

North East and North Cumbria
Congenital Heart Disease Network
(NENC-CHDN)

Annual Report 2019/20

June 2020

Document History

Title	Annual Report for NENC-CHDN 2019/20
Author(s)	Terry Phillips
Author Contact Details	North East & North Cumbria CHD Network Cardiothoracic Directorate The Newcastle upon Tyne Hospitals NHS Foundation Trust Freeman Hospital Freeman Road High Heaton Newcastle upon Tyne NE7 7DN
Owner	NENC CHD Network Board

Version Control		
Version no.	Date	Revision Summary
1.0	May 2020	Initial version
2.0	June 2020	Reviewed following comments from JW, AK and information from Tony Hermuzi.
3.0	June 2020	Final comments incorporated
4.0	13 th July 2020	Final version published and released.
4.1	20 th July 2020	Amendments/corrections added: Page 7 – Congenital Cardiac services diagram – CDDFT details added (previously missing) Page 21 – NICOR data most recent DQI score added for 2018/2019

Contributors to current version		
Role	Name	Notes
Chairperson	Jonathan Wyllie	
Clinical Director	John O'Sullivan	
Adult Lead	Louise Coats	
Paediatric Lead	Abbas Khushnood	
Network Lead Nurse	Kaye Walsh	
Governance Lead	Tony Hermuzi	
ACHD patient representative	Michelle Sinclair	
ACHD Nurse Specialist	Lorna Carruthers	
Paediatric CHD Nurse Specialist	Deb Lawson	

Table of Contents

Foreword.....	4
Introduction	5
Our Network Structure.....	6
Network achievements	10
Our Network in Numbers.....	15
Multi-disciplinary Team Meetings	26
Governance	26
Innovations/Developments for 2019/20	29
Research.....	29
Under the spotlight	33
Priorities for the coming year	37
Appendices	42

Foreword

It is a pleasure to be writing the foreword to this first formal annual report for the North East and North Cumbria Congenital Heart Disease Network (NENC-CHDN) as chair. I first came to train in the North East more than 30 years ago and have practiced both as a Neonatologist and Paediatrician with Expertise in Cardiology (PEC) and Fetal Cardiologist for more than 25 years. Our region was ahead of its time in terms of outreach clinics, training fetal cardiologists and PECs and developing clinical networks. However, that early success, based purely on relationships rather than a system, then held us back somewhat in continuing to develop a fully integrated network for the care of our patients from antenatal diagnosis through to adult life with CHD.

We now enter an exciting time full of potential and possibilities. The NHS England Congenital Heart Disease Peer review in 2019 highlighted areas on which we need to focus but the real potential comes from engaging with our patients, their families and clinicians around the region to form our clinical network delivering effective integrated care where ever it is needed. We are fortunate in the Fetal, Paediatric and Adult CHD expertise available in our regional centre which enjoys a national and international reputation as well as the added expertise in ECMO and Cardiac Transplantation. We are also fortunate to have the close support and input from the Children's Heart Unit Fund (CHUF) charity who were key in their support of the service in its earliest days and continue now to innovate and also challenge.

However, with great new and energetic Network appointments, the team now looks forward to the next 5 years as an exciting opportunity to build on the excellent cardiology and surgical expertise available in Newcastle to produce an equally excellent Clinical Network ensuring the best of congenital cardiac care with clear clinical pathways throughout our region.

However, we cannot do it alone: Please get involved and help us.

Professor Jonathan Wyllie

Chair North East and North Cumbria Congenital Heart Disease Network (NENC-CHDN)
Consultant Neonatologist – James Cook University Hospital
President Resuscitation Council UK
Vice Chair Neonatal Task Force, International Liaison Committee on Resuscitation

Introduction

The North East and North Cumbria Congenital Heart Disease (NENC-CHD) Network covers a population of 2.9 million people in the North East and North Cumbria, and is hosted by the Newcastle upon Tyne Hospitals NHS Trust (NUTH).

NUTH forms part of the national Congenital Heart Disease (CHD) Service commissioned through NHS England Specialised Services and through its Cardiothoracic Directorate delivers care to both adults and children as a Level 1 specialist surgical centre.

The network aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing the whole lifetime of care. The network will support the Level 1 centre and work collaboratively with the peripheral centres to develop and support national, regional and network arrangements that facilitate mentorship and centre-to-centre referrals.

Central to the aims of the network are compliance with the NHS England CHD Standards and Specifications¹ and to fulfil the requirements of the NHS England 2019 peer review.

The network will support the Level 1 centre and work collaboratively with the peripheral centres to develop and support national, regional and network arrangements that facilitate mentorship and centre-to-centre referrals.

This document highlights the achievements over the last year and outlines the ambitions for the coming year.

Network Vision

Our vision is to provide high quality, equitable care for CHD patients wherever they live within our region; provided closer to home when possible, ensuring seamless transition between fetal, paediatric and adult services and providing an holistic approach to care.

To achieve this we will;

- Increase collaboration to standardise care and share best practice
- Improve communication and further utilise digital solutions to provide high quality care and improve learning
- Develop protocols, pathways and guidelines to provide seamless equitable care across the region
- Set standards to provide a uniform service throughout the region
- Provide high quality information for patients and families about their care
- Ensure patients are involved in the decision making about their care through their lifetime

Network Objectives

The objectives of the network are;

- To deliver a formalised CHD Network across the North East and North Cumbria
- To provide direction and develop a Network Strategy
- To ensure equitable access to CHD services for all patients
- To work towards meeting the service standards
- To improve and support patient and family engagement
- To provide a high quality service and develop a Quality Improvement Policy
- To promote research activities in all centres and affiliated universities within the network
- To effectively communicate within all centres of the network
- To support education, training and development of the workforce in the network

These are presented in more detail, with proposed timescales, in the network action plan.

¹ <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

Network Management Team

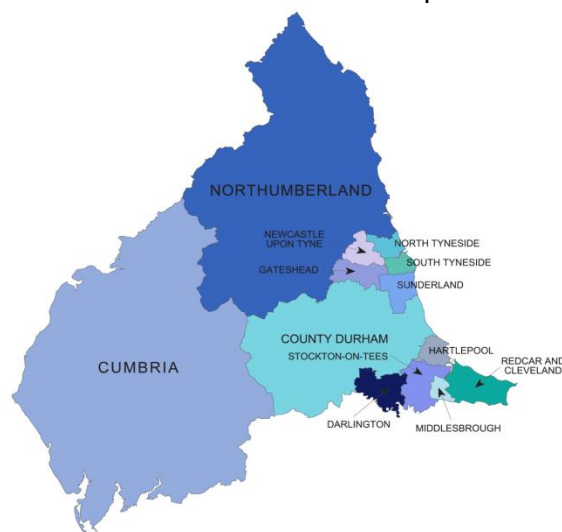
The network management team was formerly established in January 2020, comprising of the Network Chair (Jonathan Wyllie), Network Clinical Director (John O'Sullivan), Network Manager (Terry Phillips), Network Lead Nurse (Kaye Walsh) and Network Administrator (Wendy Nee).

Our network benefits from the expertise of a Paediatric Clinical Lead (Abbas Khushnood), an Adult Clinical Lead (Louise Coats) and data manager (Gwen Taylor).

The key priorities and work of the network team is determined by the network board which is responsible for ensuring that the activities of the network staff are in line with agreed network priorities and are working towards the achievement of CHD standards.

Our Network Structure

The network incorporates the Trusts providing acute services across the North East and North Cumbria. Both paediatric and adult congenital heart patients currently receive expert surgical, medical and interventional care delivered at the Freeman Hospital.



Host Provider – Level 1 Specialist Surgical Centre

- Newcastle upon Tyne Hospitals NHS Foundation Trust

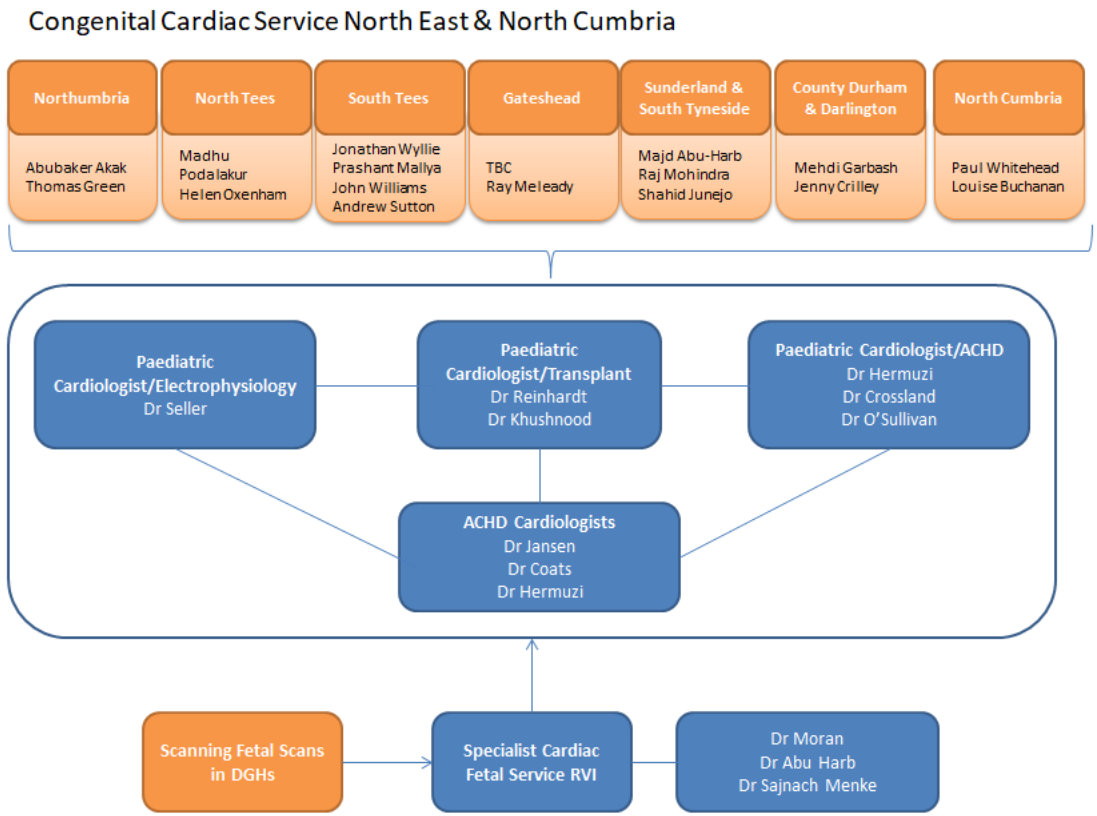
Peripheral Centres

- County Durham & Darlington NHS Foundation Trust
- Gateshead Health NHS Foundation Trust
- North Cumbria Integrated Care NHS Foundation Trust
- North Tees & Hartlepool NHS Foundation Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- South Tyneside and Sunderland NHS Foundation Trust

Together the Trusts deliver health care to a population in excess of 2.8 million (Source <https://www.england.nhs.uk/>). The network membership is multi-disciplinary, board meetings are held three times a year and are a mixture of network update and clinical focus with a standardised agenda to which all Trusts in the network are invited.

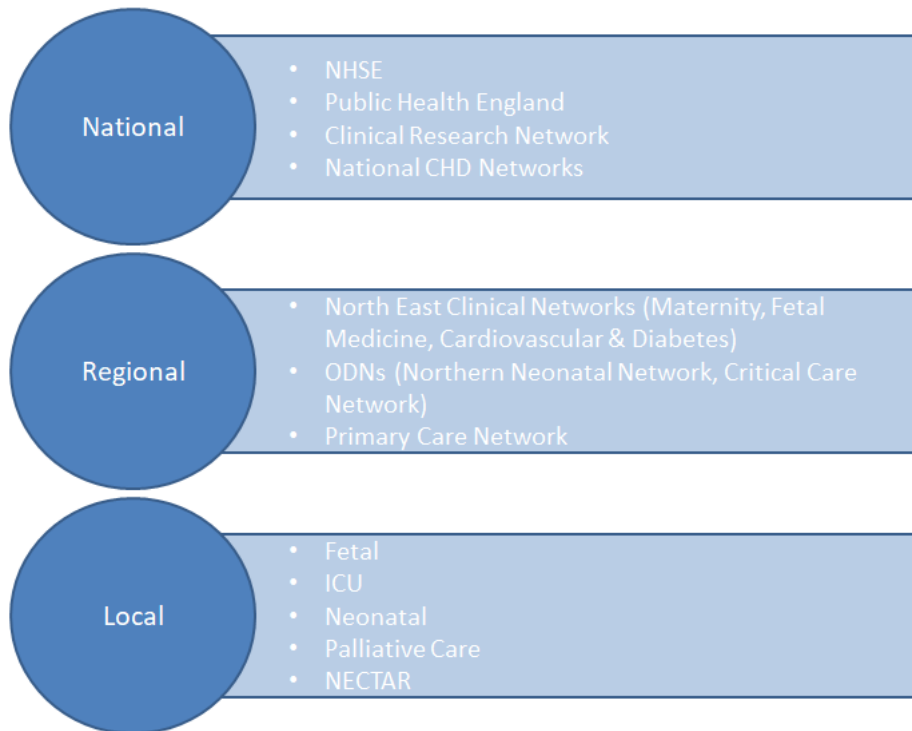
Our network aims to deliver close collaborative regional working which allows joined up care for maternity, fetal and neonatal services. As the network matures these collaborative relationships will be cemented with further engagement and expand to include wider specialities and services.

The figure below shows how the congenital heart disease service is delivered in the North East and North Cumbria.



Wider relationships

The CHD network has close relationships nationally, regionally and locally. Close collaborative working is essential to the development of robust effective protocols and pathways for CHD patients in our region and across the country.



The Cardiothoracic Directorate at Newcastle upon Tyne Hospitals NHS Foundation Trust provides a service locally, regionally, nationally and on occasion, internationally, offering outpatient and inpatient services.

For children there are 18 dedicated inpatient beds for planned and urgent treatment plus a 12-bed dedicated Paediatric Cardiac Intensive Care Unit. Adults are accommodated in the adult cardiology and surgical wards including the cardiac ITU.

The team is supported by a range of expert services including Echocardiography; Cardiac catheterisation; Electrophysiology (EP); Fetal Cardiac Service; integration with specialist children's services based at the Great North Children's Hospital (GNCH); integration with specialist adult services e.g. nephrology and hepatology.

The GNCH is located on the Royal Victoria Infirmary (RVI) site and houses all the other paediatric specialties. The fetal cardiology service is located within the Maternity Unit at the RVI. The CHD standards require CHD paediatrics services to be on the same site as the other paediatric services the Trust provides; the Trust have set a phased approach which includes co-location of CHD paediatric services to the RVI in order to achieve this standard.

Paediatric cardiology is a rapidly developing field of medicine and the networks regional Level 1 centre has an international reputation for treating heart problems in children. NUTH is a recognised centre of expertise in heart failure, for children with life threatening heart failure and the management of ACHD patients who develop heart failure later in life. Our results for congenital heart surgery are among the best in the UK.

In addition to our core congenital heart disease service, the Level 1 centre takes pride in hosting the nationally commissioned cardiothoracic transplantation specialist service. The clinical team have published widely and are recognised internationally for this work exemplified by our ongoing contribution to the International Society for Heart and Lung Transplantation.

The unit is one of the largest centres for heart transplant for children and adults with CHD in the UK and Europe, and is one of the two UK centres for paediatric heart and lung transplantation and Ventricular Assist Devices (VAD). This expertise, combined with our well established extracorporeal membrane oxygenation (ECMO) service attracts referrals of patients with high risk and challenging cardiac pathology from other paediatric and adult congenital heart centres across the UK.

Network achievements

Although the region has been working collaboratively for some time there is a need for a formal network, not only to address the national standards and specification, but to ensure we work within a clear governance structure ensuring transparency and accountability to deliver safe and effective care for CHD patients.

Launch event

The network was launched at an event on 10th January 2020 at the Freeman Hospital in Newcastle. Attendees were from across the region and across healthcare professions and provided feedback on what the network would mean for them. There were also attendees from other North East Clinical Networks, regional commissioners and neighbouring networks. A number of adult patients and parents of children with CHD attended and took part in the patient engagement session.

Overall it was felt the network would provide better care throughout the region for patients and families by offering a more structured seamless approach. Patients and families should know with confidence what to expect at each centre. Patients and families should be fully informed about the expert non-surgical options available at their local provider and those available at the Level 1 centre.

The North East and North Cumbria as a region prides itself on the maturity of a number of clinical networks who have forged collaborative links across the region for many years. However, there is a need for clear pathways of care and communication between these networks which remains a high priority for the network team. A particular example was raised with respect to neonatal transport elements of care to blend seamlessly into the antenatal plans and the postnatal interventions needed.

The development of the CHD network provides a great opportunity to align with the priorities and objectives of the Children's Heart Unit Fund (CHUF) charity. Together with CHUF the network will establish a patient engagement group to support children and families throughout their CHD journey and into adulthood.

The network is an opportunity for patients and families, as well as healthcare professionals, to embrace digital technologies. The Covid-19 pandemic has accelerated this due to the lockdown measures put in place by the Government. There has been an increase in telephone and video consultations due to the reduction in face to face outpatient capacity (due to social distancing requirements) which has been a favourable development for many patients. As a result, we are reviewing how outreach clinics will be developed across our region and this is covered in more detail later in the report.

Much feedback centred round the visibility of the network and our online presence, with discussion around a network website and social media channels. Many stakeholders see this as an opportunity to improve communication and visibility of relevant information, standardise the service across the region and share relevant guidelines. The network team have made some progress with this and this is discussed later in the report.

The appointment and development of paediatricians out with the level 1 centre with expertise in cardiology, a governance framework, education, peripheral clinics and attendance at the CHD MDT remain on the priority list for the year ahead

Many welcomed the formalisation of the network and the appointment of the network team and also acknowledged the support from CHUF in providing additional equipment and psychology

support to the regional service. While all centres are committed to regional collaboration it was felt that there is work still to be done to improve this.

The shared development of protocols and pathways regarding the delivery of babies diagnosed with fetal CHD in local DGHs rather than regional centres was seen as a positive step forward.

Engagement with the Children's Heart Unit Fund (CHUF)

CHUF carry out a large amount of work to support patients both directly in providing help and advice, and indirectly by supporting innovations in healthcare both through providing cutting edge equipment and funding staff recruitment.

CHUF currently support a Fontan nurse specialist at the Freeman Hospital, the first position of its kind in the UK. The Fontan nurse specialist looks after children and adults with a Fontan circulation ensuring their heart and liver function is monitored regularly. In addition they have recently provided support for a new post at the Freeman Hospital, a children's CHD specialist nurse for complex discharge and vulnerable babies. This post will lead on a Quality Improvement project to facilitate and support a "No Place Like Home Initiative". This role will bring care closer to home with clinics, the ward and local teams working together to reduce the length of stay in hospital, to provide a safe and timely discharge and ensure there is continued support for families once home.

CHUF also provide psychology support for children and families with CHD in the south of the region which has been very successful reducing travel time for families and increasing overall regional provision.

CHUF have supported peripheral centres across the network with the provision of additional echocardiography equipment to James Cook University Hospital (Middlesbrough), University Hospital of North Tees (Stockton), North Tyneside General Hospital (North Shields), and Sunderland Royal Infirmary (Sunderland).

Most recently CHUF have supported families with children who have been inpatients at the Freeman Hospital during the covid-19 pandemic. In addition to the support provided by the Trust, CHUF have provided meal tokens for the hospital canteen for families; games, books, art and crafts, an internet enable tablet with Disney Plus, and a virtual program called Beat Squad organised by CHUF and the Clown Doctors.

CHUF's vision is '*to support pioneering services that will positively impact heart families, inspire hope and enable Heart Heroes to reach their full potential*'. Their objectives are '*to promote the Physical and Mental Health of patients in the United Kingdom and their families suffering from the following conditions*':

- Congenital Heart Disease
- Heart disease acquired during childhood
- Pulmonary Hypertension acquired during childhood
- Solid Organ thoracic transplantation acquired during childhood
- To advance the education of the public of the above conditions and particularly but not exclusively by the support of research and the dissemination of the results thereof

Education programme

In March 2020, we contacted units across the region via Survey Monkey to ask for their feedback on education and how they would like to engage with educational events. Thirty one people responded most of who manage the care of patients with CHD. Respondents were interested in all areas of CHD lifespan and most would prefer classroom based education (75%) involving an inter-professional group sessions (68%) and using case studies (70%).

The following topics were of interest;

- Day-to-day clinical management and disease progression
- General concepts and how typical IHD issues may affect CHD patients

- Diagnosis, assessment and management process for CHD conditions
- Current best practice; when can children be treated more locally and when do they need specialist input
- The role of the specialist nurses
- Supporting children and families throughout the lifespan
- Fontan patient
- Patients with additional needs – how to make the best use of patient contacts and general anaesthesia opportunities
- Transition to adult services
- Anatomy and physiology family support
- Dental health
- Assessment of GA risk and anaesthetic considerations
- Endocarditis risk
- Anatomy and physiology complications
- Nursing care
- Long term ventilation
- Feeding difficulties
- Care of the complex cardiac patient

Respondents were primarily nurses, however feedback was received from the following disciplines;

- Interventional cardiology nurse consultant
- Advance paediatric nurse practitioner
- Clinical educator
- Consultant cardiologist
- Fetal medicine
- Cardiologist
- Consultant in Special Care Dentistry
- Neonatologist
- Consultant Clinical Psychologist

Generally respondents felt the network would help to ensure we are working to the same standards of care across the region, be able to share best practice and participate in multidisciplinary discussions.

Respondents welcomed the opportunity to attend education sessions especially with a variety of professionals who cared for patients at all points of their CHD journey to provide more rounded learning. It was felt by some that due to clinical commitments senior staff do not have the same training experience as junior staff.

Respondents noted it would be helpful to have additional up-to-date knowledge to underpin practice and improve skills to help manage different clinical situations. Reflective practice and learning were also viewed as important to learn from complaints and adverse events.

Educational webinars

The educational programme for the network was launched in April 2020 with a series of webinars. There were plans in place to host simulation events at Cumberland Royal Infirmary, James Cook University hospital and the Royal Victoria Infirmary but unfortunately, due to the pandemic these have been postponed, with the aim of delivering this type of learning next year.

Attendance at the webinars was fantastic and we thank everyone for taking the time to attend. The adult session focussed on introducing CHD, the incidence of heart failure in CHD patients, living with CHD and mental health and wellbeing. The paediatric session focussed on introducing CHD in paediatric patients, antenatal diagnosis and counselling, recognition of failure and VAD options and the value of CHD education.

The paediatric transplant session provided a stimulating & comprehensive overview of this specialised service focussing on current status of paediatric heart transplantation, pre-transplant journey including managing heart failure, the role of transplant team, transplant surgery and post-transplant care.

Following the success of these webinars we will be delivering further webinars on the CHD Paediatric Patient Journey, the Importance of Nutrition in CHD patients and Fontan patients, regional programme of education. The network team are supporting the ACHD team at the Freeman to deliver booster session on a regular basis via webinar platform.

Outreach clinics

A primary focus of the network is to support care closer to home by expanding our outreach clinics across the region and growing the use of digital technology to engage with patients and enhance staff learning.

As the network host NUTH should provide outreach clinics throughout the North East and North Cumbria. NUTH have been delivering adult outreach clinics in James Cook University Hospital bi-monthly supported by a specialist nurse for over 10 years and paediatric outpatient clinics, since 2014. A consultant-led paediatric clinic in University Hospital of North Tees started October 2018 with a virtual adult clinic due to start in July 2020. A consultant-led paediatric clinic started in Durham in February 2020 and discussions are underway to commence adult clinics. Paediatric and adult clinics were due to start at Cumberland Infirmary Carlisle in April, however these have been suspended until later this year. Discussions were also underway to begin adult clinics in Darlington or Durham but again these have been suspended until later in the year.

Specialist nurses provide a crucial role in being the link for patients and families, in explaining diagnosis and management plans, and providing support to patients and families on the wider aspects of their condition, emotional, lifestyle and social. A business case is currently being considered by NUTH Executive Team in order for us to continue to support and expand the outreach clinics.

The benefit of the outreach team means care can be delivered closer to home preventing patients and their families travelling long distances for clinic appointments.

Communication

Adult congenital heart services with the paediatric and fetal cardiac services will work together within the network to ensure that robust and co-ordinated communication, planning and cooperation continues to exist across the region. This applies to communication between healthcare professionals and between healthcare professionals and patients and families.

Ensuring effective communication between patients, families and service providers continues is a central objective for the network. Information needs to be sensitive to the physical, psychological and emotional needs of the patient and their family.

The network will ensure there continue to be written protocols which are freely available and communicated between units across the region and any new protocols will be signed off by the network board. There will be written protocols covering communication between clinicians, clinicians and parents / carers and between clinicians and children / young people. The protocols will be developed and agreed with local referring paediatricians, paediatric cardiologists, children's cardiac specialist nurses, clinical psychologists and patient groups.

Website and Social Media

Following the launch event, the network team outlined plans for developing a network website and social media channels, including Facebook and Twitter. The COVID 19 pandemic accelerated these plans as one of the ways used to ensure relevant and consistent advice was available to patients and families across the region.

The network website has been set up using the NHS networks platform <https://www.networks.nhs.uk/nhs-networks/north-east-north-cumbria-congenital-heart-disease> and contains relevant documents pertaining to the network and the network team. As the network develops all documentation relating to meetings, education, policies and protocols will be available on the website.

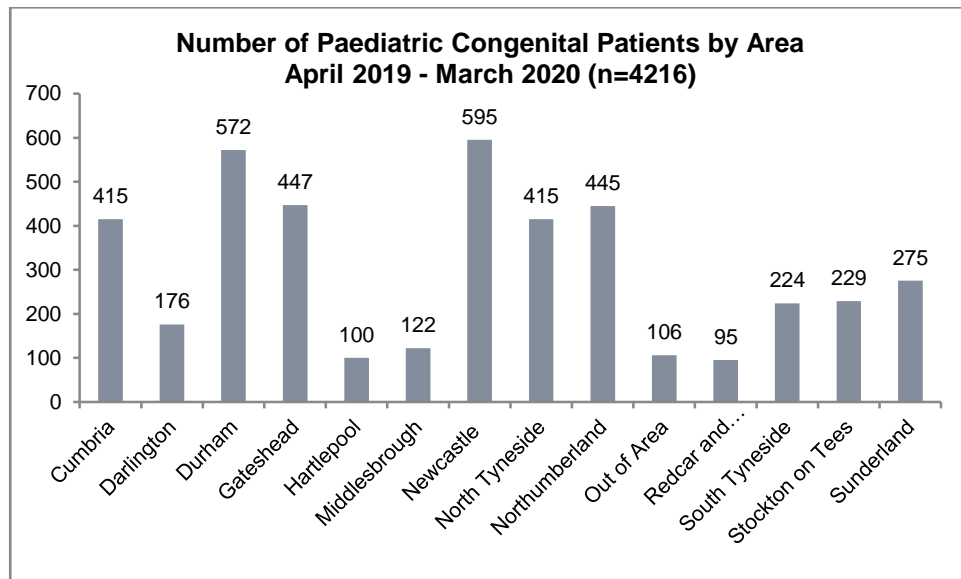
Communication through social media channels (Facebook @NENC.CHDN and Twitter @NENC_CHDN) will remain a priority for the network to ensure patients and families across our region have access to up-to-date information from the Level 1 centre.

Our Network in Numbers

As described above, our network covers a population of 2.9 million people across a wide geographical area. The information below describes the distribution of the patients who have attended the Freeman Hospital between April 2019 and March 2020 as inpatients and outpatients.

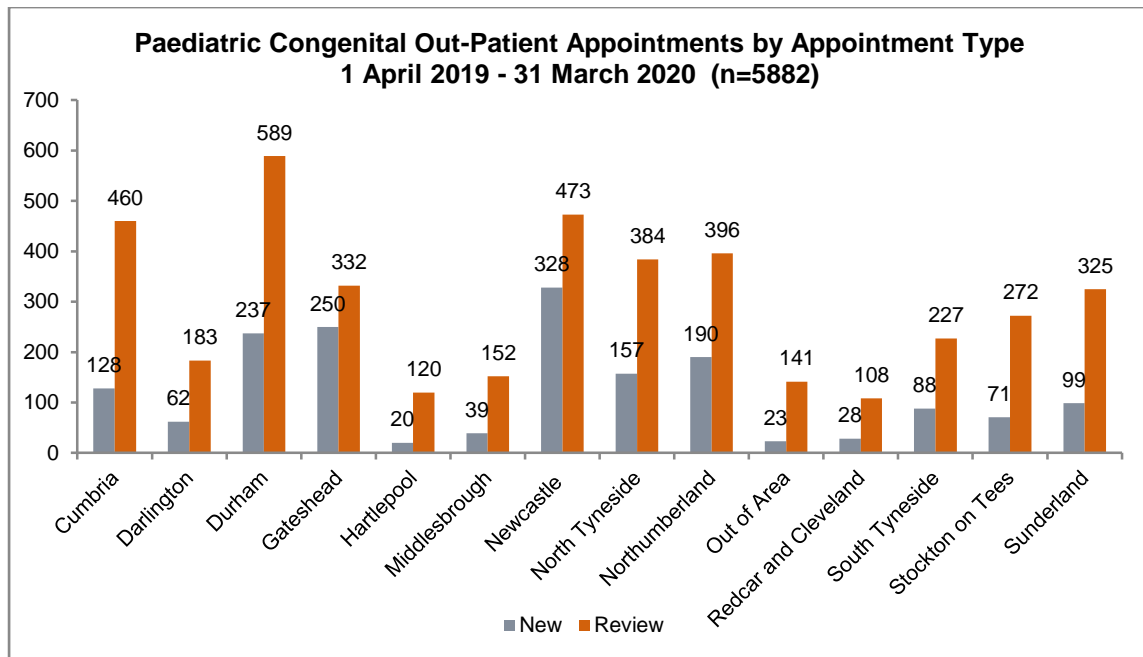
Paediatric Congenital Patients (April 2019 – March 2020)

The graph below shows the number of **paediatric patients** from across the region seen in the outpatient department at the Freeman Hospital. The largest number of paediatric CHD patients live in the Newcastle area and the least number from Redcar & Cleveland.

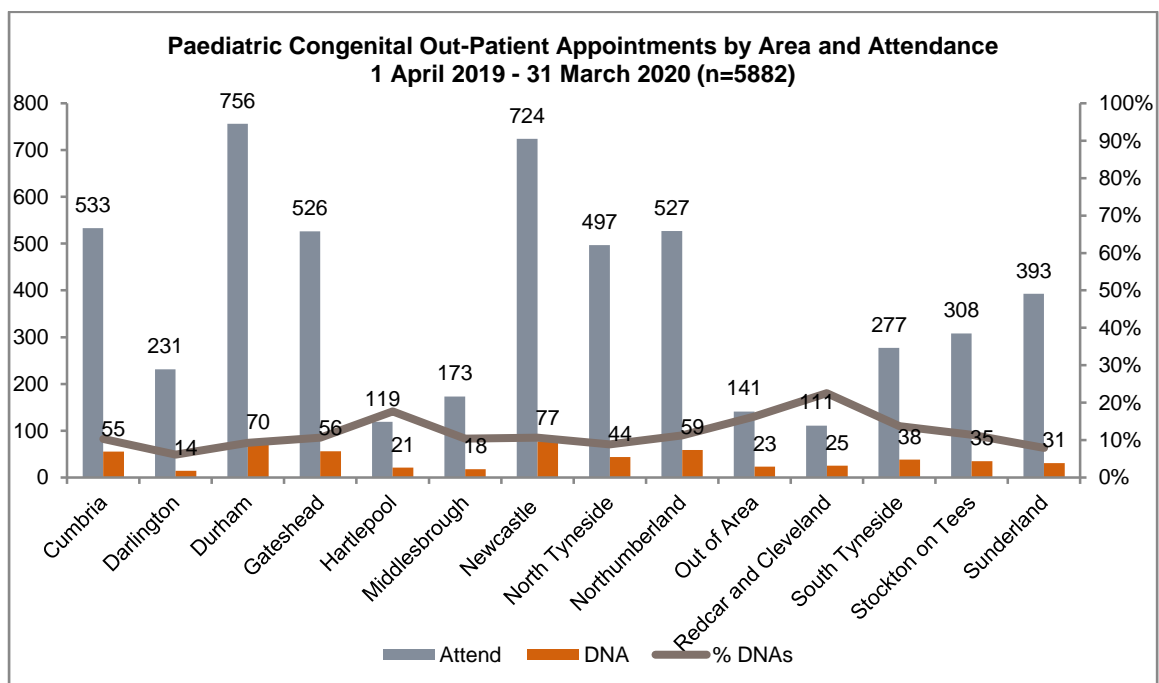


We would also like to represent CHD patients under the care of local teams and will be investigating how to collate this data during our peripheral centre visits to include in future reports.

The graph below shows the number of **appointments** for patients from across the region seen at the Freeman Hospital. Between 1 April 2019 and 31 March 2020 there were 5882 paediatric outpatient appointments, 1720 new and 4162 review².

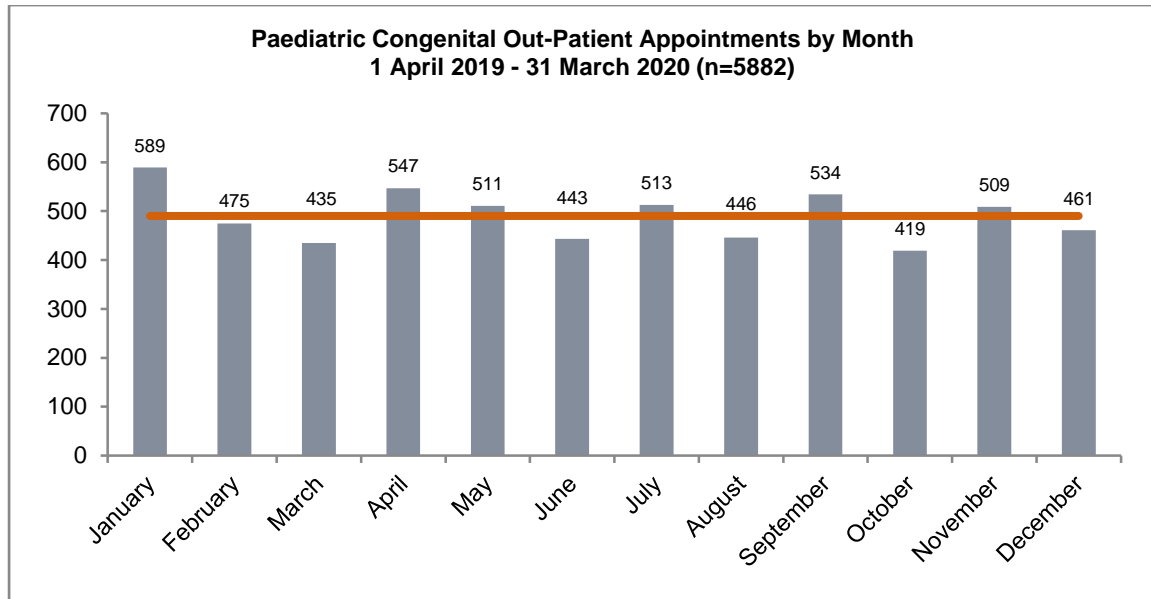


The graph below shows the percentage of paediatric patients who did not attend (DNA) their clinic appointments over the last year which is fairly uniform across the region, the average over the year being 12%. The data indicates the highest rate of DNAs was seen for patients from Redcar and Cleveland (23%) and the lowest were from the Darlington area (6%).



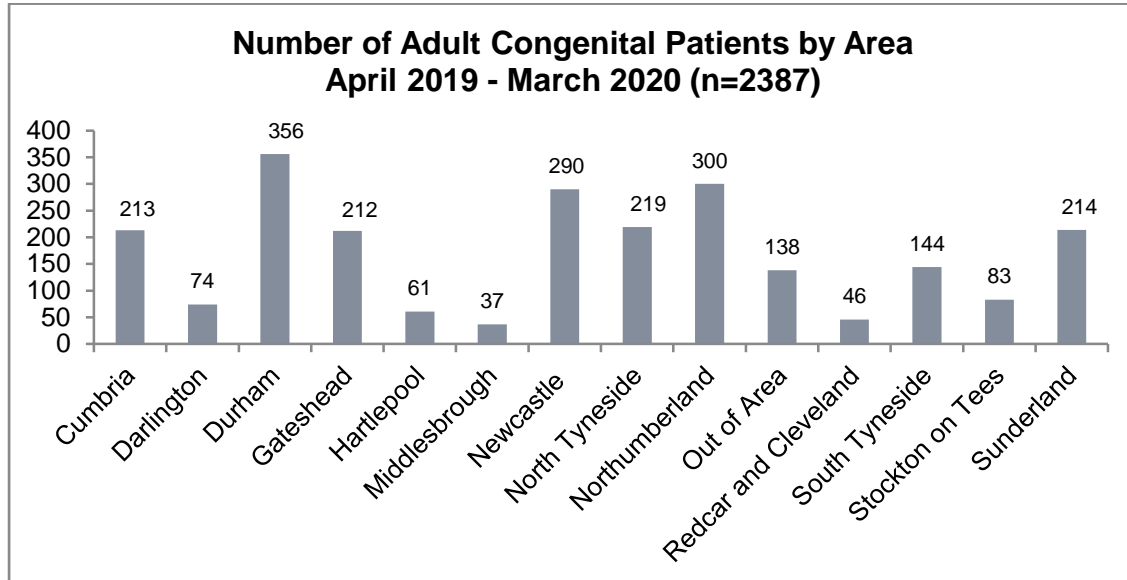
² Information generated by Information Services, NUTH.

On average 490 paediatric patients attended for outpatient appointments each month compared to an average of 480 per month over the last three years, an increase of approximately 2%.

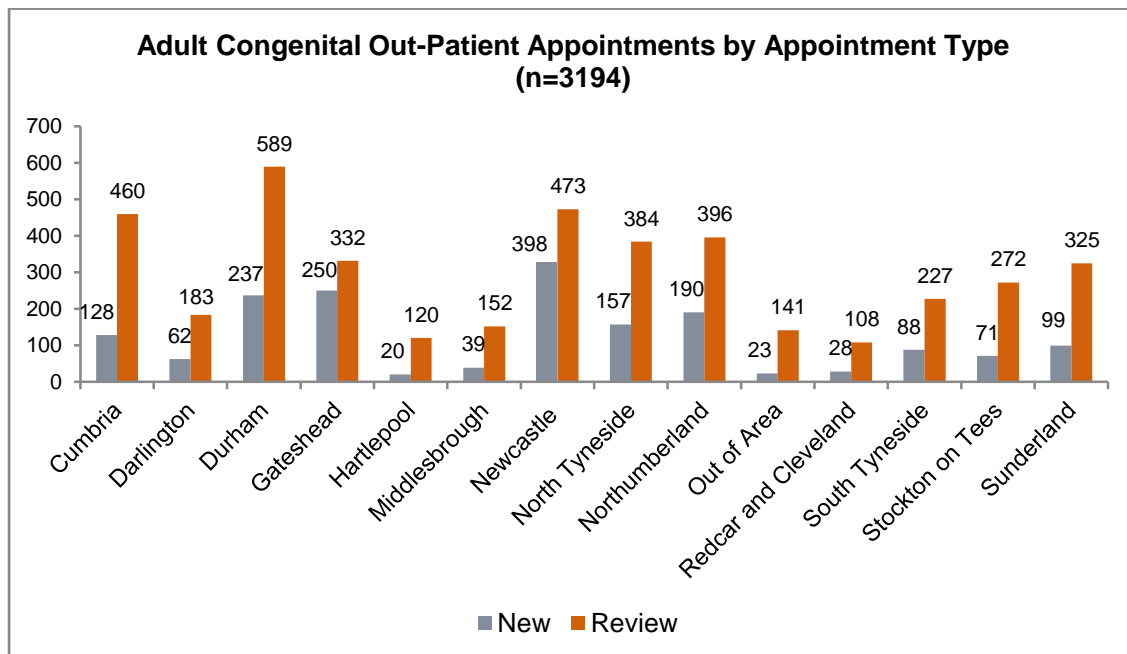


Adult Congenital Patients (April 2019 – March 2020)

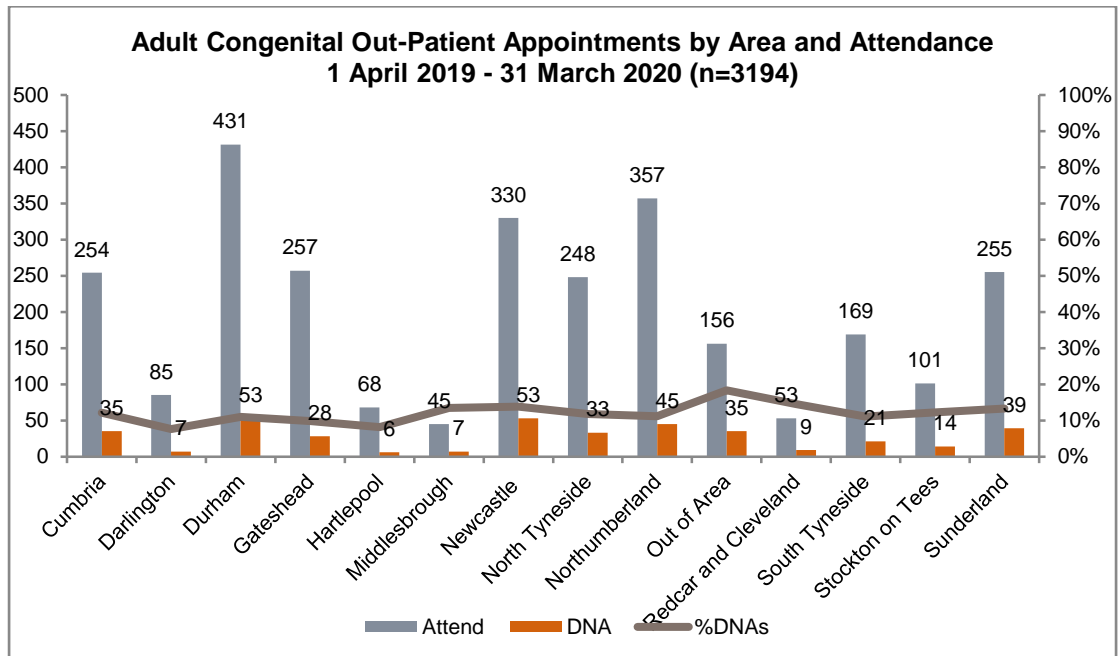
The graph below shows the number of **adult patients** (aged 16 years and over) from across the region seen in the outpatients department at the Freeman Hospital. The largest number of adult CHD patients live in the Durham area and the least number from Middlesbrough.



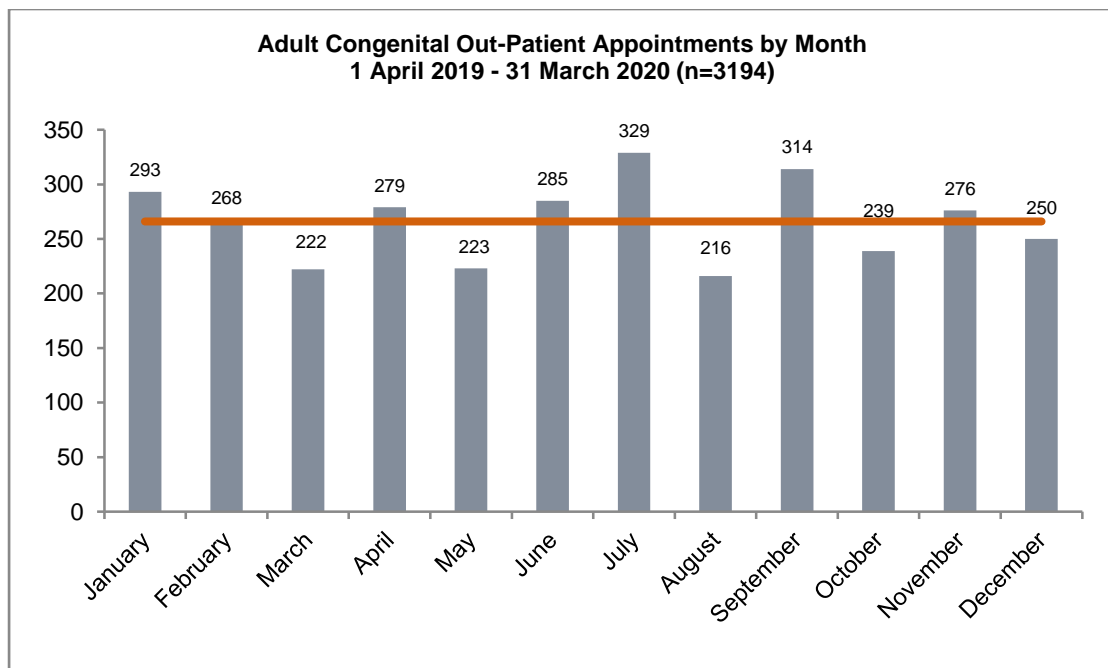
The graph below shows the number of **appointments** for patients from across the region seen at the Freeman Hospital. Between 1 April 2019 and 31 March 2020 there were 3194 adult outpatient appointments, 479 new and 2715 review.



The graph below shows the percentage of adult patients who did not attend (DNA) their clinic appointments over the last year which is fairly uniform across the region, the average over the year being 12%. The highest rate of DNAs was seen for patients from outside the region (18%) and the lowest were from the Darlington (8%) and Hartlepool (8%) areas. The average non-attendance has increased slightly (12%) compared to previous years (10% and 11%).



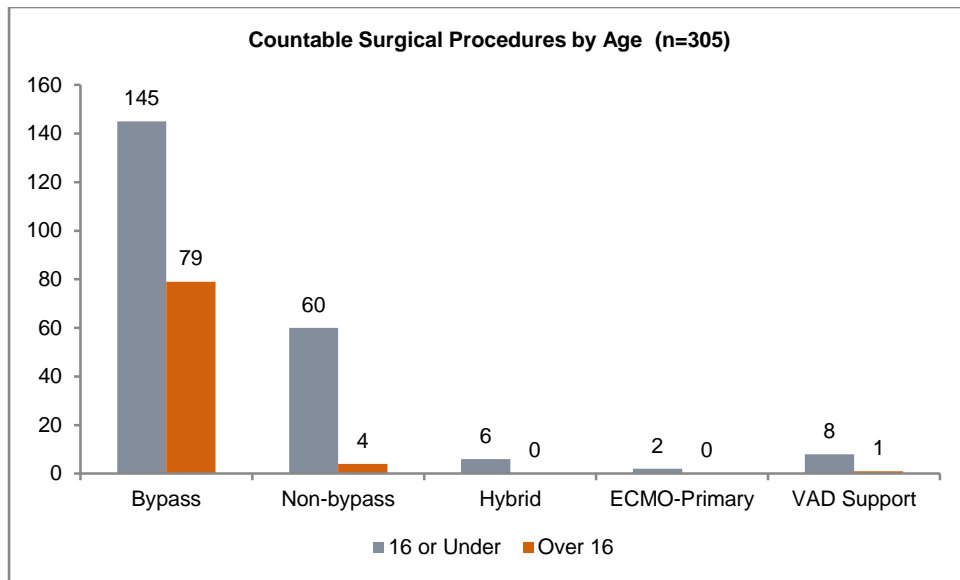
Adult attendance was 3194 between 1 April 2019 and 31 March 2020 (3194 including DNAs), an average of 266 per month compared to an average of 196 appointments each month for the previous 3 years, an increase of 26%. This fits with the predicted increase in the adult patient population.



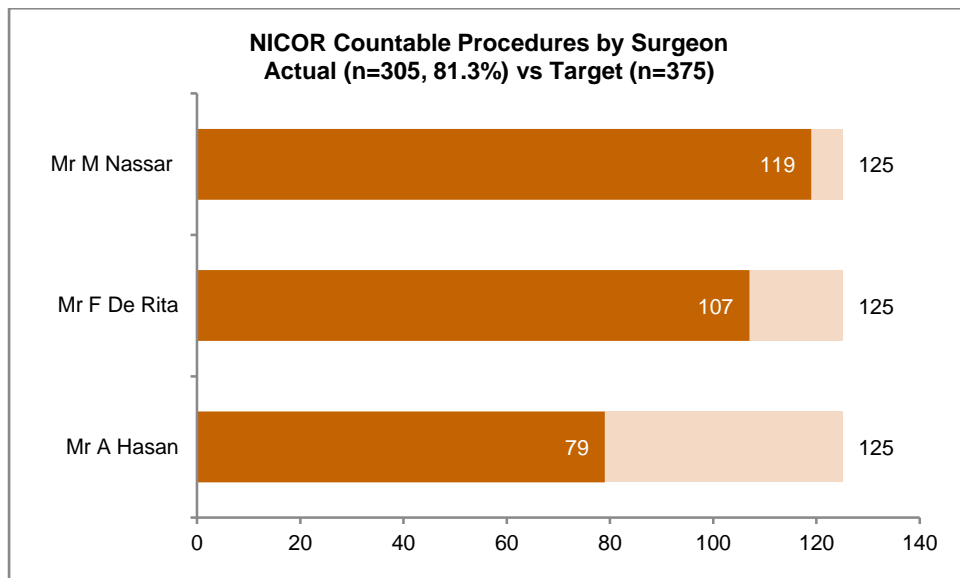
Inpatient Activity (April 2019 – March 2020)

Surgical Activity

The total number of countable surgical procedures carried out in the unit for 2019/20 was 305 which is 81.3% of the target of 375 procedures.



The target for each operator 125 procedures per year, the graph outlines the number of procedures carried out by each surgeon during 2019/20.

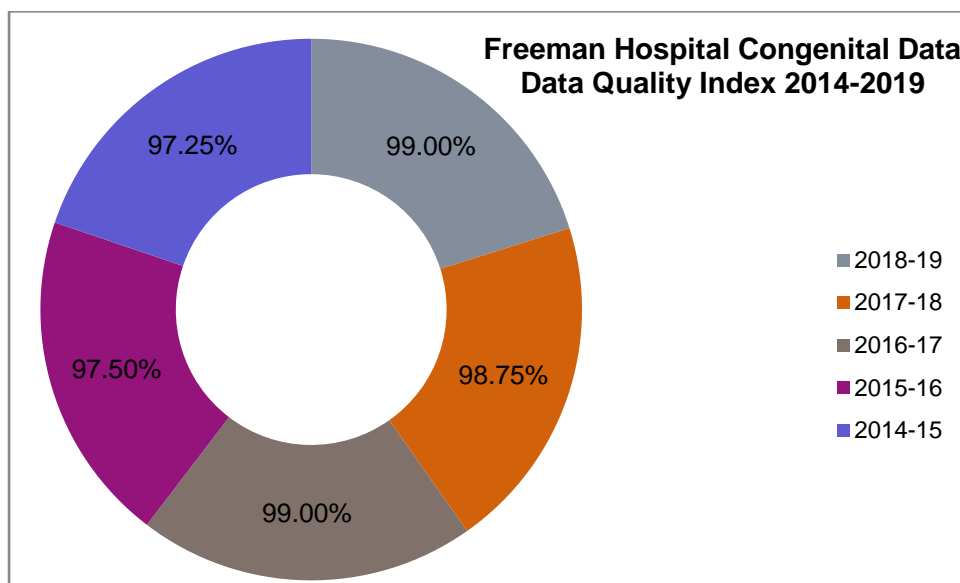


The centre regularly submits data to NICOR (National Institute for Cardiovascular Outcomes Research) on surgical outcomes for CHD patients.

CHD is present in about 0.8% of live births, and with approximately 30,000 births each year in this region, there are approximately 300 new cases of congenital heart defects per year. Our unit has been collecting data since 1986 and our team pride ourselves in our data quality that is amongst the highest in the country.

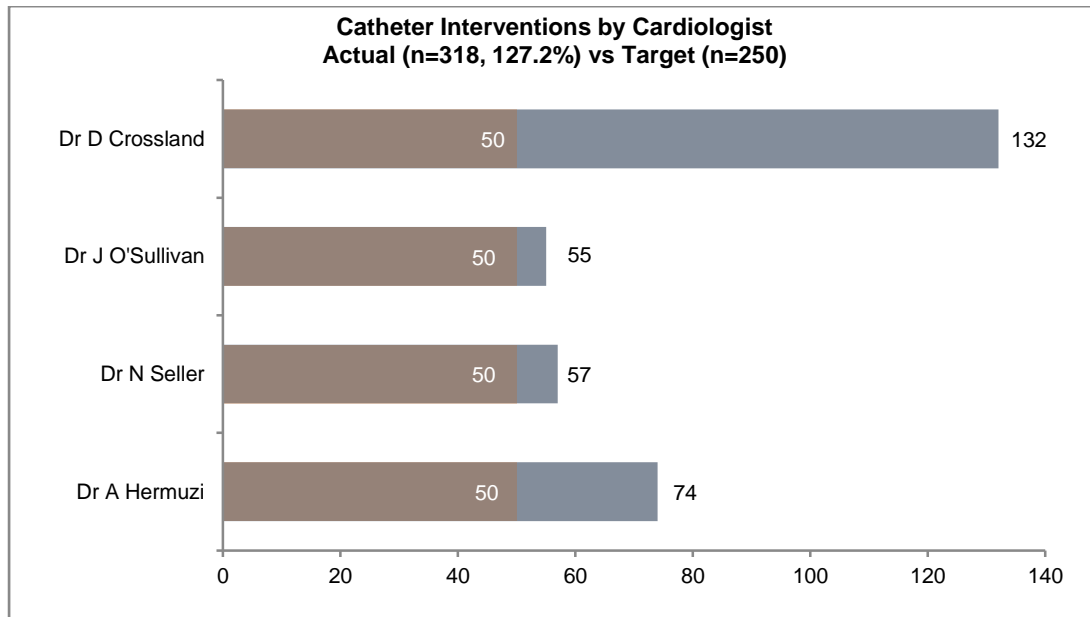
Our overall data quality index score (DQI) has been steadily increasing over the last few years, maintaining above 97%. Our most recent DQI score for 2018/19 is recorded at 99.00%.

In light of the current pandemic, NHSX and NHS Digital have delayed the publication of the 2018/19 report to September 2020.

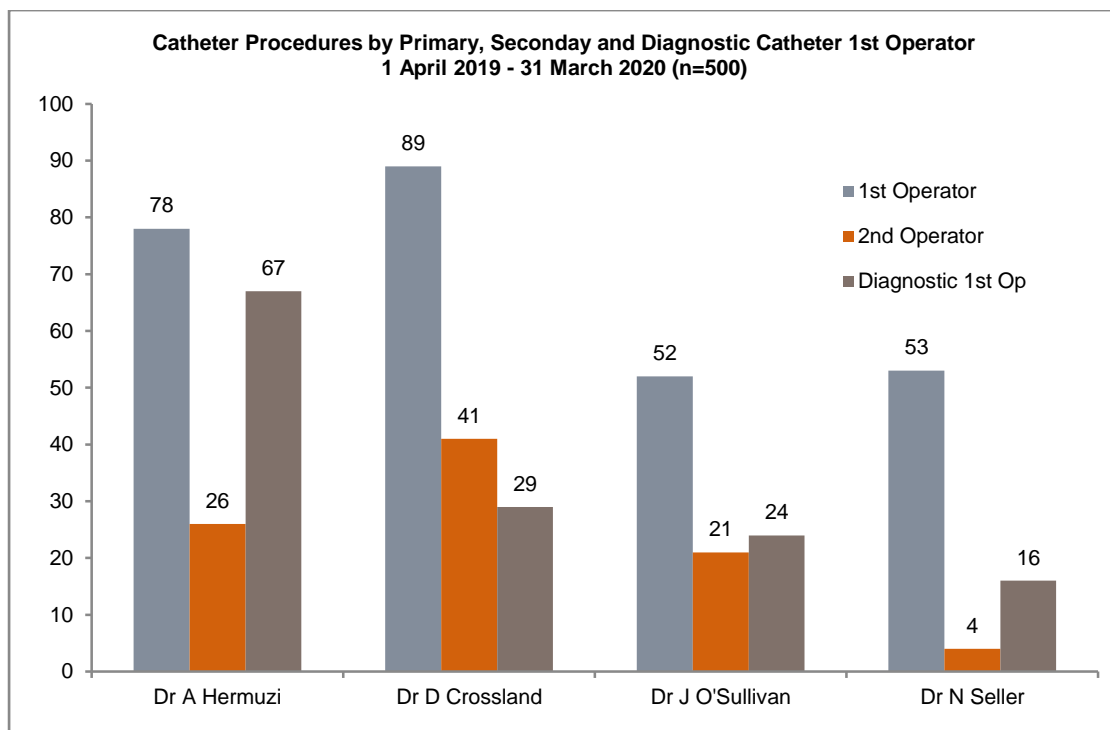


Cath lab procedures

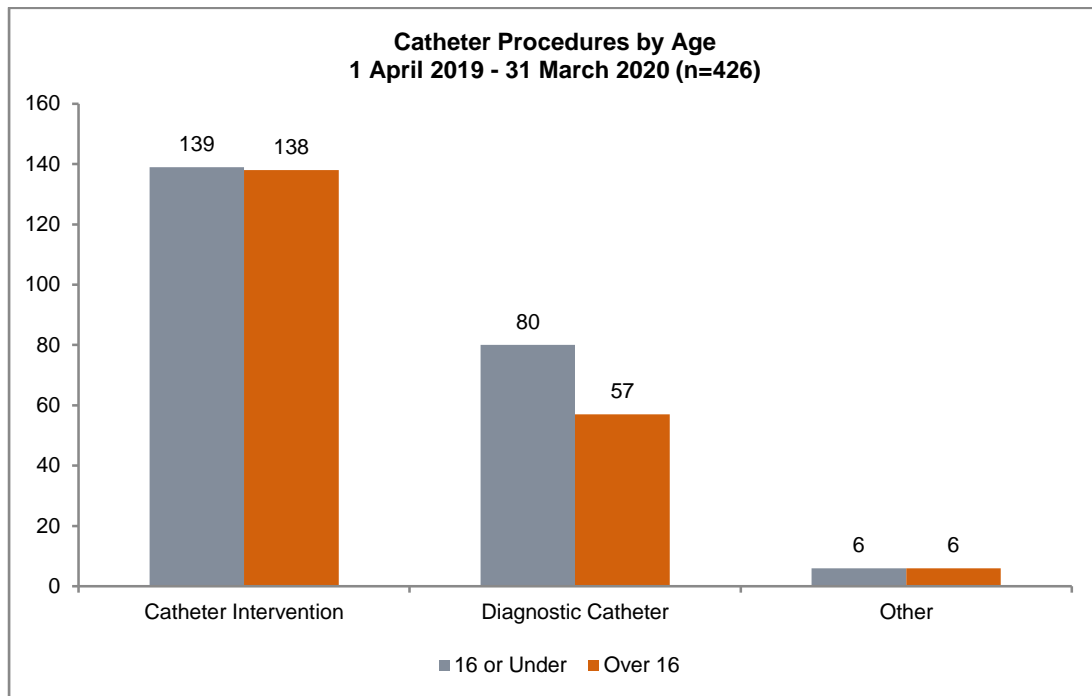
The total number of catheter interventions carried out in the unit for 2019/20 was 318 which is 127.2% of the target of 250 interventions.



The total number of interventions was higher in 2019/2020 (n=500) compared to 2018/2019 (n=319), an increase of 57%. The number of interventions includes 272 carried out as a primary operator and 92 interventions carried out as second operator (DC).

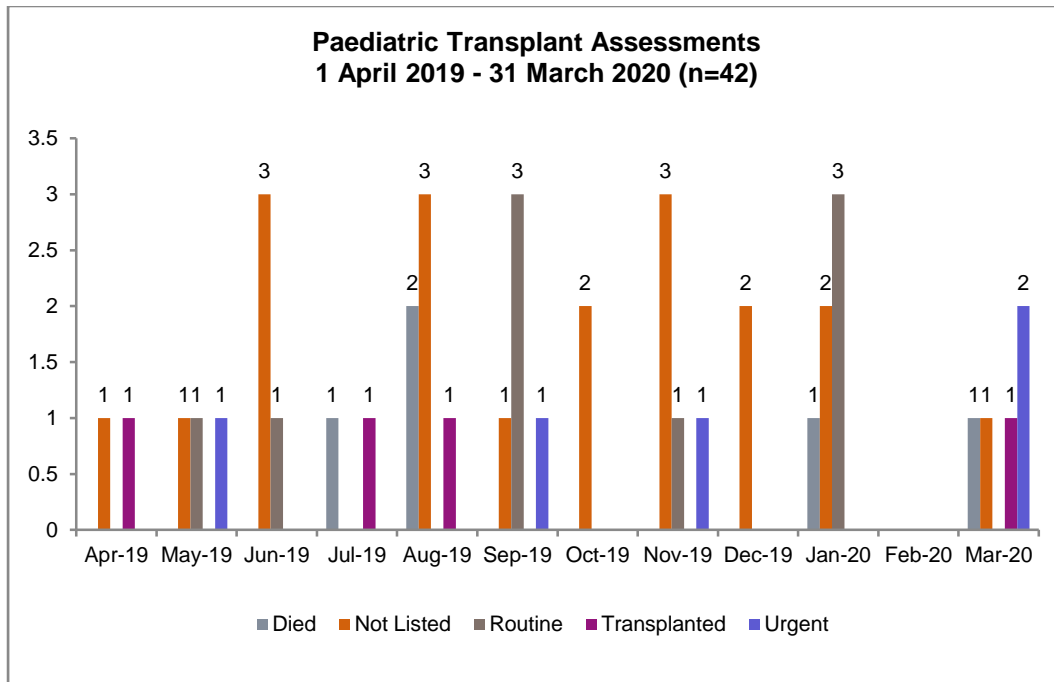
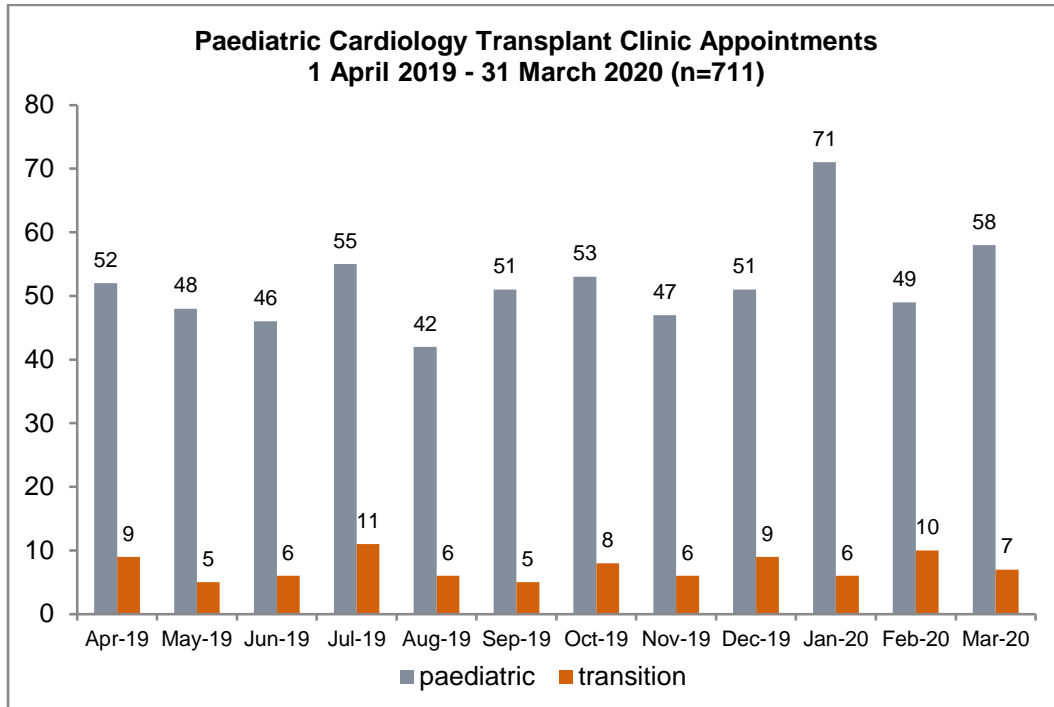


The graph below shows the number of catheter procedures by age group; similar numbers of catheter interventions were carried out in adults and children but more diagnostic catheter procedures carried out in children (80 cf. 57) which are expected.

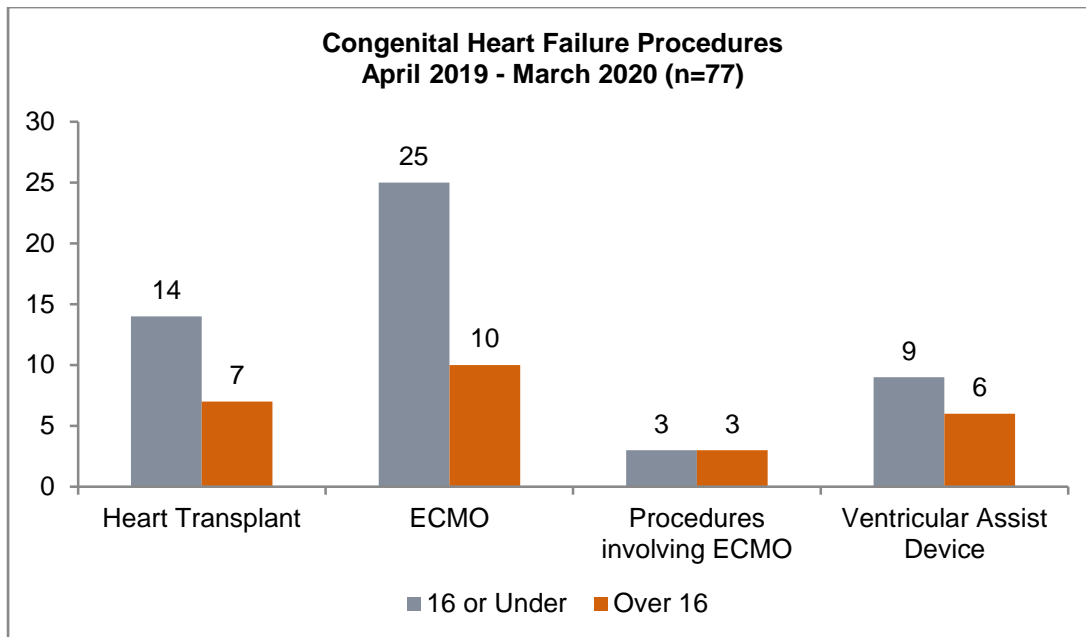


Transplant clinics

The graphs below show the number of transplant clinic appointments and assessments between April 2019 and March 2020. On average there were 52 paediatric transplant clinic appointments each month.



The graph below shows the number of procedures for heart failure patients and transplant patients including the number of VADs, ECMO procedures and procedures involving ECMO.



Multi-disciplinary Team Meetings

The joint cardiology–cardiothoracic multi-disciplinary team meeting is held weekly on a Wednesday afternoon at the Freeman Hospital.

The forum consists of congenital cardiothoracic surgeons, cardiologists, intensivists, anaesthetists, radiologists, speciality registrars and specialist nurses.

The meeting is chaired by Dr O' Sullivan and deputised by a cardiologist colleague in his absence.

All relevant issues pertaining to the care and management of the patients to be discussed are brought to the forum to reach a consensus approach for future medical or surgical management.

This plan takes into account any current clinical concerns and symptoms presentation of recent investigations and information that is known or could influence this individual patient and family.

Governance

This process has been re-organised to a 'per trust' approach in 2018/2019 and Governance lead is now Dr Hermuzi. There is a monthly joint (adult congenital and paediatric) governance meeting where both adult and paediatric activity are discussed. The rolling agenda follows a formatted trust approach.

Service requirements for mortality discussion are met via completion of documentation for child death review process which are then fed back into local and national reporting structures. Unit activity data including PRAIS scoring is reviewed at each meeting. Morbidity events as defined by NICOR are discussed using nationally published data to assess unit performance and review areas for quality improvement. NHSE quality dashboard indicators are used to stimulate discussion of areas for improvement and to identify areas of best practice such that this can be appropriately discussed with local and national commissioners.

Clinical incidents and patient complaints are shared through this meeting in order to share learning. Following the ongoing development of our regional network and videoconferencing solutions, local and network partners are now invited to take part in the learning from this meeting in order to cascade this as widely as possible. Quality improvement and audit activity within the department are reviewed for dissemination.

The annual unit NICOR report is discussed in the context of national performance at the trust Clinical Effectiveness Audit and Guidelines Committee on an annual basis.

Dr Jansen and Dr Coats organise the monthly morbidity and mortality meeting for the adult congenital service.

Clinical Effectiveness

The table below outlines the audits, quality improvement projects and service development projects undertaken in 2019/20.

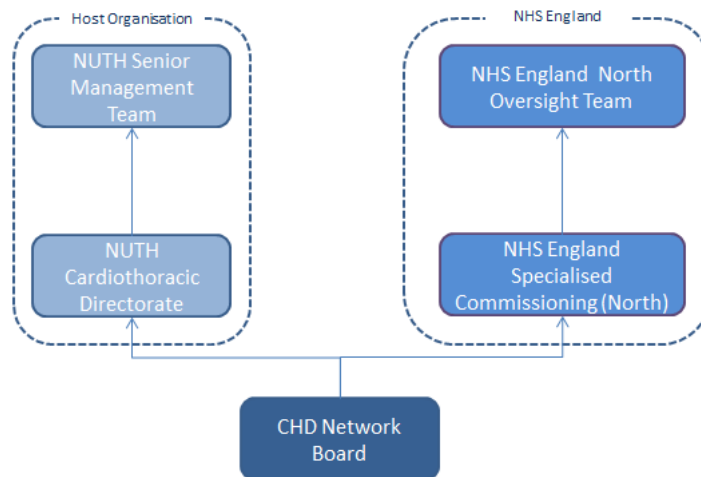
Project Title	Type	Status	Project Priority	Completion Date	Supervisor
Completion of growth charts in Paediatric patients admitted to the Paediatric Cardiology Ward at the Freeman Hospital	Audit	Final Report Produced	None	01-Jun-19	Dr. Neil Seller
Follow up of patients with Tetralogy of Fallot or related conditions	Audit	Final Report Produced	Other	01-Aug-19	Mr Homesh Ramkhelawon
A needs assessment of psychosocial difficulties in children and young people with congenital heart disease	Improvement	Final Report Produced	None	14-Aug-19	Sue Brown
Fast Tracking After Paediatric Cardiac Surgery	Review	Final Report Produced	None	31-Aug-19	Dr. Raja Aboueillela
Outcome of ECLS in ACHD population	Audit	Final Report Produced	Other	31-Aug-19	Dr. Louise Coats
Assessment of right ventricular function previous to VAD implantation in children	Review	Final Report Produced	None	01-Oct-19	Dr. J J O'Sullivan
Evaluating the effect of aortic root replacement with the Ross procedure on subsequent aortic root dilatation and regurgitation	Review	Project Registered	None	31-Dec-19	Dr. Katrijn Jansen
Contraception for women with congenital heart disease	Audit	Final Report Produced	None	14-Feb-20	Dr. Louise Coats
Audit assessing the management of patients with Transposition of the Great Arteries (TGA) post atrial switch operation against AHA/ACC 2018 Guidelines	Audit	Final Report Produced	None	14-Feb-20	Dr. Louise Coats

Network Governance arrangements

The network is governed by the North East and North Cumbria CHD Network Board, which has representatives from across the Level 1 centre and peripheral units, including clinicians, nurses, managers, patients and parent representative and commissioners.

The diagram below shows network accountability. The network team report progress and issues through the Cardiothoracic Directorate to the NUTH Executive Team, and via NHSE Specialised Commissioning to the NHSE North Oversight Team.

Network Governance Arrangements



Innovations/Developments for 2019/20

- Percutaneous pulmonary valve implantation programme: Operator signed off for independent implant procedures and programme now fully established as an alternative to surgery for many patients requiring pulmonary valve replacement.
- Device closure of Patent Ductus Arteriosus in premature neonates - awaiting formal trust approval
- Transcatheter correction of sinus venosus atrial septal defects with partial anomalous pulmonary venous drainage - in development
- Nationally commissioned for left percutaneous left atrial appendage occlusion following commissioning through evaluation
- Nationally commissioned for percutaneous patent foramen ovale closure following commissioning through evaluation.

Research

The recent restructure of the Faculty of Medical Sciences at Newcastle University has led to the creation of three core Institutes:

- Biosciences
- Translational and Clinical Research
- Population Health Sciences

Within these institutes there are several cross-cutting themes (Appendix 1). Those involved in congenital cardiac research in Newcastle have newly organised into the congenital heart disease (CHD) research group with members in all Institutes, but coming together under the theme of Reproduction, Development and Child Health. This group leads CHD research across the North East and North Cumbria-CHD Network. Clinicians hold honorary contracts appropriate to their level of involvement.

Dr Louise Coats (Clinical Intermediate Fellow; Honorary Consultant ACHD) is the Clinical and Administrative lead for the CHD research Group. The group now has a dedicated web presence (<https://blogs.ncl.ac.uk/congenitalhearts/>) to link between themes, to wider cardiovascular research page, NHS and Network sites. The group recently contributed to Newcastle's successful bid to form an Academic Health Science Partnership between Newcastle University and Newcastle upon Tyne NHS Foundation Trust.

Research meetings

This year we successfully hosted the British Congenital Cardiac Association Meeting with excellent feedback and a strong international faculty. The theme from development to destination focused on aortic disease and the Fontan circulation (<https://bccca2019.co.uk>). Due to the Faculty restructure and Covid-19 situation the format of local meetings is undergoing change. We are presently developing a seminar series with an online format (possibly moving to hybrid in the future).

The *Cardiac Morphology Meeting*, held 3-4 times each year, is a multidisciplinary clinical meeting integrating basic science concepts and advances in anatomy and development with clinical imaging and intervention.

A *Cardiac Development and Congenital Heart Disease Meeting* is held each Friday in term time at the Institute of Genetic Medicine and is a formal presentation of research, both clinical and laboratory based.

Business Research Meetings are presently held monthly, now online, but rotating between hospital and University in the future.

It is likely some further meetings will occur in conjunction with the Vascular Biology Medicine Theme under the wider heading of cardiovascular research.

The objective is to develop a comprehensive online/hybrid seminar series spanning clinical/academic research in CHD including external speakers for 2020/2021.

Research support

Clinical Research Network North East and North Cumbria

(<https://www.nihr.ac.uk/nihr-in-your-area/north-east-and-north-cumbria/>).

Clinical research is hosted by Newcastle Upon Tyne Hospitals NHS Foundation Trust, and provides the infrastructure that allows high-quality health research to take place in our region, so that patients and the public can be involved in and benefit from better health and healthcare.

Support includes;

- Study delivery teams to provide research support
- Education: Free GCP training for staff
- MedConNecT North – links with Industry/Tech etc

Over the course of the last year, we have developed strong links with the CRN cardiac research nurses who have supported one of our specialist nurses in the delivery of the Approach II study (PI Dr Louise Coats) and the Revival study (PI Mr Mohammed Nassar).

The objective over the coming years will be to develop more formal links between the newly formed congenital heart disease operational delivery network and the CRN.

Stake holders

Patient and carer involvement in research is a requirement for the Trust, University and Ethics committees and is good research practise. There are established Patient Carer Public Involvement (PCPI) Groups for young people and for adults with acquired heart disease. As we develop our own structures we will integrate these with existing Trust structures.

	Description	Contact	Frequency of Meetings
Young Persons Advisory North East group	http://www.ypagne.org	anne.mcdonnell@nuth.nhs.uk	Newly developed, remit developing
Parents Advisory group	No formal PAG in North East Informal groups only in cardiac		
NECTAR	http://www.nectar.healthcare/ Cardiovascular PCPI group	nectar@nuth.nhs.uk	Biannually
ACHD PPI Group		Sister Debbie McParlin	Ad Hoc

Achievements of the objectives set last year (below) are ongoing. The network will help support this as stakeholder involvement is a key aspect and it is likely that patient groups formalised around this network will link to PCPI groups.

The objectives are to;

- Formally integrate ACHD PCPI with the Nectar group where appropriate and with the developing NENC-CHD Network Group.
- Develop link to the newly formed YPAG North East group and work towards develop a cardiac branch in conjunction with the developing NENC-CHD Network Group

Nursing and Ancillary staff

It is expected that all nursing staff will facilitate research in general and have a positive attitude to data collection and studies being conducted. Presently 50% of specialist nurses working within congenital heart disease are GCP trained. The lead Fontan Nurse within NUTH has a specific role in supporting research in relationship to the Fontan population. The cardiac research nurses are available for support for studies that are on the CLRN research portfolio.

The objectives are to;

- Ensure all specialist nursing staff are GCP trained
- Ensure Ward and Clinic Nursing staff (Band 7 and above) are GCP trained
- Have a nurse champion/link for research in each area (adults, paed, ward, clinic, ICU)

Junior Medical Staff

Junior doctors are actively encouraged to participate in supporting research studies that are already happening and to be active in their own studies particularly in undertaking sensible pieces of short research that lead to publication. Junior doctors must be GCP trained if they are to consent patients for studies and do so under the supervision of the PI.

Consultant Staff

Those consultants who wish to be research active are encouraged to apply for formal University status and participate in and run studies and encourage others to participate accordingly. Over the course of the last year a further six clinical staff have applied for University status and joined the group.

Dissemination and Communication of Research

Research outcomes will be publicised via the CHD research group website and are supported by the NUTH Communications Department (communications@nuth.nhs.uk) and Newcastle University Press Office (<https://www.ncl.ac.uk/press/about/>).

Publications 2019/2020

A full list of publications can be found in Appendix 2.

Research Themes and Current Projects

The current research currently falls into a number of themes which are listed below, a list of current projects can be found in Appendix 3.

Active Funding

- British Heart Foundation Programme grant, 2019-2024, £1.2 million, “Development and disease of the arterial valves” Professor Deborah Henderson and Dr Bill Chaudhry
- British Heart Foundation, 2017-2020, £287,567 Investigating the role of autophagy in cardiomyocytes during heart development. Dr Helen Phillips
- MRC-Wellcome Trust– Human Developmental Biology Resource (HDBR): an embryonic and fetal tissue bank for functional genetics and cell-based research. 2018-2023, £2.936M, Professor Deborah Henderson
- MRC - Human Cell Atlas: HDBR support for call. 2018-2020, £371,528 to Newcastle. Professor Deborah Henderson (Co-I)
- Wellcome Trust – Human Wellcome Biology Initiative: HDBR support for call. 2019-2024, £432,533 to Newcastle. Professor Deborah Henderson (Co-I)
- Newcastle upon Tyne Hospitals NHS Charity, 2019 – 2020, £33,500. Length of stay (LOS) and predictors of LOS following paediatric congenital heart disease. Professor Judith Rankin, Dr Kate Best, Dr John O’Sullivan

- British Heart Foundation Project Grant (PG/20/15/35041), 2020-2023, £276,628, “Pharyngeal arch cell signalling in arch artery morphogenesis” Dr Simon Bamforth
- The Barbour Foundation PhD Studentship, £74,000, “Investigating a novel genetic cause of cardiomyopathy”, October 2020 – September 2023, Dr Helen Phillips and Dr Simon Bamforth
- Medical Research Council, 2018 - 2020, £458,114 “A cell atlas of the human outflow tract of the heart”, Dr Simon Bamforth Co-I; Prof Nicoletta Bobola (PI), University of Manchester
- The Borwick Trust PhD Studentship, 2017 – 2021; £106,000 “Identification of candidate genes for congenital heart defects”, Dr Helen Phillips and Dr Simon Bamforth
- European Institute of Innovation and Technology (EIT), 2017 – 18, £42,000, The Berlin Heart Study: mobile autonomy in children with end-stage heart failure. A qualitative study. Professor Judith Rankin, Dr Emma Simpson, Dr Zdenka Reinhardt
- NIHR 2019-2022 £741,230.00 Congenital Heart Audit: Measuring Progress In Outcomes Nationally (CHAMPION) 2019-2022, Dr Louise Coats (Co-I); Dr Sonya Crowe (PI) UCL,
- Children’s Heart Unit Fund 2018, £52,403, Fontan Research Nurse Post, Dr Louise Coats, annually renewable subject to review
- NIHR/UKRI Understanding early life determinants and pathway to life course multimorbidity. 2020
- Kolehmainen N, et al (Louise Coats, Judith Rankin, Simon Bamforth, Helen Philips, Mike Taggart co-applicants).
- Research Capability Funding 2020, Understanding what matters to adults with congenital heart disease

It should also be noted that CHUF (<https://www.chuf.org.uk>) have kindly supported some open access costs this year.

Markers of Esteem

- Dr Bill Chaudhry Elected member of Nucleus in Working Group for Development Anatomy, and Pathology ESC.
- Professor Deborah Henderson Former Chairperson of Nucleus in Working Group for Development Anatomy, and Pathology ESC.
- Dr Louise Coats: National nominated reviewer for ESC ACHD Guidelines 2020
- Dr David Crossland ISHLT Council Paediatric Heart Failure and Transplant and Mechanical Assist, co-opted member of HAWG (heart allocation working group) for ACHD listing criteria for CTAG, Secretary BCCA
- Professor Judith Rankin, Invited Member of the National Congenital Anomaly and Rare Diseases Medical and Scientific Advisory Group, Elected Member of the EUROCAT Scientific Management Committee, Fellowship through distinction, Faculty of Public Health, Invited chair, NIHR fellowships panel
- Dr Zdenka Reinhardt, CTAG Clinical Audit paediatric cardiothoracic transplant- national representative, ISHLT Council Paediatric Heart Failure and Transplant, AEPC- Treasurer for Heart Failure/Pulmonary Hypertension/Transplantation Working group, NICE committee member for Fever under 5, Council Member BCCA
- Dr Abbas Khushnood, Clinical Domain Lead, NICOR

Under the spotlight

The Patient Story

I was born ten days late at Ashington Hospital on the 14th February 1976 weighing 7lb 7oz, which is also my Dad's birthday after a normal pregnancy. In those days there were no antenatal scans! I had the umbilical cord around my neck and was grey in colour. I was taken to the special care unit as I wouldn't feed and as a precaution.

When the Doctor listened to my heart they knew there was something wrong but not sure what. I continued to be monitored as an outpatient at Ashington Hospital for about six months, in which there was no technology. I was referred to Newcastle General Hospital as Cardiology at The Freeman Hospital wasn't open! I was seen by Dr Hunter (who became my consultant) and Dr Goodwin who as my parents say; nearly hit the roof when they listened to my heart! I had a few Catheterisations and various Echo's at the General Hospital. My diagnosis: Aortic Stenosis and Co-arctation of the Aorta.



In January 1978 I had my first open heart surgery at The Freeman Hospital. I was one of the first kids to have surgery there. I was on adult ITU and then transferred to an adult ward. The other patients enjoyed seeing me recover and toddling around. They would buy me sweets from the volunteer who brought the newspaper bag around the ward. They waited until after my brother was born, he was healthy to plan my second open heart surgery. I had this in September 1978 and was a patient on Ward 23. My parents say the staff were fantastic. They not only looked after me but also my Mam who stayed throughout.



In January 1989 I had an Aortic Balloon Dilatation and stayed overnight on Ward 23 myself, I was now a teenager. My parents said the lovely staff always helped me to be ready each morning and doing my hair.

Over the years I had yearly check-ups in outpatients which were all absolutely fine. The staff were always kind, caring and supportive to me and my family. I lived a "normal" life; being in the Girl Guides, ski-ing with the school, socialising with friends, learning to drive, going to college studying Nursery Nursing, having a part time job in a coffee shop. I was never allowed to do cross country at school but I was pleased with that! It looked awful! At the age of 18 I was transferred over to Adult Congenital Heart care in which Dr O'Sullivan eventually became my consultant. In my early twenty's I had some plastic surgery at the RVI on my sternum scar in which it made a good improvement.



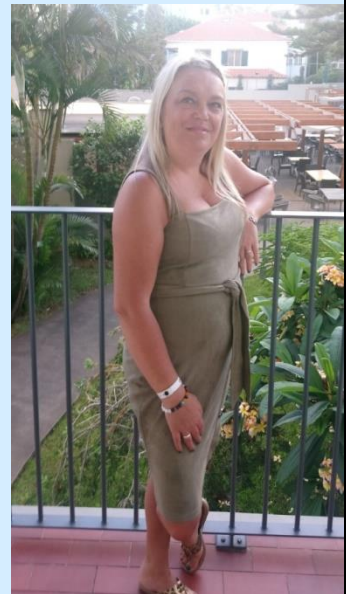
In May 2006 I had my third open heart surgery. I was a bit poorly afterwards and had to stay in hospital for about five weeks. The staff were amazing; flexible with Ivan my partner and family visiting me, caring, helping me to get ready and very kind. Amanda who at the time was my liaison nurse was always there to listen, support and give the best advice. In January 2008 I had my fourth & final open heart surgery. I had lots of complications afterwards & was very poorly. I was in hospital for about ten weeks this time. Again the critical care, ward staff and Amanda (liaison nurse) were fantastic AGAIN. Myself, Ivan or family could not have got through it without

their support & care. Dr Crossland then became my consultant. Both myself and Ivan have the greatest respect & trust for him.

I did absolutely fantastic for the next ten years. Every time I have an outpatient appointment I would take the lovely staff some cakes I had baked for them. The Liaison Nurses are always at the end of the phone remembering who you are; questions are always answered efficiently and are always positive & caring. Debs and Lorna are now the two Liaison Nurses who I have contact with. When my Dad was sixty he had a party but instead of presents he asked for donations for the ACHD fund raising about £1000. When I was forty I had a weekend away with my Mam and friends (there were 47 of us) we raised about £250

In August 2018 I returned from Zante feeling unwell; Ivan and my Mam took me to Cramlington Hospital. Two weeks later I woke up in Critical Care at The Freeman Hospital, I had Bacterial Meningitis, Sepsis and temporary renal failure. I recovered amazingly and was back to work within three months as a Teaching Assistant for children with Autism. There was some damage done to my heart as a result of this. Dr Crossland, Debs and Lorna have fully supported me throughout this, they are always at the end of the phone or an email, at my appointments and as an inpatient. I had a Body Shop Party in the November and raised £225 for the Critical Unit to say thank you.

I was invited to the CHD network launch event in January at The Freeman Hospital. It was very informative and meeting professionals from different aspects of CHD. During a patient group at the event there were lots of different ideas discussed about ACHD. I spoke about how as an adult it is very boring in hospital, no free TV, restricted visiting etc and how this can have a big impact on recovery. I suggested that an activities co-ordinator would be a way forward. This person could provide activities on the ward, give information before coming into hospital, be involved in the transition from paediatric to adult services and support in outpatients. After being in contact with Kaye Walsh, Lead Nurse CHD Network for North east & Cumbria she has spoken to the clown doctors who are funded by the CHUF and are looking at funding an activities co-ordinator for ACHD.



I am going to be, as a patient advocate involved in the progression of this programme. By being part of this network I can speak on behalf of myself and other patients to move forward.

Everything the Freeman Hospital has done for me, Ivan and my family it is a way of saying a HUGE THANK YOU ♥

A day in the life of..... Adult Congenital Nurse Specialist

We work 5 days a week Mon-Fri 8am-6pm. We are known as adult congenital nurse specialists. We are specialists in dealing with adults who have congenital heart disease, from teenagers to adults in their 80's.

Our team is made up of 3 nurses; two band 7's and a band 6. All our team come from intensive care backgrounds both adult and paediatric, all of us have looked after babies and children with congenital heart disease. One of our band 7 nurses is the UK's first Fontan nurse specialist, looking after children and adults with a Fontan circulation ensuring all surveillance of their heart and liver is monitored on a regular basis. This role is funded by the charity Children's Heart Unit Fund (CHUF).

Our medical team comprises of 7 consultants, 5 of whom also look after paediatric patients. We have a lead consultant Dr Katrijn Jansen and another purely adult consultant Dr Louise Coats.

We aim to ensure all our congenital patients receive holistic care whether at home or in hospital. We are jacks of many trades, wearing a lot of caps!

Any questions or queries the patient may have they can discuss with us, either face to face, via telephone, email, or video link.

Our outpatient's clinics run every weekday and surgical clinics run each Wednesday. We have 3 weekly MDT meetings to discuss FALD (Fontan associated liver disease patients), JCC (to discuss prospective surgical patients) and an adult EP (electrophysiology) to discuss any rhythm issues. Once a month we offer an outreach service at James Cook Hospital, our outreach clinics are due to expand in the future.

Our job does not just include advice for surgical or interventional procedures. We can help and advice with medication queries, family issues, diet, exercise, alcohol, drugs, smoking, pregnancy, contraception, or finances. We are also available to offer support to patient's families.



Paediatrician with Expertise in Cardiology (PEC)

As the network establishes its collaboration with the regional centres, training and supporting local clinicians is vital to the development of the cardiology services. Paediatricians with expertise in Cardiology (PECs) would improve standards of care for cardiac children and their families within a well-managed clinical network.

Dr Abbas Khushnood is keen on providing training and education to clinicians with an interest in congenital heart disease. The objective would be to develop a comprehensive clinical training model allowing senior clinicians gain adequate exposure and echocardiography skills in treating children with cardiac disease. Senior paediatric trainees have increasingly shown interest in the sub-specialty and they can enrol into the SPIN module offered by HEE NE (Details are available on <https://madeinheene.hee.nhs.uk/paediatric-cardiology/SPIN>).

Establishing a strong PEC network is pivotal to managing increasing cardiac work load and larger expansion in outreach clinics in the future.

Priorities for the coming year

The primary focus for the first 12 months of the newly formalised network is to increase visibility of the network and enhance engagement across the region. The formalisation of the network has provided the foundation for our way forward and cemented our objectives for the coming year.

Central to any network is a clear vision and strategy for the way forward, and transparency in governance processes by which the network operates. Our network Strategy & Governance Framework is currently under review and is due to be published later this summer.

Outline Work Plan for 2020/21

- 1. Outreach clinics**
 - a. Widen the reach of care close to home
 - b. Outline outreach clinic roadmap/project plan
- 2. Peripheral centre assessments**
 - a. Assessment against the national standards
 - b. Staff skills assessment
 - c. Assess local needs and priorities
 - d. Increase engagement with peripheral centres, identify their needs from the network team and wider network
 - e. Formalise information needed on service and supplied to network annually
- 3. Governance**
 - a. Enhance communication across the network
 - b. Develop a Communication Policy
 - c. Develop a Network Strategy & Governance Framework.
 - d. Redesign MDT to ensure wider attendance and identify audit lead
 - e. Form a working group for protocols and pathways
- 4. Patient Engagement**
 - a. Establish network patient engagement group
- 5. Education**
 - a. Establish network training and education programme
 - b. Define the PEC role and development of training within the region

Progress so far

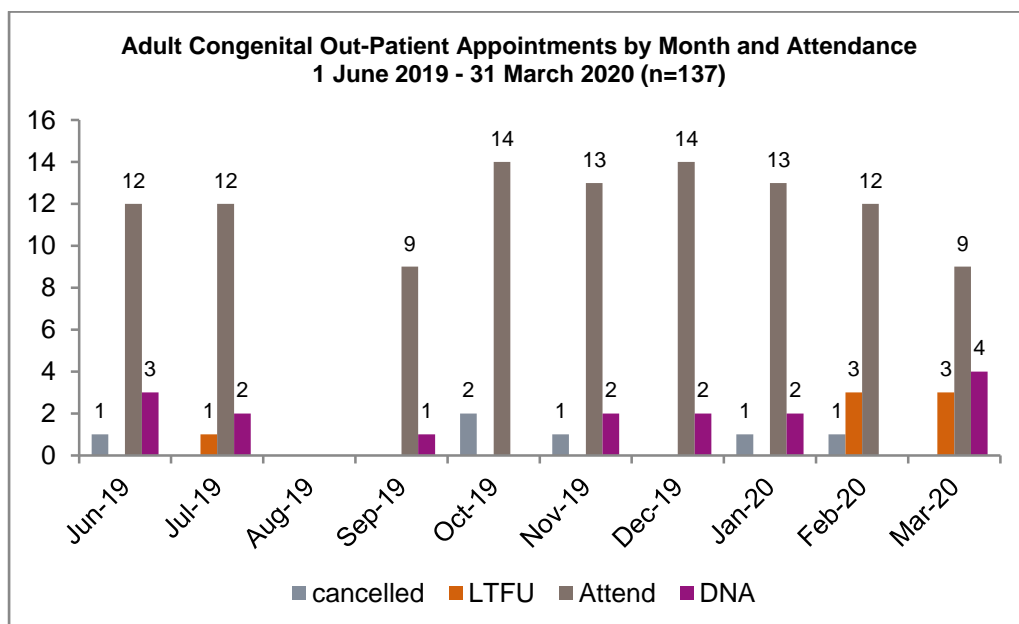
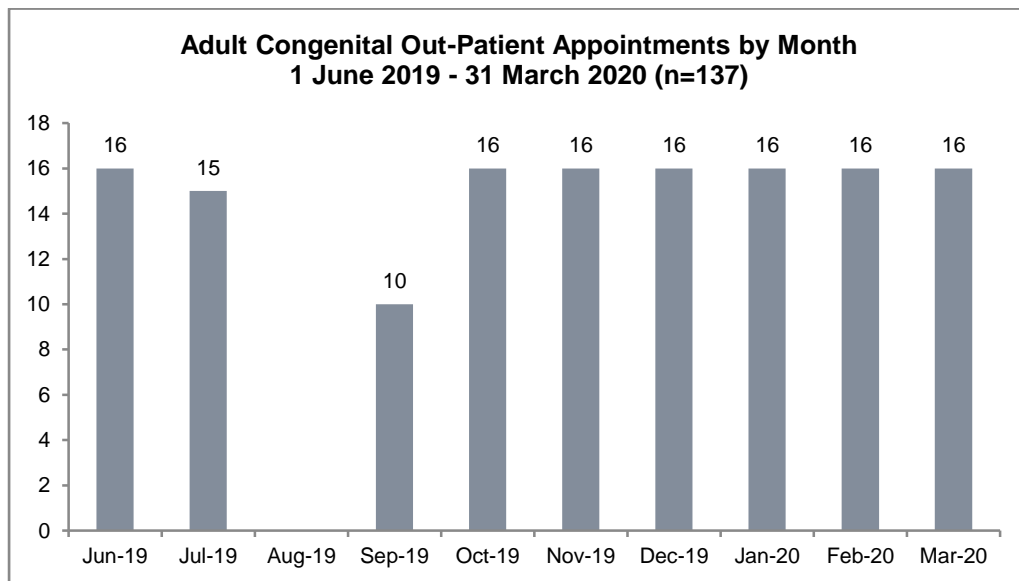
Action	Progress/status
Formalise the NENC CHD Network	Complete
Develop a Network Strategy & Governance Framework	In progress
Patient Reference Group	In progress We have engaged with a number of patients and we have a new patient representative on the network board
Develop a Communication Policy	In progress We have created a network website, Facebook and Twitter accounts.
Develop a Network Education Programme	In progress This has started and we have contacted healthcare professionals from across the region asking for feedback on how they see education being delivered. See further details below.
Outreach clinics	In progress Clinics established in Middlesbrough, Stockton and Durham and are in progress in Carlisle. See further details below.
Self-assessment of peripheral centres	Delayed Due to the covid-19 pandemic we have been unable to visit units across the region. We have designed a proforma which we will use during our visits.

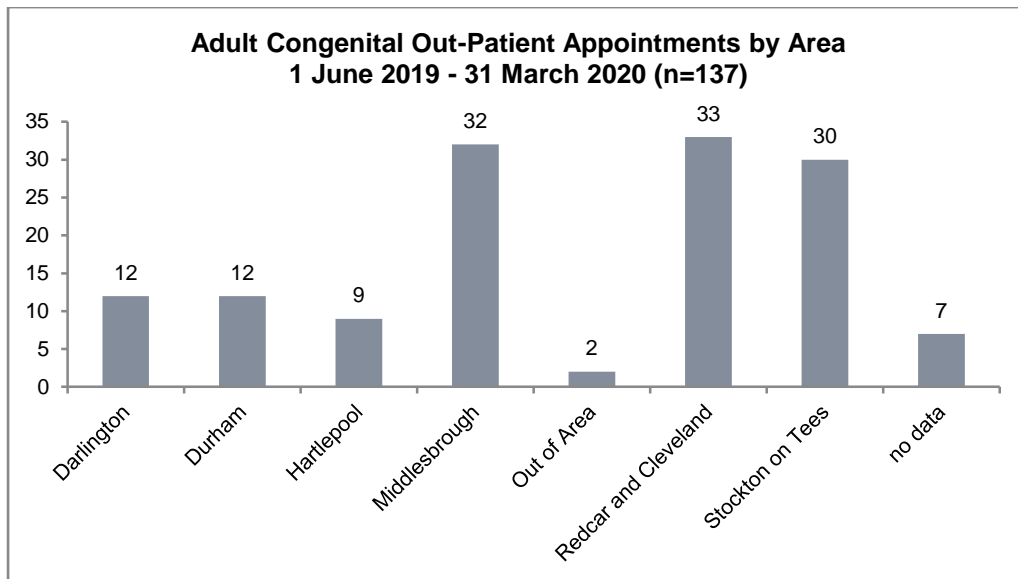
Outreach clinics

As discussed above, we have made some progress in expanding the outreach service across the region and aim to develop this further. The outreach clinics, together with the clinics held at the Level 1 centre, will be designed to incorporate digital technology to provide more virtual clinics which have been well-received by a number of patients, particularly adults with CHD during COVID 19.

Paediatric appointments are more challenging and work on virtual clinics for this patient cohort is underway. We will also work to develop the role of PECs within the peripheral centres allowing children and families to attend appointments closer to home and also enhance the learning and improve the skills of the local teams.

The graphs below show the adult congenital appointments arranged at James Cook University Hospital outreach clinic, by month and by area. The graphs also show the number of DNAs (average 11%), patients lost to follow up (average 5%) and cancelled (average 4%) appointments.





Peripheral centre assessments

Peripheral centre assessments against the national standards

Assessments of the peripheral centres within each network form a central element of the national review of congenital heart disease networks across the country.

During the first few months of the formalised network we have been creating templates in order to complete these assessments. As most trusts are now planning restoration of services we will be visiting each centre to discuss the requirements against the national standards.

It is intended that in the future that the network report will include work reported by PECs in order to have a complete picture of network provision and needs.

Peripheral centre skills assessments

Similarly to unit assessment against the standards, we will be asking trusts to identify their specific learning needs and assessing how these compare against the national standards. We will work with trusts on formalising an educational programme to suit the requirements as identified by these assessments.

The Lead nurse for the network has commenced a programme of webinars and although feedback from a survey showed most people still preferred face-to-face education, the webinars have proved very successful and will remain a central means of our educational delivery.

Further information is outlined below.

Educational programme

We are establishing an educational programme to meet the needs of the units across the region and have taken into consideration the feedback that was provided during the launch event and subsequent survey. The first sessions on StarLeaf have already taken place and were a huge success with very positive feedback.

. Working in collaboration with regional networks, our educational offer will ensure equal access to education and training in all centres for all healthcare workers.

Patient engagement group

Patients and families remain at the heart of our network and their opinions and ideas for the future of the service and how it is delivered is key to success and longevity of the network.

A patient engagement session was held during the network launch event in January, successful discussion and feedback was received and it is now time for us to build on this.

COVID 19 has affected our plans for creating the Patient Engagement Group, but now as we navigate our way to a new normal, we will pursue this as a priority, possibly with a focus on digital technology.

In addition to our current parent representative we have successfully appointed a patient representative to the network board, and a parent of CHD patient has delivered a powerful patient story within the educational webinar.

Appendices

Appendix 1 - Newcastle University New Institutes and Themes within the Faculty of Medical Sciences

Appendix 2 - Publications

Appendix 3 - Research Themes

Appendix 1 - Newcastle University New Institutes and Themes within the Faculty of Medical Sciences

Three core Institutes have recently been created in the Faculty of Medical Sciences at Newcastle University:

- Biosciences
- Translational and Clinical Research
- Population Health Sciences

Within these institutes there are several cross-cutting themes which are outlined below. Those relevant to the congenital heart disease (CHD) research group come together under the theme of Reproduction, Development and Child Health which leads CHD research across the network.

New Institutes

Institute 1: Newcastle University Biosciences Institute

Tackles fundamental research problems requiring a cross-disciplinary combination of state-of-the-art technologies including genomics, proteomics, bioimaging, molecular, cell and structural biology, 3D tissue engineering, stem cells and bioinformatics.

Institute 2: Newcastle University Translational and Clinical Research

Clinical academics and NHS clinicians form a thriving interdisciplinary research environment, sharing knowledge and expertise in the pursuit of new diagnostics, therapeutics and medical interventions and generating significant impact through clinical implementation and adoption.

Institute 3: Newcastle University Population Health Sciences Institute

Delivers research to enhance the health and health care of individuals, patients and populations, focusing on prevention, interventions, implementation, and policy from care to cure. Undertakes research on relevant underpinning methodologies including: biostatistics, health economics, behavioural sciences, data science, qualitative and quantitative research.

1.	Ageing and Geroscience
2.	Applied Cancer Therapeutics and Outcomes
3.	Behavioural Science and Psychology
4.	Cell signalling
5.	Chromosome Biology and the Cell Cycle
6.	Discovery of Medicine
7.	Immunity and Inflammation
8.	Innovation, Methodology and Application
9.	Mechanisms and Management of Long Term Conditions
10.	Mental Health, Dementia and Neurodegeneration.
11.	Mitochondrial and Neuromuscular Diseases
12.	Molecular and Cellular Microbiology
13.	Molecular Mechanisms of Life
14.	Neuroscience, Neurodisability and Neurological Disorders
15.	Nutrition, Exercise and Metabolism
16.	Precision Medicine, Genomics and Informatics
17.	Public Health and Health Inequalities
18.	Regenerative Medicine, Stem Cells and Transplantation
19.	Developmental Biology, Reproduction and Child Health
20.	Vascular Biology & Medicine

Appendix 2 - Publications

Newcastle authors in bold.

Vangl2 in the dentate network modulates pattern separation and pattern completion on May 29, 2020. Cell Reports. In Press.

Alqahtani A, Skelton A, Eley L, Annavarapu S, **Henderson DJ, Chaudhry B**. Isolation and next generation sequencing of archival formalin-fixed DNA. J Anat. 2020 May 19.

Santos-Ledo A, Washer S, Dhanaseelan T, Eley L, Alqatani A, Chrystal PW, Papoutsi T, **Henderson DJ, Chaudhry B**. Alternative splicing of jnk1a in zebrafish determines first heart field ventricular cardiomyocyte numbers through modulation of hand2 expression. PLoS Genet. 2020 May 18;16(5):e1008782.

Chaudhry B, Henderson DJ. Cilia, mitochondria, and cardiac development. J Clin Invest. 2019 Jun 17;129(7):2666-2668. doi: 10.1172/JCI129827. eCollection 2019 Jun 17.

Dewhurst P, **Coats L**, Parikh JD, Hollingsworth KG, Gan L. The role of flow rotation in the adult right atrium: a 4D flow cardiovascular magnetic resonance study. Physiol Meas. 2020 Apr 16;41(3):035007.

Lopes BS, **Coats L, Anderson RH**. Commentary: Shunting Between the Left Ventricle and Right Atrium Can Be Produced by Straddling Tricuspid Valve With Dual Orifices. Semin Thorac Cardiovasc Surg. 2020 Spring;32(1):143-144.

Rico-Armada A, **Crossland DS, Coats L, Reinhardt Z, Hermuzi A, Seller N**, Hasan A, **O'Sullivan JJ**. Outcome for children following admission to hospital with a first episode of heart failure, due to heart muscle disease, in the ventricular assist device (VAD) era. Cardiol Young. 2019 Jul;29(7):888-892.

Crossland DS, Jansen K, Parry G, Harper A, Perri G, Davidson A, **De Rita F, Hermuzi A, Nassar M, Seller N**, MacGowan GA, Hasan A, **O'Sullivan JJ, Coats L**. Outcome following heart transplant assessment in adults with congenital heart disease. Heart. 2019 Nov;105(22):1741-1747.

Vittery E, **O'Sullivan J**, Polyviou S, **Coats L, Chaudhry B**. Anatomical Details Should Accompany Studies of Hypoplastic Left Heart Syndrome. Pediatr Cardiol. 2019 Jun;40(5):1101-1102.

Agarwal R, **Chaudhry B, Jansen K, O'Sullivan J**, Hudson M, Allen J, **Coats L**. Tissue oxygen saturation assessment of microvascular perfusion in adults with Fontan palliation and comparator groups using vascular optical spectrophotometry: a pilot study. Physiol Meas. 2019 Jul 1;40(6):06NT01.

Khushnood A, Butt TA, Jungschleger J, Henderson P, **Smith JH, De Rita F, Nassar M**, Page A, Messer S, Large S, Dark JH, Parry G, **Reinhardt Z**, Hasan A. Paediatric DCD (Donation after circulatory determined death) Heart Transplantation using donor normothermic regional perfusion and ex-situ heart perfusion: A case report. Paediatric Transplantation 2019, Sep;23(6):e13536.

Chaudhry B, Henderson D, Anderson R. Double-outlet right ventricle is not hypoplastic left heart syndrome. Nat Genet. 2019 Feb;51(2):198.

Stothard CA, Mazzotta S, Vyas A, Schneider JE, Mohun TJ, **Henderson DJ, Phillips HM and Bamforth SD**. Pax9 and Gbx2 interact in the pharyngeal endoderm to control cardiovascular development. *J Cardiovasc Dev* 2020 Dis. 2020 May 25;7(2):E20.

Phillips HM, Stothard CA, Shaikh Qureshi WM, Kousa AI, Briones-Leon JA, Khasawneh RR, Sanders R, O'Loughlin C, Mazzotta S, Dodds R, Seidel K, Bates T, Nakatomi M, Cockell SJ, Schneider JE, Mohun TJ, Maehr R, Kist R, Peters H, **Bamforth SD** Pax9 is required for cardiovascular development and interacts with Tbx1 in the pharyngeal endoderm to control 4th pharyngeal arch artery morphogenesis. *Development*. 2019 Sep 23;146(18):dev177618.

Bailey KE, MacGowan GA, Tual-Chalot S, Phillips L, Mohun TJ, **Henderson DJ, Arthur HM, Bamforth SD, Phillips HM** Disruption of embryonic ROCK signaling reproduces the sarcomeric phenotype of hypertrophic cardiomyopathy. *JCI Insight* 2019. Mar 5;5(8):e125172.

Crowe L, **Simpson E, Reinhardt Z, Rankin J**. Parental responsibility for pediatric ventricular assist devices: Views of families on the acceptability of hospital discharge. *Pediatr Transplant*. 2020 Feb;24(1):e13636.

Reinhardt Z. Paediatric heart transplantation: an update. *Arch Dis Child*. 2019 Dec;104(12):1216-1222.

Singh E, Redgrave R, **Phillips HM**, Arthur HM. Arterial endoglin does not protect against arteriovenous malformations. *2020 Angiogenesis*. 1-8

Socio-economic inequalities in mortality in children with congenital heart disease: A systematic review and meta-analysis. Best KE, Vieira R, Glinianaia SV, **Rankin J**. *Paediatr Perinat Epidemiol*. 2019 Jul;33(4):291-309.

Multi-Centre Publications

Park JE, Botting RA, Domínguez Conde C, Popescu DM, Lavaert M, Kunz DJ, Goh I, Stephenson E, Ragazzini R, Tuck E, Wilbrey-Clark A, Roberts K, Kedlian VR, Ferdinand JR, He X, Webb S, Maunder D, Vandamme N, Mahbubani KT, Polanski K, Mamanova L, Bolt L, **Crossland D, de Rita F**, Fuller A, Filby A, Reynolds G, Dixon D, Saeb-Parsy K, Lisgo S, **Henderson D**, Vento-Tormo R, Bayraktar OA, Barker RA, Meyer KB, Saeys Y, Bonfanti P, Behjati S, Clatworthy MR, Taghon T, Haniffa M, Teichmann SA. A cell atlas of human thymic development defines T cell repertoire formation. *Science*. 2020 Feb 21;367(6480):eaay3224. doi: 10.1126/science.aay3224.

Burch M, Taylor A, Mehew J, Dominguez T, **Crossland D**, Lewis C, Taylor R, Clift P, Al-Attar N, Venkateswaran R, Banner N. Prioritising transplantation for adult congenital heart disease, UK national data. *Int J Cardiol*. 2020 May 15;307:36-40.

Niky Ghorbani, Vivek Muthurangu, **Abbas Khushnood**, Leonid Goubergrits, Sarah Nordmeyer, Joao Filipe Fernandes, Chong-Bin Lee, Kilian Runte, Sophie Roth, Stephan Schubert, Sebastian Kelle, Felix Berger, Titus Kuehne, Marcus Kelm. Impact of valve morphology, hypertension and age on aortic wall properties in patients with coarctation: a two-centre cross-sectional study. *BMJ Open* 2020 Mar 25;10(3):e034853. doi: 10.1136/bmjopen-2019-034853

Page DJ, Miossec MJ, Williams SG, Monaghan RM, Fotiou E, Cordell HJ, Sutcliffe L, Topf A, Bourgey M, Bourque G, Eveleigh R, Dunwoodie SL, Winlaw DS, Bhattacharya S, Breckpot J,

Devriendt K, Gewillig M, Brook JD, Setchfield KJ, Bu'Lock FA, **O'Sullivan J**, Stuart G, Bezzina CR, Mulder BJM, Postma AV, Bentham JR, Baron M, Bhaskar SS, Black GC, Newman WG, Hentges KE, Lathrop GM, Santibanez-Koref M, Keavney BD. Whole Exome Sequencing Reveals the Major Genetic Contributors to Nonsyndromic Tetralogy of Fallot. *Circ Res*. 2019 Feb 15;124(4):553-563.

Norrish G, Field E, Mcleod K, Iliina M, Stuart G, Bhole V, Uzun O, Brown E, Daubeney PEF, Lota A, Linter K, Mathur S, Bharucha T, Kok KL, Adwani S, Jones CB, **Reinhardt Z**, Kaski JP. Clinical presentation and survival of childhood hypertrophic cardiomyopathy: a retrospective study in United Kingdom. *Eur Heart J*. 2019 Mar 21;40(12):986-993.

Heart Failure in Adult Congenital Heart Disease: From Advanced Therapies to End-of-Life Care. **Crossland DS**, Van De Bruaene A, Silversides CK, Hickey EJ, Roche SL. *Can J Cardiol*. 2019 Dec;35(12):1723-1739.

Boersma LV, Ince H, Kische S, Pokushalov E, Schmitz T, Schmidt B, Gori T, Meincke F, Protopopov AV, Betts T, Mazzone P, Foley D, Grygier M, Sievert H, De Potter T, Vireca E, Stein K, Bergmann MW; following investigators and institutions participated in the EWOLUTION study. Evaluating Real-World Clinical Outcomes in Atrial Fibrillation Patients Receiving the WATCHMAN Left Atrial Appendage Closure Technology: Final 2-Year Outcome Data of the EWOLUTION Trial Focusing on History of Stroke and Hemorrhage. *Circ Arrhythm Electrophysiol*. 2019;12(4):e006841. (**Participating Institution: DS Crossland**)

Urschel S, McCoy M, Cantor RS, Koehl DA, Zuckerman WA, Dipchand AI, **Reinhardt Z**, Kanter KR, Ballweg JA, Sparks J, Kirklin JK, Carlo WF. A current era analysis of ABO incompatible listing practice and impact on outcomes in young children requiring heart transplantation. *J Heart Lung Transplant*. 2020 Feb 28:S1053-2498(20)31394-2.

Denfield SW, Azeka E, Das B, Garcia-Guereta L, Irving C, Kemna M, **Reinhardt Z**, Thul J, Dipchand AI, Kirk R, Davies RR, Miera O. Pediatric cardiac waitlist mortality-Still too high. *Pediatr Transplant*. 2020 May;24(3):e13671.

Kirk R, Dipchand AI, Davies RR, Miera O, Chapman G, Conway J, Denfield S, Gossett JG, Johnson J, McCulloch M, Schweiger M, Zimpfer D, Ablonczy L, Adachi I, Albert D, Alexander P, Amdani S, Amodeo A, Azeka E, Ballweg J, Beasley G, Böhmer J, Butler A, Camino M, Castro J, Chen S, Chrisant M, Christen U, Danziger-Isakov L, Das B, Everitt M, Feingold B, Fenton M, Garcia-Guereta L, Godown J, Gupta D, Irving C, Joong A, Kemna M, Khulbey SK, Kindel S, Knecht K, Lal AK, Lin K, Lord K, Möller T, Nandi D, Niesse O, Peng DM, Pérez-Blanco A, Punnoose A, **Reinhardt Z**, Rosenthal D, Scales A, Scheel J, Shih R, Smith J, Smits J, Thul J, Weintraub R, Zangwill S, Zuckerman WA. ISHLT consensus statement on donor organ acceptability and management in pediatric heart transplantation. *J Heart Lung Transplant*. 2020 Apr;39(4):331-341.

Sallmon H, Moledina S, Albert DC, Beghetti M, Berger RMF, Bonnet D, Bukova M, Koestenberger M, Meinel K, **Reinhardt Z**, Tulloh RMR, de Wolf D, Hansmann G. Recommendations from the Association for European Paediatric and Congenital Cardiology for training in pulmonary hypertension. *Cardiol Young*. 2019 Nov;29(11):1323-1327.

Norrish G, Ding T, Field E, Ziolkowska L, Olivetto I, Limongelli G, Anastasakis A, Weintraub R, Biagini E, Ragni L, Prendiville T, Duignan S, McLeod K, Iliina M, Fernández A, Bökenkamp R, Baban A, Kubuš P, Daubeney PEF, Sarquella-Brugada G, Cesar S, Marrone C, Bhole V, Medrano C, Uzun O, Brown E, Gran F, Castro FJ, Stuart G, Vignati G, Barriales-Villa R, Guereta LG, Adwani S, Linter K, Bharucha T, Garcia-Pavia P, Rasmussen TB, Calcagnino MM, Jones CB, De

Wilde H, Toru-Kubo J, Felice T, Mogensen J, Mathur S, **Reinhardt Z**, O'Mahony C, Elliott PM, Omar RZ, Kaski JP. Development of a Novel Risk Prediction Model for Sudden Cardiac Death in Childhood Hypertrophic Cardiomyopathy (HCM Risk-Kids). *JAMA Cardiol.* 2019 Sep 1;4(9):918-927. doi: 10.1001/jamacardio.2019.2861.

Norrish G, Ding T, Field E, McLeod K, Ilina M, Stuart G, Bhole V, Uzun O, Brown E, Daubeney PEF, Lota A, Linter K, Mathur S, Bharucha T, Kok KL, Adwani S, Jones CB, **Reinhardt Z**, Omar RZ, Kaski JP. A validation study of the European Society of Cardiology guidelines for risk stratification of sudden cardiac death in childhood hypertrophic cardiomyopathy. *Europace.* 2019 Oct 1;21(10):1559-1565.

Martin CA, Yue A, Martin R, Claridge S, Sawhney V, Maury P, Lowe M, Combes N, Heck P, Begley D, Fynn S, Snowdon R, **Seller N, Murray S, Shepherd E**, Ezzat V, Gajendragadkar PR, Honarbakhsh S, Takigawa M, Cheniti G, Frontera A, Thompson N, Massouillie G, Kitamura T, Wolf M, Duchateau J, Klotz N, Vlachos K, Bourrier F, Lam A, Pambrun T, Denis A, Sacher F, Cochet H, Jais P, Hocini M, Haissaguerre M, Iriart X, Thambo JB, Derval N. Ultra-High-Density Activation Mapping to Aid Isthmus Identification of Atrial Tachycardias in Congenital Heart Disease. *JACC Clin Electrophysiol.* 2019 Dec;5(12):1459-1472.

Spectrum of congenital anomalies among VACTERL cases: a EUROCAT population-based study.

van de Putte R, van Rooij IALM, Marcelis CLM, Guo M, Brunner HG, Addor MC, Caverro-Carbonell C, Dias CM, Draper ES, Etxebarriarteun L, Gatt M, Haeusler M, Khoshnood B, Klungsoyr K, Kurinczuk JJ, Lanzoni M, Latos-Bielenska A, Luyt K, O'Mahony MT, Miller N, Mullaney C, Nelen V, Neville AJ, Perthuis I, Pierini A, Randrianaivo H, **Rankin J**, Rissmann A, Rouget F, Schaub B, Tucker D, Wellesley D, Wiesel A, Zymak-Zakutnia N, Loane M, Barisic I, de Walle HEK, Roeleveld N, Bergman JEH. *Pediatr Res.* 2020 Feb;87(3):541-549. doi: 10.1038/s41390-019-0561-y. Epub 2019 Sep 9. PMID: 31499513

Appendix 3. Research Themes

Epidemiology

- Survival and risk factors for survival in children born with congenital heart defects, Professor Judith Rankin, Dr Svetlana Glinianaia and the EUROlinkCAT team
- Geographical variations in the prevalence of congenital anomalies in Europe, Professor Judith Rankin, Dr Svetlana Glinianaia and the EUROlinkCAT team
- Educational achievements and needs of children born with congenital heart defects, Professor Judith Rankin, Dr Svetlana Glinianaia and the EUROlinkCAT team
- Socioeconomic inequalities in mortality in children with congenital heart diseases; a systematic review and meta-analysis, Dr Kate Best, Professor Judith Rankin
- Prevalence of congenital heart defects in Europe: a registry based EUROCAT study, Valentina Mamasoula, Professor Judith Rankin
- Maternal age and congenital heart defects, Valentina Mamasoula, Professor Judith Rankin

Causation of CHD

- Genes in Hypoplastic Left Heart. Dr John O’Sullivan and Dr Bill Chaudhry
- The myocardium in Hypoplastic Left Heart. Dr John O’Sullivan and Dr Bill Chaudhry
- Development of the Aortic Valve. Professor Deborah Henderson and Dr Bill Chaudhry
- Developmental origins of Hypoplastic Left Heart. Professor Deborah Henderson and Dr Bill Chaudhry
- Planar cell polarity signalling in development of the heart and as a factor in congenital heart defects – Professor Deborah Henderson
- Cilia and congenital heart malformation. Professor Deborah Henderson and Dr Bill Chaudhry
- Using mouse models to investigate the genetics underlying development of congenital heart disease, Dr Simon Bamforth
- Identification of candidate genes for congenital heart defects, Dr Helen Phillips and Dr Simon Bamforth
- A cell atlas of the human outflow tract of the heart, Dr Simon Bamforth
- The role of autophagy during heart development underlying congenital heart defects. Dr Helen Phillips
- Rho GTPases in congenital heart defects. Dr Helen Phillips

Paediatric Cardiology and Advanced Heart Failure

- Systematic Review of Caregivers Experiences of Paediatric Inpatient Cardiac Services, Rachel Smith, Niina Kolehmainen
- Understanding the experiences of children with mechanical support, Dr Emma Simpson, Dr Zdenka Reinhardt, Professor Judith Rankin
- A needs assessment of psychosocial difficulties in children and young people with congenital heart disease. Dr Sue Brown, Dr Emma Simpson
- Creating an educational platform for professionals and patients to learn about heart failure and its therapy. Dr Emma Simpson, Dr Zdenka Reinhardt
- Determining the psychological needs of children with congenital heart disease to target intervention more effectively. Dr Lisa Crowe, Dr Emma Simpson, Professor Judith Rankin
- Early life factors in Multimorbidity Louise Coats, Simon Bamforth, Helen Phillips, Judith Rankin, Mike Taggart, Niina Kolehmainen

- Understanding inborn errors of metabolism in paediatric cardiomyopathy; Dr Helen Phillips and Dr Simon Bamforth.

Fontan

- Following the Fallot and Fontan/Single Ventricle populations to discover biomarkers of complications, Dr Louise Coats
- Understanding right heart haemodynamics to develop a novel assist device for the Fontan circulation, Dr Louise Coats, Mr Mohamed Nasser (with Dr Lian Gan, Durham University)

ACHD

- Testing the Validity of ECG Parameters in Predicting Adverse Outcomes in Congenital Heart Disease, Dr Louise Coats
- Understanding what matters to Adults with Congenital Heart Disease to develop Better Service Provision, Dr Louise Coats
- Approach IS II study International Study on Patient-Reported Outcomes and Experiences in Adults with Congenital Heart Disease (CI: Dr Philip Moons Leuven Belgium, PI: Dr Louise Coats)
- Revival Study/Registry - Ross for Valve Replacement in Adults (CI Richard Whitlock Ontario Canada, PI Mohamed Nasser)