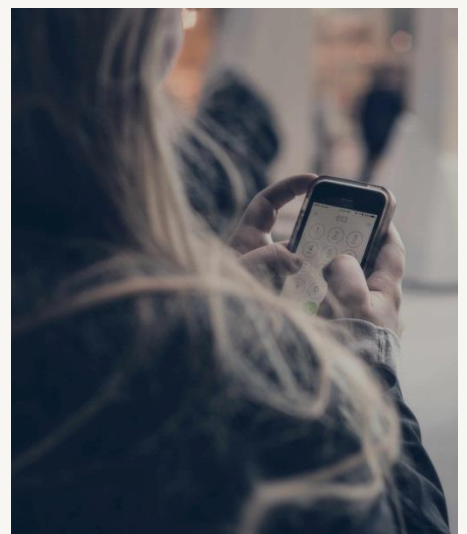


facebook.com/groups/HeartChildrenGlos

How you can get involved in improving CHD services

Here are some of the ways you can get involved:

- Contact us directly by email – Rachel.Benefield@uhbristol.nhs.uk
- [Sign up](#) to receive our newsletters and emails
- Come to an engagement event near you
- Speak to us in clinic – we are coming to clinics around the region
- Join an online reference group to input on a particular topic. We will have a number of areas where we want your input. The first is likely to be helping us design our website—what information you want to see and in what format
- Feedback directly to your local clinician who will then be able to pass your views on to the network team





Patient Story: *Thank you from the bottom of my heart*

My name is Osob Elmi and here's my story.

I was diagnosed with congenital heart disease at birth. Since then I have had open heart surgery three times at Bristol's Children's Hospital and the Heart Institute. I am now 21.

The level of care you receive and the way you are treated plays a key role in absorbing the overwhelming truth that you will have to live with for the rest of your life. During my years at the Children's Hospital in particular the privilege of having one consultant from birth to the age of 18 has been incomparable.

He was responsible for monitoring my progress and development from when I was fragile and young up until when I became an adult and was transferred to the Heart Institute. Saying goodbye was not easy.

But once I became a patient at the Heart Institute things only became better. From my experience at the hospital I can tell you that the staff made my transition easy for me and my family, making my time and experience worthwhile.

One can only imagine the stress and tough times the family of a patient undergoing heart surgery can go through, but the staff played a key part in helping us to cope with everything. From offering spare rooms and extra bedding for a family member, to giving biscuits and cups of tea, they were understanding and always willing to compromise. Each and every staff member was keen to help and I can honestly say, they treated me as if I was their own. This then took the pressure off my parents, knowing that I was in very good hands.

Having to live with this condition is difficult at times, but I know that I will be treated and looked after by professionals and people who know exactly what they are doing.

When you combine the talented doctors and nurses we have with the advanced facilities and resources that are available and accessible, anyone with a medical condition can almost feel they are no different to someone who is 100% healthy - well that's my opinion of course.

So I would like to take this opportunity to thank my previous consultant Dr Martin, my surgeon Mr Stoica and all the nurses and staff members at the Children's Hospital and the Heart Institute who work day and night to change - and save - lives.



“Receiving the news that you have a lifelong illness can be hard hitting and daunting. You only realise the severity of your condition once your brain starts to cherish the concept of life”.

Useful Websites for ACHD Patients

The Somerville Foundation has a useful booklet on a number of lifestyle issues for adults with congenital heart disease.

http://www.thesf.org.uk/documents/flyers/TSF_Lifestyle-Issues_web.pdf





Young People: *What really matters to me?*

As our patients grow up, we want them to feel part of their health journey and be able to tell us about what matters to them. Young people who have been cardiac patients in Bristol Royal Hospital for Children have been given the opportunity to say how they would like to be involved in reviewing and developing the cardiac service. All patients aged 12-21 who had been seen at the hospital in the previous 12 months were contacted with responses received from 34 young people to date. Young people were asked both how they would like to be involved and also what was important to them. Some young people asked to be kept informed but did not want to be involved, others wanted to take part by email or post and some said they would like to attend a group.



Based on their responses the following has been planned:

- There will be quarterly email/letter consultation that may include topics highlighted by young people
- Every six months young people who have asked to take part in consultation groups will be invited to a workshop which will include looking at an overview of the changes made.
- There will be an annual newsletter, specifically for young people, which will be sent to all those who have responded and want to be involved and/or kept informed.

Young people's priorities stated on the questionnaires included:

- supporting me in understanding my condition
- moving to adult services
- communication
- involving me in decisions about my care.

We will be sharing an update on the work that this group are doing through the network newsletter on a regular basis.

If you have a teenager (aged 12-21) who hasn't been contacted but would be interested in getting involved then please contact Sara Reynolds, the Young Persons Involvement Worker on Sara.Reynolds@UHBristol.nhs.uk or on 0117 3427443.

If your child is under 12 but still keen to be involved, please let us know as we will be looking at some more age appropriate opportunities for our younger patients.

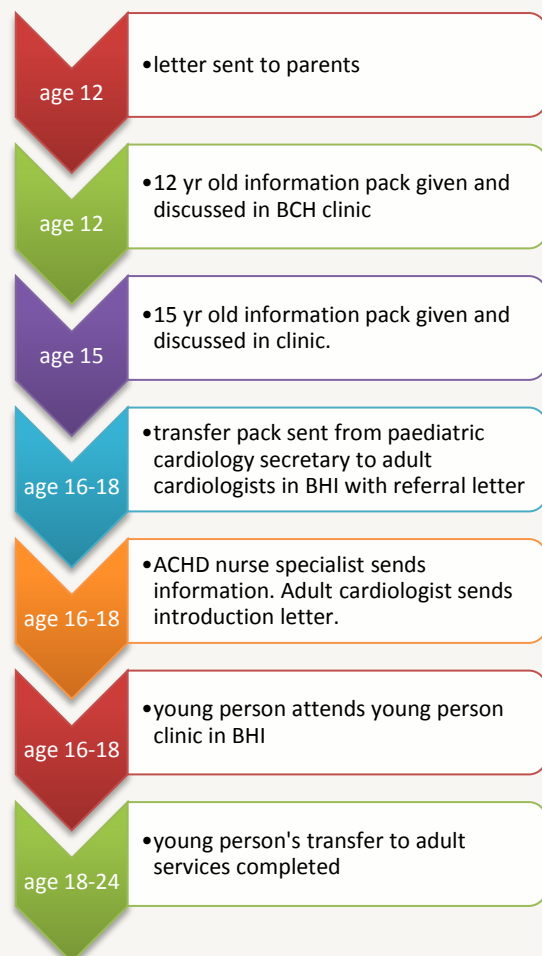
Transition to Adult's Services

The process of moving from children's services to adults services is called Transition.

This process should begin at around 12 years of age, with the medical and nursing team helping to prepare the young person for their transfer to the adult services at around the age of 16yrs-17yrs.

Around 200 young people a year transfer to the adult congenital services. The process should broadly follow the steps outlined in the ladder below.

If transition does not take place appropriately young people can be lost from long term follow-up which may have adverse consequences on their physical and mental health. If you have questions about your transition to adults services please speak to your consultant at your next appointment



Patient Information

The recently published Congenital Heart Disease [standards](#) state patients should be provided with high quality information throughout their care including when transferring between different hospitals. This should include accessible information about the service and the hospital including information about amenities in the local area, travelling, parking and public transport. Information must be made available in a wide range of formats and on more than one occasion.

Information should include advice relevant to the patient's condition on the following areas:

- exercise and sports participation;
- sex, contraception and pregnancy;
- dental care and endocarditis prevention;
- smoking, alcohol and drugs;
- tattoos, piercings and intradermal procedures;
- careers;
- travel;

As a Network we are currently gathering together the information held in each clinical area, including fetal, maternity, children's and adult services. We are also looking at support services within the hospital, support groups and charity groups which will help to inform and support patients and their families. Information for teenagers and young adults and those with learning disabilities will also be identified. Looking at the needs for those who are hearing and visually impaired will also be part of this.

No doubt there will be gaps in the information we have gathered and we will look at the areas where further information is needed. If you are aware of areas where you feel new information on a particular topic may be helpful please do get in touch and let us know. Consideration will be given to a variety of languages including Welsh.

As mentioned elsewhere in the newsletter work is underway to build the Network web-site for patients, families and health care professionals. The information for patients and families will be available on the web site and will be added to on an on-going basis. Clinical protocols and guidelines will also be found here.

Patient Involvement at the Cardio vascular biomedical research Unit (CV-BRU)

The Cardiac Research Nurses have been working to find different ways of engaging with patients; most recently they have visited schools to talk about their work, asked young people to design logos for a website, and spent time with a group of young people who helped to design a leaflet for a new patients group.

They are also developing two new patient groups, a young people (8-16 year olds) group and a parent group. This is an exciting opportunity for the groups to come together once every 12 weeks, to work with our researchers on a range of topics from designing the research that is conducted in the centre, to exploring new ways of letting people know about the work. Our new groups will meet once every 12 weeks and everyone who joins will get paid for their time.

If this sounds like something you might be interested in then we would love to hear from you. To find out more please call Noreen on 01173287837 or email her at

Noreen.Hopewell-Kelly@uwe.ac.uk



“Tops and Pants”: Engaging children in patient feedback

Richards B, Brookes W, Williams V, D’Souza N A

The paediatric ward in Princess of Wales Hospital in Bridgend has developed a novel way to gather patient feedback and using this to improve their children’s services. They introduced a “Tops and Pants” tool for gaining qualitative feedback from patients.

Children admitted to the paediatric ward at POWH are encouraged by their play specialists to complete and decorate paper tops and pants about their stay. The children then hang their paper washing on the “washing line” display board on the ward to create an attractive and appealing display of patient feedback. The feedback is addressed under a ‘you said, we did’ framework.

Looking at feedback received in August 2016, ~128 Children were admitted to the paediatric ward; of these, 44 children engaged with “Tops and Pants”, some with help from their parents. There were 73 “Tops” comments recorded in comparison to 40 “Pants” comments. Friendly staff was the most commonly recorded top comment 31/73 (42%). Conversely, “Pants” comments included having a cannula 5/40 (13%) and being woken up 5/40 (13%). Unsurprisingly the playroom and its PS4 received high praise. Surprisingly there was feedback relating to sick bowls not being large enough and the seagulls being too noisy! Anecdotal feedback from parents about this tool was very positive, praising its engaging and informal style.

The team at POW have found this feedback method to be really valuable and have gone on to run other engagement events.

Engagement across the network

As a network team we continue to want to hear from patients and parents and have been doing so in a number of ways.

Evening listening event (Gloucester): An evening event took place on March 22nd in a Gloucester community centre attended by more than 50 people. This event was run by Heart Children Gloucestershire and was an opportunity for families to hear from members of the Bristol medical team, ask some questions, eat lots of cake and generally have a good time. The FAQs and videos of the consultants’ answers can be found [here](#).

Clinic Visits: The Network Team plans to visit a number of paediatric and adult outpatient clinics to speak to patients and families about their experiences of the service and things which may be helpful. Visits have taken place in Exeter and Taunton paediatric clinics and several more are arranged. Feedback from these visits has been fed back to the local teams, the Bristol team and will be fed back to the Network board.



Upcoming Patient Engagement Events:

May 15th 7-9pm, Exeter Listening Event

Hosted by Heart Families South West as an opportunity for parents to meet and to hear updates and ask questions of Dr Tometzki, Dr Pieles and Mr Parry. Register with sally@heartfamilies.org.uk

May 15th 2-5pm, NHS England Consultation Event, Bristol

There is a national consultation being run by NHS England into proposals they have made for how CHD services should be run. There are a series of events around the country to hear people’s views. This event is in the Education Centre at University Hospital Bristol, BS2 8HW.

Register: james.dunn2@uhbristol.nhs.uk

See the consultation:

<https://www.engage.england.nhs.uk/consultation/chd/>

Consultation info for young people:

<http://youngpeoplechd.co.uk/>

The ACHD Arrhythmia Service

The success of modern surgical techniques in the treatment of children born with congenital heart defects has led to many patients living well into adulthood. However, for some patients, the scar tissue that results from surgical intervention can lead to the development of abnormal heart rhythms ("arrhythmias"), which may cause symptoms of palpitations or breathlessness. These symptoms can often be treated effectively with medication. However, for some patients, medication is insufficient to control the heart rhythm problems and they may require a procedure called an "ablation".

In the Bristol Heart Institute, Dr Ashley Nisbet and Dr Graham Stuart, Consultant Cardiac Electrophysiologists (Heart Rhythm Specialists) undertake ablation procedures to treat heart rhythm problems in adults with congenital heart disease. Many patients require only sedation and local anaesthetic, although for some a general anaesthetic may be preferred. The procedure is undertaken by passing a few small wires into the heart via small punctures in the vein in the groin, to record a detailed ECG from the inside of the heart ("cardiac electrophysiology study"). This involves stimulation of the heartbeat through the wires to bring on the arrhythmia to help us understand where it is coming from. Using specialized equipment, we can create a 3D image of the chambers of the heart to identify the areas of scar tissue that may be responsible for the abnormal rhythm. When we find the problem areas, we can then burn away the abnormal electrical tissue using a fine wire through which we deliver heat using radiofrequency energy, also known as "ablation". This often results in an improvement in symptoms, although some very complex patients may require more than one ablation procedure to control their arrhythmias.

Cardiac arrhythmias in adults with congenital heart disease can sometimes indicate an underlying problem with other aspects of cardiac function. Patients and caregivers should therefore be alert to the development of symptoms of palpitations, and consider prompt referral for assessment by the local ACHD team.

The Arrhythmia Alliance provides more information on heart arrhythmias for patients and clinicians (<http://www.hearhythmalliance.org>)

Outpatient Improvements in Bristol Children's Hospital

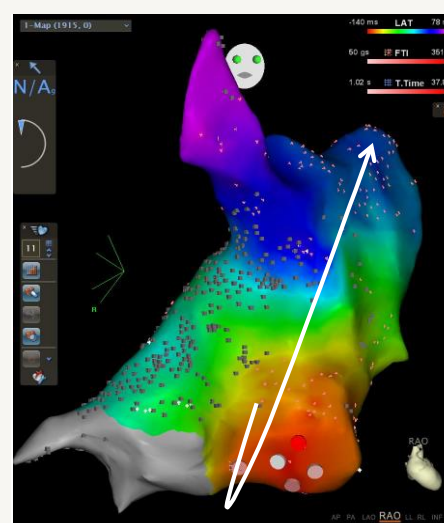
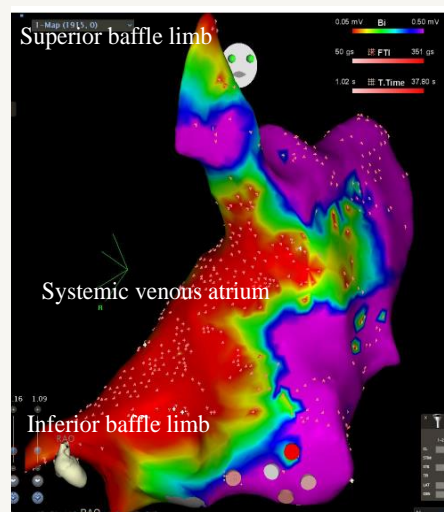
Feedback received from parents has highlighted difficulties in booking appointments, which will be improved through use of Partial Booking. This is a system that allows administrative teams to plot in the patient's next anticipated appointment date, sending the parent an invitation six weeks before we are due to see them so that a convenient appointment date and time can be arranged.

The hospital will also be making greater use of the Outpatient Appointment Centre. The Appointment Centre provides patient benefits such as longer opening hours (including Saturdays) and staff specialised in handling outpatient appointments.

The current contact details for queries regarding Cardiology and Cardiac Surgery outpatient appointments are as follows:

- Cardiology – Clinic Coordinator - 0117 342 7954
- Cardiac Surgery – Cardiac Service Coordinator - 0117 342 8862

Pictures of a 3D map of the heart of a patient who had undergone a Mustard procedure for transposition of the great arteries.



The top panel shows an extensive area of scar tissue (red area) and the bottom panel shows the direction of the abnormal electrical signals propagating around the lower part of the chamber. The pink dots are where ablation burns were delivered and successfully stopped the arrhythmia.

ACHD Clinical Nurse Specialists in South Wales

Congenital heart disease is a success story of modern medicine. However it is often complex and may affect all areas of a person's life; patients need specialist advice, support and lifelong care (Marelli et al, 2007). The role of the Adult Congenital Heart Disease (ACHD) Clinical Nurse Specialists (CNS) is integral to this patient group; they are the first point of contact and principle key worker/advocate for patients and their families. They value and respect each adult as unique and develop individuals with their best interests at heart, whilst also acknowledging the special needs of patients and their families.

Due to an awareness of the increasing ACHD population essential investment was approved to establish, develop and improve ACHD services across South Wales. Part of this funding enabled recruitment of two full time ACHD Clinical Nurse Specialists; Sarah Finch and Bethan Shiers, in June 2015. These CNSs have a leadership role across the entire network and patient pathway to enhance patient care. The newly appointed CNS team were in a unique position to set up and lead services from scratch. They were able to prioritise care and take ownership of services in collaboration with the multidisciplinary team. By adopting a 'hub and spoke' model from the local specialist centre in Cardiff (University Hospital of Wales) they help facilitate care closer to home, supporting the delivery of services in peripheral clinics. Hence there is increased 'specialist' clinic availability and greater numbers of patients are reviewed in a timely manner. In addition specialist clinical expertise is delivered into a secondary care setting, with designated clinical leads/link professionals and thus 'up-skilling' local practitioners'. The CNS team also work closely with their Specialist Surgical Cardiac Centre in Bristol to provide ongoing support for patients who are referred for complex surgery and procedures.

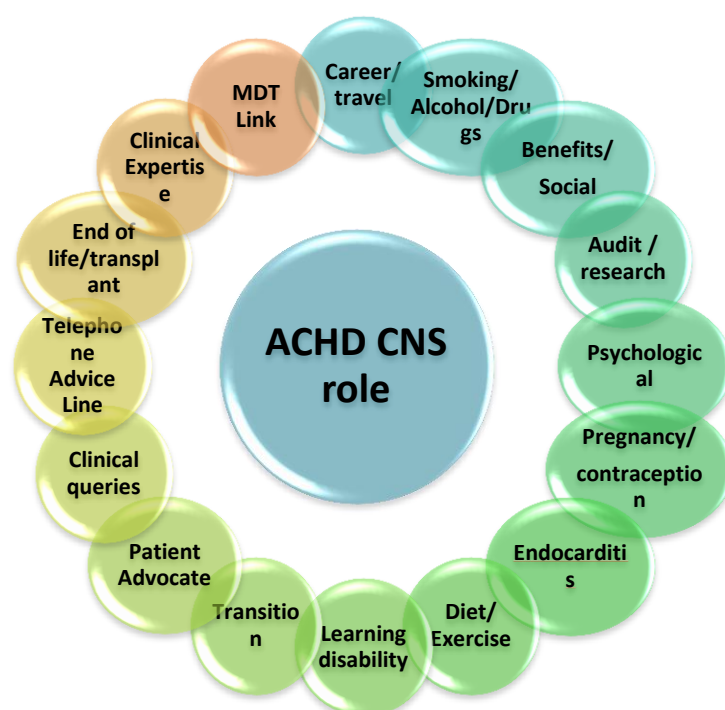
The ACHD CNS team has a huge remit, however the overall priority is to enhance and improve quality of life for patients with Congenital Heart Disease. In achieving this, the CNS will see patients during their clinic appointment (or ad hoc) and provide education and support regarding individual cardiac anatomy and any procedures or surgeries. They will discuss lifestyle issues and provide health promotion such as smoking cessation, safe alcohol consumption, healthy diet and exercise that is suitable for their heart condition. They provide advice on pre-pregnancy counselling and suitable contraception. The CNS will also review medication and compliance and provide information on endocarditis prophylaxis. The CNS team strive to always take into consideration patients' physical, psychological, social, cultural and spiritual needs; listening to patients and families but respecting their opinions, feelings and rights to privacy and dignity.

The care of a patient with CHD is often multi-faceted with many individuals or health care teams involved. The CNS team are ideally positioned to act as a patient advocate. They can facilitate appropriate discussion between patients and professionals and aid informed participation in decisions about care. Additionally the CNS will also provide further specialist support for patients with learning disabilities in line with the Mental Capacity Act 2005. The team are currently working alongside learning disability colleagues to champion and enhance care pathways for this particularly vulnerable patient group.

People with CHD can often feel very lonely or isolated, day to day activities can be difficult and symptoms can change very rapidly. An area we are particularly proud of is the 'ACHD Telephone support/ advice line'. This provides patients with a crucial point of contact to seek support. The CNS team receive approximately 280 phone calls a month. This has had a positive effect on reducing inappropriate hospital admissions and GP consultations, whilst increasing satisfaction. The team are currently auditing patients' perception of this line of support.

We are proud that our ACHD CNS service has achieved such a vast amount in the past 18 months. However we acknowledge there are areas where further input and development are required and are passionately working towards achieving these goals in the near future.

** The CNS team has also been integral to the development and initiation of dedicated 'Transition Clinics' in South Wales – this has been highlighted in the [previous edition](#) of the Congenital Heart Disease Network newsletter.**



Clinical Education & CPD

Children's Nurses	Adult Nurses
Children's Faculty Cardiac 1 + 2 BRHC FacultyOfChildrensNurseEducation@UH.Bristol.nhs.uk	Adult Southbank University, (UWE) 6 days in London 20/4, 4/5, 18/5 31/6 29/6 Sampsom3@lsbu.ac.uk
Paediatric Study Day 28/4/17 UHBristol Education Centre FacultyOfChildrensNurseEducation@UH.Bristol.nhs.uk	EuroGUCH May 5th-6th Lausanne ESC wp1.euroguch.com/registration/
15th Introduction to Congenital Heart Disease Including specific ACHD day. 3 rd -7 th July www.introtochd.co.uk	15th Introduction to Congenital Heart Disease Including specific ACHD day. 3 rd -7 th July ACHD day 7 th July www.introtochd.co.uk
Multi-Professional Adolescent and Young Person Masterclass 27/3/2017 UHBristol Education Centre	Adult Congenital heart Disease Study Day 17/9/2017 UHBristol Education Centre
5th Annual CCNA Conference 21 June 2017 j.fleet@worc.ac.uk	Regional training days
British Congenital Cardiac Association, conference November 2017 London www.bcs.org	British Congenital Cardiac Association, conference November 2017 London www.bcs.org
RCN competencies for Band 5 and 6 Children and young people's cardiac nursing www.rcn.org.uk	RCN competencies for Band 5 and 6 Adult Congenital heart disease nursing www.rcn.org.uk
Shadowing in Level 1 centre, wards, JCC, OPD Bristol Royal Hospital for Children	Shadowing in Level 1 centre, wards, JCC, OPD Bristol Royal Hospital for Children

Welsh Audit Day

The Welsh Health Specialised Services Committee held its annual review/audit of Congenital Heart Disease Services in Wales on 10 January 2017. The meeting was attended by clinicians and health managers from South Wales, Bristol, Manchester and Birmingham. There were also contributions via a video conference link from North Wales, Manchester and Liverpool. The Wales and Southwest CHD Network Team was also in attendance.

For the first time the audit day was split into two with a morning session for adult congenital services and the afternoon for fetal and paediatric cardiac services. In both meetings there was a focus on how services across Wales are doing at achieving the NHS (England) care standards. Surgical and catheter activity was reviewed with careful consideration of clinical outcomes. Cardiff was able to present its work as a Level 2 centre. Access to MRI services was an area of discussion – it was good to see waiting times for routine MRI in Wales coming down. Because WHHSC commissions specialist services, there was less emphasis on the provision of Level 3 services – it looks like the Cardiac and CHD Networks will need to drive this forward.

As always it was useful for clinicians and managers to see examples of good practice being carried out by other teams.

Welcome to the team



Name:

Dr Michael Yeong

Current post:

Locum Consultant Paediatric Cardiologist

Specialities:

Echocardiography – the use of ultrasound to diagnose and monitor congenital and acquired heart disease

Cardiac MRI - the use of an MRI machine to create clear pictures showing the inside of your heart in a non-invasive manner and without radiation

Medical qualifications:

MBBS BSc (Med) (UNSW), FRACP

Professional profile:

Dr Yeong undertook extensive training in general paediatrics in Sydney, Australia before embarking on further training in Paediatric Cardiology. He trained in paediatric cardiac centres in Australia and New Zealand namely the Green Lane Paediatric and Congenital Cardiac Service, Starship Children's Hospital, Auckland New Zealand and Mater Children's Hospital, Brisbane, Australia. He then undertook further subspecialty training in cardiac MRI at the prestigious Boston Children's Hospital, USA under the tutelage of Professor Andrew Powell and Professor Tal Geva. He expanded his congenital cardiology knowledge by taking up an Adult Congenital Heart Disease Fellowship with Dr Graham Stuart at the Bristol Heart Institute. Dr Yeong joined the Paediatric Cardiology team at the Bristol Royal Hospital for Children in 2017.